

Establishing Social Capital Among People Living with HIV/AIDS (PLWH)

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Abstract—People living with HIV/AIDS (PLWH) are often isolated from society due to stigma. Self-resistance of being infected HIV/AIDS brings about depression for PLWH. *Rumah Cemara* is an organization for PLWH that handling of these cases to establish social capital for PLWH through trust and social network. Program that *Rumah Cemara* aims is to increase quality of life in aspect of mental, physical, social and economic.

Keywords—People living with HIV/AIDS (PLWH); Social capital; *Rumah Cemara*

I. INTRODUCTION

HIV (*Human Immunodeficiency Virus*) is a virus which attacks immune system as the effect of AIDS (*Acquired Immune Deficiency Syndrome*). The spreading of HIV can be detected through unsafety sex, drug injection, a child of mother is positive HIV and blood transfusion. There is only available anti-retroviral to decrease development of virus, yet still no medicine is found to heal the virus.

There is no medicine or medical treatment to reduce HIV/AIDS causing people living with HIV/AIDS tend to be depression. Besides, people's perception about PLWH are connected to amoral behavior such as using drugs and free sex. This thing brings PLWH down to perception that can be felt by them. Perception is foundation to justify them in internal and external aspects such as needs of socialization, spirit of carrying on life.

PLWH is likely marginal group due to stigma that ties them so that causing less spirit for being productive in living a life and even tend to be skeptical of having vision in the future. Therefore, PLWH assembles themselves into an organization called *Rumah Cemara* to help one another in recovering mental, physical, social, even economic. Things that *Rumah Cemara* do is an attempt to establish social capital.

It is categorized as social capital because it represents source involving expectation of reciprocity and beyond any individual so that it will take widely relation to shape trust and value together [1].

This case is interested to research because PLWH is hardly to accept themselves, open status, positive perception and socialization, now struggling to establish trust, social network and norm.

II. CONCEPT OF PEOPLE LIVING WITH HIV/AIDS (PLWH)

People are detected positive HIV/AIDS known as PLWH (People Living With HIV/AIDS). Appearing of PLWH begins with people "at risk" which is prostitute, drugs injection,

homosexual, a child of mother is positive HIV/AIDS, prisoner [2].

PLWH bears burden of complicated suffering than other people have chronic disease due to the problem of PLWH is not only medical but also social problem that is felt heavier and affect their mental. The impact of those problems make PLWH feel not safe, disrespected, having mental disorder and bad psychosocial such as too much worry and depression, isolated by society and family, self-alienation, not having better medical treatment, less opportunity to have a job, resistance on process of giving a birth and resistance of getting education, even committing to suicide [3].

III. PERCEPTION OF PLWHA

HIV/AIDS is an object that ties to a process how to mean each other. This thing is because of HIV/AIDS causing organization process, interpretation as stimulus that is received by organism or individual so that it becomes a meaning, and kind of activity that integrates individual [4].

Perception is constructed by internal factor; prejudice, attitude and personality, desire or expectation, attention, learning process, physical, mental disorder, value and motivation and external factor; family background, receiving information, knowledge, social needs, intensity, measurement, opposite, new experience, familiar of an object [5].

PLWH's feeling when detected positive HIV/AIDS is denial. These denial is like reluctant to consume ARV (antiretroviral) when symptom appears making PLWH feel depression so that late medical treatment. Those feeling delivers PLWH into a prejudice of death. Those things occur due to PLWH have less knowledge about HIV/AIDS even they receive negative information to control the virus.

PLWH's family are totally supporting them such as advising, taking them to hospital for treatment, reminding them to take medicine, and fund them to take any medical treatment. Besides supporting from parents, motivation comes from their children. PLWH are reluctant to take ARV but when they look at their kids who still need mother's compassion finally it takes them a little push to live normal life so that they can take care of their family. And another motivation is received from their friends who are PLWH too in *Rumah Cemara*.

Process of understanding and another factor that shape perception finally describing PLWH on self-perception. It starts with negative perception but slowly turns into positive perception. It can be proven from the result of researcher's observation on PLWH's daily activities who are useful for themselves such as running a private enterprise, exercise, and work in *Rumah Cemara* to help another PLWH or other people.

IV. SOCIAL CAPITAL OF PLWH

Developing is interdisciplinary thing because it cannot only focus on one aspect but it takes all aspects to be integrative. Discussion about development is not only about money, land, source as economic resource, or ability as human's resource but also involving honesty, rule, procedure, cooperation playing role as social capital. Nowadays social capital have found its position between economic resource and human's resource [6].

Component of programs are designed by Rumah Cemara to increase PLWH's quality of life such as counseling, service of management case, accompany anti-retroviral (ARV) therapy, daily meeting with other PLWH (People Who Living A Life With HIV/AIDS), meeting with the expert relates to social substance such as diffusion of innovation, role, cooperation, solidarity and participation.

Things that Rumah Cemara do is an attempt to establish social capital among PLWH. Social capital is a part of social life, relation, norm, and trust which push participant to act more effective to accomplish purpose [7].

A. Relationship in trust

Trust is an important component of society. A group which is its member distrust each other will not develop. Trust in one another appears when all members of group respect each other and being honest. Sub-component of trust is honest and respect each other. Therefore, lying, insulting, disrespecting are not allowed. When all members of society or social organization count on one another and being honest each other so that trust will appear among them.

PLWH have shared trust among them when they already know having same disease. So many suffers that PLWH experience make them know how far their companion face that problem, so that they can show a respect. Respect is pointed to those whom they meet first time in Rumah Sakit Hasan Sadikin (RSHS) and ask them to join their campaign to start over. It begins with respect then turning into trust through program of Rumah Cemara until it persuades them to have a new spirit to carry on.

Honesty is personal and private things which are part of trust. Honesty in relationship of PLWH can be seen from accompany of PLWH recondition from behavior at risk such as addicted to drugs.

Program of rehabilitation in Rumah Cemara use peer approach involving counseling process and community. Rehabilitation begins with voluntary and a warm welcome but rules are tight for them. For those who have to stay in Rumah Cemara after getting through first stage, they can see their family every Saturday. For those who do not have to stay must report and having counseling in the afternoon or night.

Leisure time outside rehabilitation activity gives them a chance to do activity at risk. But based on trust, client is able to hold the principle when the chance always offers them to make the same mistake. Even when they get through rehabilitation, they are honest to Rumah Cemara that they use drugs again. Lying is pointless due to voluntary, warm welcome and

understanding each other have been implanted. Trust becomes determinant factor among PLWH which molds social network.

B. Social network among PLWH

It has been discussed about important of social network in society. Social network links to another situation such as physical that is explained by Durkheim, high rate of committing suicide in society with social integration. Coleman explains about exceptional high rate student's achievement from poor family only based on strength of social capital [8].

Network is relation model among member of society or social organization as represent human being as human social, so that human being can obtain desire and fill their needs with simply, safe, effective and also optimal.

PLWH is only an individual who bears burden of suffering HIV/AIDS. Rumah Cemara coordinates action to establish network associative. Obstacles that must be faced is to figure out infected people due to report of infected people is only carried out from hospital. This situation is because of HIV/AIDS taboo to be accepted normally among society. Rumah Cemara try to close to people at risk such as prisoner and addict people to do persuasive approach.

Things that PLWH do is based on sympathy and empathy to increase PLWH's quality of life as hope. For example, looking for and calling on PLWH who are first time infected, giving them some comprehensive informations and asking them to get rehabilitation with Rumah Cemara's "style" which is peer approach, offering them to do mediation with their family, treating them with medical treatment such as providing ARV.

Interaction among PLWH, Rumah Cemara focuses on reciprocity. This dependency aims so that PLWH is pro active and they depend on one another between individual and community. Dependency is molded with involvement of PLWH in event of Rumah Cemara such as The International AIDS Candlelight Memorial and Campaign of moral support for PLWH.

Spirit that is carried on by Rumah Cemara as organization based on community is to grow solidarity. So that individual of awareness is main priority and if there is an argument can be finished through discussion. PLWH have good potential in establishing social capital.

C. Norm as social control

Norm is rule that plays guidance for behavior in society as a step to achieve and keep unwritten purpose but admitted its existence. Norm talks about right or wrong thing.

Norm exists among PLWH whose purpose is to not to do activity at risk such as taking drugs and free sex because those things will spread the virus quickly and contagious to another subject. Desire of exercise is not only physical needs, routine exercise is a must for PLWH. Therefore, Rumah Cemara builds Boxing Camp supported by tools and good infrastructures also practice schedule so that it motivates PLWH to keep exercising.

Besides, in every gathering of PLWH, drugs become stuff that cannot be brought to that place. PLWH who join Rumah Cemara having a lot of activities such as the international AIDS

candlelight memorial, peer counseling and adherence counseling. There is unwritten rule which say that every PLWH have to shift participate in one of those events. It makes norm as social control.

Social capital of group's behavior is directly described through norms, values, rules that are obeyed by society. Therefore, the more effective norm is obeyed the more potential social capital is developing.

V. ESTABLISHING SOCIAL CAPITAL IN INCREASING QUALITY OF LIFE

Prosperity life is not only based on economic resource or human resource but also it takes social capital. Trust, social network, and norm are component that will establish social capital. PLWH interprets how social capital plays its role to increase quality of life.

Relationship of social capital with physical is the main point of HIV/AIDS's problem having tight dependency. PLWH suffers symptom of HIV/AIDS that attacks physical. Through trust and network, PLWH receive comprehensive information from another PLWH about HIV/AIDS such as ARV dose which should be taken everyday, Rumah Cemara engages cooperation with hospital and being facilitator in accomodation of delievering ARV from hospital to PLWH.

Relationship of social capital with mental. PLWH have been through the lowest phase in their lives which is oppressed by depression due to their allienation about HIV/AIDS. PLWH pulls off themselves from social life to curse for what happen to them. Their trust is molded by those who bear same burden but made it through and it motivates them to do the same thing. Strength of social network tighten their mental to stuggle their future.

Relationship of social capital with social life. For Rumah Cemara, information of infected HIV/AIDS have to be known by parents no matter what. Rumah Cemara often becomes third side to make PLWH's family understand. Besides, discussion in Rumah Cemara talks about how PLWH get close to society, beginning with making a friend, reaching relationship, when the time is right (about a year) they begin to open their status, give them time to think then follow them back from their reaction. Shaping relationship with government, organization and organization international.

Relationship social capital with economic condition. PLWH tend to get discrimination making them to live a life independent in economic activity. Now, as foundation of volunteer Rumah Cemara can have sponsor and plait cooperation with government so that they are no longer difficult to fund event that they organize and even they can feed themselves who are 95% positive HIV/AIDS. Social network and norm push PLWH to organize business training and fund another PLWH to build their own enterprise such as trade juice, pet shop, convection.

VI. CONCLUSION

PLWH's perception on themselves is denial when they are first time infected as HIV/AIDS then symptoms that they experience causing self-acceptance of their status but tend to have prejudice of death due to less information about HIV/AIDS. It controls PLWH's behavior on social life such as being anti-social for months or even years. These conditions are slowly turning into good situation due to motivation that they receive from family, companion and other PLWH who join in Rumah Cemara so that it motivates them to start over taking care of them and making a contact with society.

PLWH gather themselves in organization called Rumah Cemara which try to give compassion to those who are infected and increasing PLWH's life with establishing trust, tight social network and norm that they obey together. Those attempts are well proven with better life of PLWH in physical aspect such as supporting of getting medical treatment. Mental aspect such as brand new spirit to carry on life. Social aspect such as training them to approach family and society. Economic aspect such as willing to live independently fulfilling their needs as member of organization, business training for them now it is proven with they build their own enterprise such as being trader or having convection.

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