SOCIAL EMPOWERMENT TO DEAL WITH NEGATIVE STIGMA AND DISCRIMINATIVE TREATMENT AGAINST PEOPLE WITH HIV/AIDS

Argyo Demartoto¹, Siti Zunariyah¹, Tyas Nur Haryani²

Abstract
The existence of people with HIV/AIDS or PWHAs in daily life results in a variety of social problems to themselves, family, friend, neighbor, surrounding environment, and wide society. This qualitative research with phenomenological approach aimed to analyze social empowerment to deal with negative stigma and discriminative treatment against PWHA in Surakarta, Indonesia. Primary data was collected from PWHAs, Solo Plus Peer Support Group, health workers, Surakarta AIDS Commission, and NGOs caring about AIDS. The result of observation, in-depth interview, and some related documents were analyzed using community empowerment theory and labeling. The result of research showed that social empowerment with intensive information education and communication on HIV/AIDS can change people’s interpretation on PWHAs. Government policy supporting PWHAs’ need, improved participation of PWHAs in such activities as HIV/AIDS overcoming in family, community, work environment, and society, and sustainable facilitation can solve social medical problem of PWHAs. The presence of improved capacity and social-cultural structure of society conducive to HIV/AIDS is expected to overcome negative labeling and discrimination against PWHA.

Keywords: PWHA empowerment, social economic and medical support for PWHAs

Abstrak

¹Department of Sociology, Universitas Sebelas Maret, Surakarta, Indonesia
²Department of Public Administration, Universitas Sebelas Maret, Surakarta, Indonesia
¹argyodemartoto_fisip@staff.uns.ac.id
Argyo Demartoto, Siti Zunariyah, dan Tyas Nur Haryani
terkait dianalisis dengan teori pemberdayaan masyarakat dan labelling. Hasil penelitian menunjukkan bahwa pemberdayaan sosial dengan Komunikasi Informasi Edukasi yang intensif tentang HIV/AIDS dapat mengubah interpretasi masyarakat terhadap ODHA. Kebijakan pemerintah yang mendukung kebutuhan ODHA, meningkatnya partisipasi ODHA dalam berbagai kegiatan termasuk penanggulangan HIV/AIDS baik di keluarga, komunitas, lingkungan kerja dan masyarakat, serta pendampingan yang berkelanjutan dapat mengatasi masalah sosial medis ODHA. Dengan adanya peningkatan kapasitas dan struktur sosial budaya masyarakat yang kondusif terhadap HIV/AIDS diharapkan dapat mengatasi label negatif dan ketidakadilan terhadap ODHA.

**Kata kunci :** pemberdayaan ODHA, dukungan sosial ekonomi dan medis bagi ODHA

**INTRODUCTION**

HIV/AIDS endemic and death of people with HIV/AIDS (PWHAs) impact on people and state’s interest (Moremen, 2010; Lather, 2013; Yi et al, 2015). Iceberg phenomenon in HIV/AIDS case in Indonesia also becomes discourse attracting much attention. It is confirmed with the HIV endemic development increasing over times and having spread throughout Indonesia. Although Indonesia has signed the framework of human right requiring citizens to respect and to protect all citizen’s human rights regardless HIV/AIDS status, but discriminative treatment embarrassing, underestimating, blaming, and labeling negatively is still received by PWHA, thereby limiting their activity freedom (Shaluhiyah et al, 2015).

Considering the data of Surakarta AIDS Commission, it can be seen that there were 2,857 HIV/AIDS cases during 2005-2018 in Surakarta: 974 HIV, 1,883 AIDS, and 701 deaths. HIV/AIDS is (more than 80 percents) largely developed by productive age group (15-49), particularly males, but the proportion of female patients tends to increase. HIV/AIDS cause in Surakarta is dominated by risky sexual behavior and Injection Drug Users (IDU’s). It triggers the people to assess HIV/AIDS negatively, assuming that HIV/AIDS is transmitted by an individual or a group of individuals with amoral behavior such as sex workers and IDUs. Meanwhile, PWHAs consist of not only the group formerly considered as vulnerable one but also common people. Originally infecting the HIV-high risk group such as homosexuals, High Risk Men (HRM), sex workers, and IDUs only, now HIV/AIDS also infects women, wives or housewives loyal
to their husband or partner. So, not only the stigmatized group but also the most vulnerable group including women and infant are exposed to HIV/AIDS (Lather, 2018).

HIV/AIDS developed by an individual impairs his/her function as a member of community, for example, PWHAs stigmatized and treated discriminatively by community are affected psychologically, thereby tending to be introverted and limiting their social interaction with surrounding environment particularly new people. Stigma and discrimination felt firstly by PWHAs instead come from their family, when they know about PWA’s positive HIV status. Family stigma experienced by nearly all PWA includes declination and ejection, and even stringent declination from surrounding people, so that family has no option but evacuating PWHAs to another place. Most citizens decline the presence of PWHAs living in their neighborhood and they consider them as disgrace. Meanwhile, PWA has equal right before the law. International Human Right Law ensure equal protection before the law from discrimination based on anything like race, skin color, language, religion, politic or opinion, origin, and other status including HIV status. In addition, everyone is entitled to live, to get highest standard of physical and mental health, privacy, to work, to move to other place, to get married and to build family, to access education, to assemble, and to join insurance program. To get those rights, there should be an empowerment for community including PWHAs (Dodds et al, 2008; Christenson et al, 2008; Chambers et al, 2015).

In social empowerment, individual, community, and society are active actors that initiate and contribute to social activities to improve powerless situation and condition, in this context to deal with negative stigma and discriminative treatment against PWHAs (Gutierrez, 1995; Perkins and Zimmerman, 1995; Miller and Keys, 1996; Macaulay and Cook, 1996; Macaulay et al, 1999; Mo and Coulson, 2010). The characteristics of powerful individual, community, and society are knowing their weakness and strength, having commitment and responsibility, independent and creative, having self-controlling ability, not blaming others, interacting socially, adapting to their environment, and appreciating themselves ad others (Kirst-Ashman, 2007). Every individual, community,
and society can solve problem in integrated manner based on knowledge, identification, and evaluation of problem as the social empowerment process. An individual can learn from experience and deal with the future challenge through developing potential resource existing thereby resulting in community sustainability and independency (Arneson and Ekberg, 2005; Kim et al, 2008; Gray and Zide, 2012; Kirst-Ashman and Hull Jr, 2014). This research aims to study social empowerment to deal with negative stigma and discriminative treatment against PWHAs in Surakarta, Indonesia.

**METHODS**

Descriptive phenomenological approach in this qualitative research consists of intuiting, analyzing and describing the community empowerment action to deal with negative stigma and discriminative treatment against PWHAs (Spiegelberg, 1994). This research was conducted on PWHAs coming from high risk group, common people, and members of Solo Plus Peer Support Group (PSG). Manager Program Surakarta AIDS Commission dan Chairperson of Solo Plus PSG knowing the existence of and facilitating PLWHAs became key informant. Meanwhile, Director of LSM SPEK HAM Surakarta, a clinician from Dr. Moewardi Hospital of Surakarta, VCT counselor and psychologist in Manahan Public Health Center (Puskesmas Manahan) of Surakarta, and People Affected by HIV/AIDS (PABHA) serve as supporting informant. Techniques of collecting data used were observation, in-depth interview, and documentation related to PWHA empowerment program in Surakarta. To test data validity and reliability, the author identified data operationally to apply credibility, dependability, confirmability and transferability, thereby resulting in trustworthiness (Miles et al, 2014). Meanwhile, data analysis was conducted by preparing field note; sorting the meaningful note relevant to the objective of research; categorizing by statement in early categorization; and arranging the theme by category into sub theme and a descriptive narration from informants’ experienced with community empowerment to deal with negative stigma.
and discriminative treatment against PWHA thereby yielding a research report (Colaizzi 1978, Miles et al, 2014; Morrow et al, 2015)

**RESULT**

The subject of social empowerment to deal with negative stigma and discriminative treatment against PWHA is PWHAs themselves as well as all stakeholders. Government, non-government, and community are actors and important components in dealing with PWHA’s powerlessness. Individuals infected with HIV/AIDS should not be deprived for their living right. They are just like other common people who still have rights and obligations. No clause says that virus can deprive an individual’s right. In this case, discriminative behavior discrediting their position within society leading to the deprivation of human right can be considered as the infringement of human rights. So can be the problem occurring to PWHAs.

Two domains require PWHAs’ attention: helping themselves and making them the activist to raise other PWHAs’ apprehension. A number of cases experienced by PWHAs clearly demonstrate social problem generated more than the medical problem. It is this social problem that instead becomes main problem to PWHAs as it pertains to their interaction with social environment in which they should undertake their life naturally. Community’s poor knowledge on HIV/AIDS is the main cause of stigma and discrimination against PWHA. Improved knowledge on HIV/AIDS evidently can reduce stigma and discrimination, but high education level does not ensure that they have sufficient health knowledge. Community should at least have sufficient knowledge on risk factor, transmission, prevention, and medication of HIV/AIDS. If all classes of society have this knowledge, it can minimize their stigma against people with HIV/AIDS.

In this case, indeed there should be a change in community’s interpretation on PWHAs. It becomes the main key to supporting other PWHAs’ needs including the needs for law protection, improved skill, healthcare, improved economy, and etc. People can help remove stigma and discrimination by showing off their support, for example AIDS Reflection Night activity helps advocate and improve concern with PWHAs,
implement the treatment program without waiting for help from outside, thereby reducing family burden with family members living with HIV/AIDS. Meanwhile, community can mobilize its resource and therefore many more activities can be done without being dependent on grant from donor.

PWHA needs government’s political commitment from local to international level. Government policy in Surakarta has attempted to pay attention to what is felt, needed, and not needed, what circumstance the PWHA need in order to live healthily both physically and psychologically, and etc. Therefore, effective policy, service, program, and strategy are the client-centered ones, meaning positioning the PWHA to be the center. In Surakarta, improved support and treatment evidently highly support the successful attempt of preventing HIV/AIDS. Paying sufficient attention to support and treatment can erode the excessive fear within society (either infected or not infected), grow the feeling of secure and comfortable, and thus, HIV/AIDS begins to be considered seriously and duly by everyone. Connecting prevention to support and treatment is one of most reasonable ideas ever thought in the attempt of coping with HIV/AIDS.

PWHA becomes an important part in the attempt of coping with HIV/AIDS because their life is touched and affected directly by this virus. They are the most appropriate source of understanding on HIV/AIDS. Everyone should have such understanding, particularly those the job of which is related HIV/AIDS. PWHA deserve healthy life. No one wants to be sick or infected with something with unknown medicine. If there is still an individual infected with HIV, it means that the preventive measure taken has not been optimal yet. Therefore, the attempt of preventing HIV cannot stop to the prevention only, but it should be integrated into the attempt of supporting and giving service to those who have been infected. Even it should be thought of what will be done when this support and service is not given duly, e.g. violating ethical code, discriminatively, or not given at all.

A consequence of intensive information education and communication about HIV/AIDS is that many people will likely feel necessity for undertaking test voluntarily. Then, those with known status from AIDS-typical clinical symptoms existing or surveillance, the identity
of which is divulged to the corresponding one. So, there should be support and service programs to those who have undertaken test, with both either positive or negative result. Support and service for PWHAs have actually started since they know their HIV status, i.e. informed consent about the corresponding one, counseling that should be given before and after, and confidentiality that should be upheld. All of those highly affect the one’s physical and mental health subsequently. Unfortunately, these three principles are still often violated in practice. Some people are tested without their knowledge and permission. What do we feel when we are informed that we are infected with HIV or event called infected with AIDS inappropriately? Pre-and post-test counseling is also provided in undisciplined manner. Pretest counseling prepares people that will undertake test, while post-test counseling is very vital, because it is the first information and understanding an individual brings to home after he/she has gotten his/her diagnosis. Coming home and bringing a diagnosis of severe disease without adequate understanding will exert adverse effect, from depression to more fatally suicide attempt. Similarly, divulgence can impact on the impaired social relationship and on unnecessary discrimination.

This effect of all violations can be public (common) or even very private in nature, including the effect on physical health, mental health, financial (e.g. using entire fund up for antiretroviral medication without adequate information), family relation, sexual relation, marriage, child, safety, life sustainability (not understanding non-symptomatic period and productivity), and problem during death (clothing annihilation, bed cover, excessive plastic use, etc). It also includes the effect on the attempt of preventing HIV/AIDS. Powerful PWHAs getting counseling will be able to keep others (sexual partner, health worker, injection users/pierced ear/tattoo, and baby) from its transmission just like they take care of themselves.

If an individual is sick, the first thing he/she finds will be the healing to recover his/her condition. It is true to all diseases, including HIV. However, the reality the PWHAs should encounter is the absence of healer. Very big expectation is always relied on antiretroviral drugs. Despite imperfection, these drugs can evidently lower an individual’s blood virus level down to undetectable one. This drug is still studied continuously.
Because its price is unaffordable to community, its procurement cannot be done evenly and there is no guarantee for its availability. Facility and monitoring ability over the effect of this drug are still very low. For example, the high-cost viral load test leads to the very small number of clients in laboratory, so that the laboratory officers become less skillful, and reagents become expired, and recent and balanced information on this drug is inadequate.

Information can help PWHAs make consideration in order to make the best decision to them and others. If an individual is rich of information, it will be easier to him/her to make consideration and decision wherever he/she is. Therefore, healthcare service catering on vital counseling in Surakarta is integrated into one package along with the test so that it should be provided in more disciplined manner. There should be no test without counseling. Counseling can also be undertaken after the test package has been completes, as long as the one needs it. The challenge arising here is that such counseling has not been common yet. The one going to counselor or psychologist to get consultation is often labeled as the one in trouble and tend to be viewed negatively even by those needing him/her.

The first and frequently the only relation the PWHAs establish is the one with health worker examining him/her. Then, he/she will relate again to the health workers during his/her life. Health workers also become role models to society and other service provider concerning how to treat PWHAs because they are considered as knowledgeable. Health workers’ inadequate information and understanding give the space for excessive fear and discrimination, from underestimating confidentiality to declining to take care of the patient. It affects physical and mental health. There should be improvement in the treatment ethic practice among the health workers. Empowerment should be conducted in patients as well to enable the patient to understand this presence of ethics, so that they can contribute more actively to their treatment process without being too dependent on others. PWHAs’ body immune is lower, so that some other diseases can attack them, called opportunistic infection (OI). In AIDS-stage patient, OI can result in death. In this case, the development of therapies like medicinal herb, massage, acupuncture and the growth of medicinal plants for
HIV/AIDS should be encouraged and supported in order to fill in the vacuum of medical drugs.

Religion has been a kind of therapy to most members of society in Indonesia. It should also be developed for HIV/AIDS. In addition to non-medical therapies aforementioned, many more therapy forms can be explored and learnt. For example, meditation, art therapy (e.g. music), proportional exercise therapy, diet, hobby (e.g. gardening, singing), and performing healthy and balanced life. Peer support group is actually one of non-medical therapies aforementioned. Sharing problem and thinking of finding the solution together have been known as the way of helping others emotionally and practically.

Support group managed by and for PWHAs is very meaningful to community empowerment to deal with negative stigma and discriminative treatment against PWHAs. Just like special group for PWHAs, some support groups involve close people like family, friend, and also volunteer. Stigma and discrimination accompanying PWHAs becomes important factor behind the emergence of support groups. To PWHAs in Surakarta, Solo Plus Peer Support Group is the only place where they feel comfortably, can get out of isolation, maintain their confidentiality, are secure and supported. Solo Plus PSG becomes a body in which support is given and treatment is provided, education and information dissemination on HIV/AIDS occurs, and compensates the lack of counseling service that should be existent accompanying all HIV tests but is often not implemented. Solo Plus PSG develops into advocacy material voicing apprehension on living with HIV/AIDS, attempts to influence the policy maker, and contributes to decision making in Surakarta. The principle that evidently can answer PWHAs’ need and ensure the effective existence of the group is to design program and group structure that are PWHA-oriented as actor and target group of social empowerment all at once to deal with negative stigma and discriminative treatment against PWHA. Program and activity design and form are developed by taking PWHAs’ capacity, limitation, and reality into account.
A certain identity given by community to individual based on the characteristics considered as minority and or the one with certain deviating behavior. Similarly PWHA also occupies the position as primary deviant, because HIV/AIDS they develop makes them characterized by community, considered as minority, and can result in social reaction when they interact with them. Stigma is experienced and felt, including self-stigmatization. PWHA are isolated, expelled, and declined for their existence in family, residence, school, and healthcare service; thus they feel guilty and uncomfortable with people’s view despite not occurring stigma in fact. It leads PWHA to withdraw from their social environment because they feel that others do not want to interact with them, thereby only interacting with environment they consider safe and wanting to accept them (Pinto et al, 2007; Yi et al, 2015; Shaluhiyah et al, 2015).

Negative stereotype can result in discrimination against PWHA so that they are limited, expelled, and abused. The limitation the PWHA experience includes, among others, they are not allowed to live in and close to family, not involved in the activities in their residence, not getting good healthcare service due to demographic factor and etc. Stigma and discrimination against PWHA are affected by internal and external factor. Internal factor consists of age, sex, interpretation on HIV/AIDS, people with HIV/AIDS, and compliance with religion. External factor includes knowledge on HIV/AIDS, education level, and institution’s support. Most fundamental thing resulting in stigma and discrimination is internal factor in the form of interpretation on HIV/AIDS and people with HIV/AIDS, while external factor is in the form of knowledge on HIV/AIDS (Chambers et al, 2015). People have misinterpretation on HIV/AIDS and people with HIV/AIDS. They consider HIV/AIDS as the disease resulting from amoral deed such as free sex, prostitution, and drug user only, so that they tend to generalize that PWHA are a group of amoral people or coming from amoral family. A very limited knowledge on HIV/AIDS instead encourages stigma to arise. People know the surface only, assuming that HIV/AIDS is infectious disease with unknown medicine. They do not know clearly how the (HIV/AIDS) disease infects and how to prevent HIV/AIDS.
transmission, so that the only thing they can do is to avoid any contact with people with HIV/AIDS. It results in big fissure leading to discriminative action (Moremen, 2010).

Stigma and discrimination the PWHAs encounter leads them to perform the behavior like the people label them. Secondary deviant the PWHAs generate as the way of coping with stigma and discrimination they experience is psychological effect occurring. As a result of psychological pressure, PWHAs indicates incompliance with drug consumption and thinking that they will die quickly. It is because of stress as the result of psychologically stressed situation experienced, as indicated with depression, silence, and sometimes crying when they remember that they develop HIV/AIDS and are considered as deviating. It is intended to those stigmatizing and discriminating PWHAs. Prejudice or assumption developing within community concerning HIV/AIDS without change over times makes the community keeping assessing that people with HIV/AIDS are the negative minority. This view is true to any aspect of life (Champbell et al, 2011; Chambers et al, 2015; Lather, 2018).

In line with PWHAs’ psychological need, stigma and discrimination against PWHAs should be removed from all domains. Community empowerment in stigma and discrimination program should be applied at individual, community, institutional, and structural level (UNAIDS, 2014). The program at individual level is manifested into counseling and psychological support to the target of stigma and discrimination, integrated care and support program to improve the quality of life, peer support program and support group, to prevent discrimination from occurring (Li et al, 2011; UNAIDS, 2014). At community level, society is expected to monitor any form of infringement against PWHAs’ rights. In addition, people are authorized to develop anti-stigma program (Jirapaet, 2000; Brashers et al, 2004; Marin et al, 2007; Boneh and Jaganath, 2011; Blanchard et al, 2013). At institutional level, it is manifested into the establishment of occupational health program and non-discrimination training and medical care related to HIV stigma for health workers, social workers, uniformed service and workers in education sector (White, 1989; DelCasino, 2001; Van Rompay et al, 2008; Mo and Coulson, 2012). At
structural level, it is manifested into law reform to protect people with HIV/AIDS, women, child and all high risk groups from stigma and discrimination. In addition, training is given for all stakeholders related to human rights in order to achieve the law as fairly as possible to people with HIV/AIDS, women, child, and high risk group (Teasdale and Besser, 2008; Kim et al, 2008).

CONCLUSION

HIV is a health problem unnecessarily connected to moral. Everyone will be potentially infected with HIV/AIDS. Therefore, if we want to assess PWHAs, we should make self-reflection (look at the mirror). PWHAs are just like us. What distinguishing PWHAs from us is that they lose their body immune, and we do not. PWHAs feel glad, sad, angry, happy, confused, having a dream and expectation, can feel disappointed and fear, just like the one whose shadow can be seen on the mirror.

REFERENCES


