

# MODEL FOR DEVELOPMENT OF COMMUNITY HEALTH CARE AS PARTNERS ON STIGMA AND QUALITY OF LIVING WOMEN WITH HIV/AIDS

Nursalam Nursalam<sup>1</sup>, Ernawati Ernawati<sup>2</sup>, Shrimarti Rukmini Devy<sup>3</sup>, Ferry Efendi<sup>1</sup>

<sup>1</sup>Faculty of Nursing, Universitas Airlangga, Surabaya, Indonesia

<sup>2</sup>Student of Doctoral Program, Faculty of Nursing, Universitas Airlangga, Surabaya, Indonesia

<sup>3</sup>Faculty of Public Health, Universitas Airlangga, Surabaya, Indonesia

## ABSTRACT

Women living with HIV / AIDS have low quality of life because of the strong stigma in society. The quality of life of women with HIV/AIDS is influenced by various factors including low social capital. The purpose of this research was to develop a model of community healthcare as partners (CHCP) on stigma and quality of women living with HIV/AIDS. This research was conducted using a cross-sectional approach in 119 people with multi-stage cluster sampling. The instrument of this study used questionnaire and data analysis used Structural Equation Modeling (SEM) based on variance or component based SEM, well-known as Partial Least Squares (PLS). Development of an HIV/AIDS cadre empowerment model, after a path analysis study and formulating strategic issues through focus group discussions (FGD) and expert discussions was in accordance with the research conducted. The influence of demographic factors, cadres' personal resources, cadre social contextual resources, and nurse support showed t-statistic >1.96 and p-value <0.05. This means that there was a significant influence on

all of these variables on the ability and empowerment of HIV/AIDS cadres. The resulting coefficient was positive, 0.502. Thus, it can be interpreted that the higher empowerment of HIV/AIDS cadres to the ability of HIV/AIDS cadres, the tendency can increase the cadres' empowerment. The Model of Community Health Service Development as a partner has a great influence on the stigma and quality of life with HIV/AIDS. The cadre personal resources factor was the strongest factor affecting cadre empowerment in HIV/AIDS, thus, the role of cadres as a partner in HI /AIDS becomes important to increase motivation in the sufferer.

**Keywords:** Community health, HIV/AIDS, Quality of Life, Stigma

## Correspondence:

Nursalam Nursalam

Faculty of Nursing, Universitas Airlangga, Surabaya, Indonesia

nursalam@fkip.unair.ac.id

## INTRODUCTION

Women living with HIV/AIDS have low quality of life because of the strong stigma in society (1). The quality of life of women with HIV/AIDS is influenced by various factors including low social capital and community support in reducing stigma (2,3). Community empowerment through the transformative role of cadres is believed to be a key approach in overcoming the problem of widespread HIV/AIDS stigma in the community (4,5). During this time, cadres who have been in Indonesia, such as posyandu toddlers, posyandu elderly, mental health and others (6). HIV/AIDS cadres are not widely known in the community and, so far, the model of empowering them to reduce stigma and improve the quality of life of women with HIV/AIDS has not yet been developed.

Stigma in sufferers is the main reason this disease continues to be a global epidemic (7). The population of women is predicted to increase along with social vulnerability to stigma (8). Every day there are an estimated 5000 new cases of HIV, more than 43% occur in women (9,10). The number of PLWHA worldwide in 2017 is estimated at 36.9 million, 18.2 million of which occur in women (more than 15 years) (UNAIDS, 2019). In the incidence of HIV sufferers in several European countries, Latin America and China, more than half are women. Likewise in Asia and the Pacific it is still focused on key populations and their partners (2,8), while, in Indonesia, the highest number of cumulative AIDS sufferers among housewives is 14,721 people with the highest percentage of AIDS risk factors from heterosexual sex risk (71%) (13).

A cadre is a volunteer recruited from, by and for the community, whose job is to assist the health services (14,15). The presence of cadres is often associated with routine services at the posyandu. As a posyandu, a cadre must be willing to work voluntarily and sincerely, willing

and able to carry out posyandu activities, as well as willing and able to move the community to carry out and participate in posyandu activities (1,16). The role of nurses is as health workers who directly intersect in the community and have long been at the forefront of integrating partnerships with communities through empowerment relationships to address the health gaps of vulnerable groups (17). The partnership strategy addresses the critical challenges of health human resources in Indonesia (18). The model of empowerment of HIV/AIDS cadres based on community partnerships has so far not been developed.

The concept of empowerment of the Health Empowerment Theory (HEI) by Shearer focuses on a relational process that facilitates deliberate participation in the achievement of health goals and promotion of wellbeing (19). Reformulation of empowerment thinking is still in the order of concepts, not yet fully realized in nursing practice (20). Cadre empowerment in Indonesia has been well-implemented, but HIV/AIDS cadres still have not contributed greatly due to social stigma in the community. The concept of health empowerment that has been applied so far is still focused on health workers only and has not integrated community elements, namely health cadres. This can be strengthened by the practice model offered by the community as partner (Anderson and McFarlan, 2011). The purpose of this research was to develop a model of community health care as partners on stigma and quality of living women with HIV/AIDS.

## METHODS

This research was conducted using observational analytics with the aim of analyzing several factors that influence the empowerment of HIV/AIDS health cadres based on community as partner using a cross-sectional approach. The

study population was all HIV/AIDS health cadres with the following criteria: 1) Women; 2) Muslim; 3) Active as a cadre in the community at least the last 3 months; and 4) Have received exposure to the problem of HIV/AIDS. The sample size in this study was 119 people with multi-stage cluster sampling. Cadre self-efficacy instruments used the New General Self-Efficacy Scale (Gilad, Stanley and Dov, 2001), Instruments of contracting fear used the Multicomponent AIDS Phobia Scale (Harrell and Wright, 1998), spiritual value questionnaire refers to the spiritual dimension (Yusuf et al., 2016), and the HIV-Knowledge Questionnaire measured knowledge (Carey and Schroder, 2002), Modification of the Berlin social support scale was also used as an instrument of support (Schwarzer and Schulz, 2013). Literature review (21,22) was also used, according to which the mythical instrument from the misconception questionnaire was prepared (Bhagavathula et al., 2015). The instrument recognizes diversity developed from a literature review (Cavaleros, Van Vuuren and Visser, 2012). Data analysis used structural equation modeling (SEM) based on variance or component, better known as partial least squares (PLS). An HIV/AIDS cadre empowerment model was developed after a path analysis

study and formulating strategic issues through focus group discussions (FGD) and expert discussions. The FGD was held and expert discussions were conducted to evaluate the new models found and prepare the forms of nursing intervention resulting from the development of the model.

## RESULTS

### Characteristics of Research Respondents

The study was conducted on health cadres, which were divided into the Hope Family Program (PKH), Citizens Care for AIDS (WPA), and Peer Support Groups (KDS). Overall, health cadres showed an average age of 32.5 years (SD = 8.83; CI = 30.89 - 34.1). The longest experience of becoming HIV/AIDS cadre from the peer support group is seven (7) years (SD = 2.23; CI = 1.08 - 3.92), while WPA cadres are still relatively new in the last two years. Table 1 shows that the majority of respondents have high education in senior high school and bachelor degree (50/119, 42.0% Vs. 51/119, 42.9%). Most of the respondents' jobs were as entrepreneurs (84/119, 70.6%) with the largest income being upper minimum regional (75/119, 63.0%).

**Table 1. The Characteristics of Respondents**

Indicator	N	%
<b>Age</b>		
20 – 29 years	47	39.5
30 – 39 years	47	39.5
40 – 49 years	25	40.0
<b>Duration as a Cadre</b>		
1 – 3 years	96	80.7
4 – 6 years	4	3.4
> 6 years	19	15.9
<b>Education Background</b>		
Elementary School	5	4.2
Junior High School	13	10.9
Senior High School	50	42.0
Bachelor	51	42.9
<b>Occupation</b>		
Farmer	6	5.0
Civil Servant	5	4.2
Housewives	24	20.2
Entrepreneur	84	70.6
<b>Economy Status</b>		
Under Minimum Regional Income	44	37.0
Upper Minimum Regional Income	75	63.0

### Inner Model Evaluation

Evaluation of the structural model or inner model is a stage to evaluate the goodness of fit, which includes the coefficient of determination and predictive relevance and hypothesis testing. Based on testing the inner model, the R-square value on the variable empowerment of HIV/AIDS cadres is 0.657 or 65.7%, which is described in terms of demographic factors, cadre personal resources, cadre social contextual resources, nurse support, and community line of resistance. The remaining 34.3% is contributed by other variables not discussed in this study. The R-square value on the capability of HIV/AIDS cadres is 0.252 or 25.2% and it is illustrated that the empowerment of cadres is 25.2%, while the remaining 74.8% is contributed by other variables. Predictive relevance (Q2) shows a value greater than 0, which means that the model is said to be good enough.

### Effect of Factors on Community Health Care as a Partner

Significance testing was used to test whether there is an influence of exogenous variables on endogenous variables. The test criteria state that, if the t-statistic value  $\geq$  T table (1.96) or P value  $< 0.05$ , then the existence of a significant influence of exogenous variables on endogenous variables is stated. The results of significance and model tests can be determined through the following figures and Table 2.

Hypothesis testing in the model development showed that demographic factors ( $p = 0.001$ ), cadres' personal resources ( $p = 0.000$ ), cadre social contextual resources ( $p = 0.000$ ), nurse support ( $p = 0.004$ ) and the community's line of resistance ( $p = 0.033$ ) indicate there was a significant influence to empowerment of HIV/AIDS cadres. The effect of empowering HIV/AIDS cadres on the ability of

HIV/AIDS cadres also showed significant influence ( $p = 0.000$ ). Thus, it can be interpreted that the higher value of t-statistic was cadre personal resources with - 9.007; this means that personal resource factor was the strongest factor affecting cadre empowerment in HIV/AIDS. The higher of

value of personal resources of cadres, showed the factor is able to increase the empowerment of HIV/AIDS cadres, so the role of cadres as a partner in HIV/AIDS becomes important.

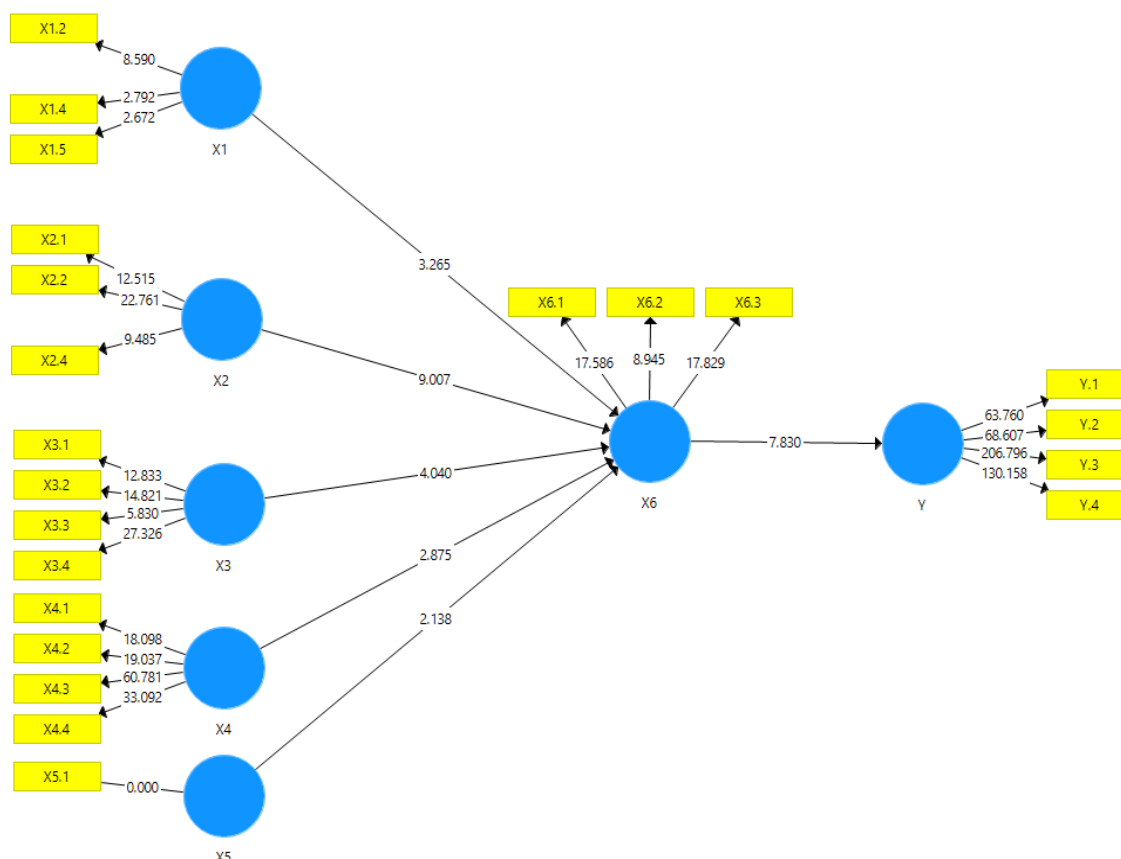


Figure 1. Inner model of Development of Community Health Care as Partners on Stigma and Quality of Living Women with HIV/AIDS

Table 2. Effect of Factors on Community Health Care as a Partner

Influence	Original Sample (O)	T-statistic ( O/STDEV )	P Value
Demographic factors (X1) influence empowerment of HIV/AIDS cadres (X6)	0.191	3.265	0.001
Cadres Personal Resources (X2) influence empowerment of HIV/AIDS cadres (X6)	0.549	9.007	0.000
Cadre social contextual resources (X3) influence empowerment of HIV/AIDS cadres (X6)	0.254	4.040	0.000
Nurse support (X4) influences empowerment of HIV/AIDS cadres (X6)	0.165	2.875	0.004
Community line of resistance for HIV/AIDS cadres (X5) influences empowerment of HIV/AIDS cadres (X6)	0.125	2.138	0.033
Empowerment of HIV/AIDS cadres (X6) influences ability of HIV/AIDS cadres (Y)	0.502	7.830	0.000

## DISCUSSION

The cadre personal resources factor was the strongest factor affecting cadre empowerment in HIV/AIDS, thus, the role of cadres as a partner in HIV/AIDS becomes important to increase motivation in sufferers. Cadre is a component of the community that is able to be a mobilizer and facilitator of the extension of health workers in primary health services in

meeting the needs of the community. The WHO recognizes active community participation as a key element of the program's success in achieving equitable healthcare. A 'grassroots' approach by exploring the potential of the community to manage important aspects of the community so that they can become partners for health services that have been provided by the government is necessary.

The empowerment of HIV/AIDS cadres is the result of transforming the right relationship between cadres and healthcare systems that support, encourage, enable or produce transcendence and self-actualization. The principle of building empowerment from health empowerment intervention through the use of social services and social support, which is interpreted as a positive relationship with others, emphasizes the importance of warm interpersonal relationships and mutual trust. The indicators used are connectedness to health services, self-actualization and respect for diversity.

Empowerment of cadres as partners must be able to build a cadre's self-capacity by education and open exchange of ideas through critical dialogue and reflection of critical thinking so that the ability of cadres increases with indicators capable of assisting PLWHA in meeting physical, emotional, social and spiritual needs to overcome stigma problems and improve the welfare and quality of life of women with HIV/AIDS in their areas. The concept of empowerment has three interrelated dimensions, namely: (1) the development of a more positive and stronger self-perception; (2) building knowledge and capacity for critical understanding of social and political realities in the surrounding environment; (3) strategies to strengthen resources and functional competencies to achieve personal and shared goals. The community participates in efforts to tackle HIV and AIDS by: (1) Promoting healthy living behaviors; (2) Increasing family resilience; (3) Preventing the occurrence of stigma and discrimination against HIV-infected people and families; (4) Forming and developing AIDS care for citizens; and (5) Encouraging citizens who have the potential to carry out risky HIV-infected behaviors to go to a voluntary counseling and testing service facility.

The model for development of community healthcare as partners on stigma and quality of living women with HIV/AIDS can be used as a good intervention. The concept of Community as Partner was introduced by Anderson and McFarlane (2008), which states the nursing process includes assessment; analysis and diagnosis; planning; community implementation and evaluation. Each client is seen with five variables, namely physiological, psychological, developmental, socio-cultural and spiritual, interacting synergistically with one another, interacting reciprocally with the internal and external environment. The aim of the Community-as-Partner model is to promote healthy communities while maintaining and promoting existing public health programs through collaboration, partnerships, and participation.

The community as partner model identifies community subsystems, which include health and social facilities, education, physical environment, communication, recreation, transportation and safety, economy (compensation incentives) as well as local government policies (communication access with stakeholders) (10). This social resource, according to the theory of social capital, is social capital to build a network of advice (access to communication with stakeholders), trust (access to internal communication of cadres) and communication (access to communication with the community) (8).

The combination of education interventions, community involvement, contacts with groups of people infected and affected by HIV/AIDS and ongoing counseling (ECCC) was identified as more effective than using a single approach (7). Stigma in people with HIV will have an impact: (1) Worse health; (2) Declining quality of life; (3) Refusing access to care; (d) Violence; (e) Poorer quality of life. Gaudine (2010) found the effects of stigma on people living with HIV are: avoided, experiencing anger and rejection, seen as socially

ill, and hiding the disease. Perspectives of family members about HIV-related stigma are: being shunned by neighbors, seen as poor parents, discriminated against by health professionals, listening to discussions about people with HIV, keeping secrets, financial difficulties for the family, and fear of contracting HIV. Whereas the perspectives of community members and leaders including health professionals are: stigma as a fair gift, avoidance and ostracism by neighbors, damage to family reputation, and fear of contracting HIV.

Quality of life (QOL) is an important measure of wellbeing or patient welfare. Quality of life is defined as an individual's perception of their position in life, in the cultural context and value system in which they live and their goals, expectations, standards, and concerns in relation to them. The WHO defines an individual's quality of life basically as a subjective evaluation of their own personal lives embedded in the context of their culture and values.

## CONCLUSION

The cadre personal resources factor was the strongest factor affecting cadre empowerment in HIV/AIDS, thus, the role of cadres as a partner in HIV/AIDS becomes important to increase motivation in sufferers. Cadre is a component of the community that is able to be a mobilizer and facilitator of the extension of health workers in primary health services in meeting the needs of the community. The model for development of community healthcare as partners on stigma and quality of living women with HIV/AIDS can be used as a good intervention.

## REFERENCES

1. Sousa LRM, Moura LKB, Valle ARM da C, Magalhães R de LB, Moura MEB. Social representations of HIV/AIDS by older people and the interface with prevention. *Rev Bras Enferm.* 2019;72(5):1129–36.
2. Trickey A, May MT, Vehreschild JJ, Obel N, Gill MJ, Crane HM, et al. Survival of HIV-positive patients starting antiretroviral therapy between 1996 and 2013: a collaborative analysis of cohort studies. *Lancet HIV.* 2017;4(8):e349–56.
3. Alsayed NS, Sereika SM, Albrecht SA, Terry MA, Erlen JA. Testing a model of health-related quality of life in women living with HIV infection. *Qual Life Res.* 2017;26(3):655–63.
4. Rabkin M, De Pinho H, Michaels-Strasser S, Naitore D, Rawat A, Topp SM. Strengthening the health workforce to support integration of HIV and noncommunicable disease services in sub-Saharan Africa. *Aids.* 2018;32:S47–54.
5. Besada D, Goga A, Daviaud E, Rohde S, Chinkonde JR, Villeneuve S, et al. Roles played by community cadres to support retention in PMTCT Option B+ in four African countries: A qualitative rapid appraisal. *BMJ Open.* 2018;8(3).
6. Jiang S, Lv L, Li Q, Wang J, Landfester K, Crespy D. Tailoring nanoarchitectonics to control the release profile of payloads. Vol. 8, *Nanoscale.* 2016. p. 11511–7.
7. Potez C, Bridou M, Fouéré S, Montreuil M. The role of psychological factors in the uptake of HIV testing. *Ann Med Psychol (Paris).* 2018;176(6):559–66.
8. Vakili F, Alipour A, Merghati Khoei E, Rasoolinejad M. HIV infected women vulnerability for presenting sexual dysfunction: The role of sexual dysfunctional beliefs. *Sexologies.*

- 2019;28(4):177–82.
9. Fan S, Liu Z, Luo Z, Yu M, Ouyang L, Gong H, et al. Effect of availability of HIV self-Testing on HIV testing frequency among men who have sex with men attending university in China (UniTest): Protocol of a stepped-wedge randomized controlled trial. *BMC Infect Dis.* 2020;20(1).
10. Oyaro P, Kwena Z, Bukusi EA, Baeten JM. Is HIV self-testing a strategy to increase repeat testing among pregnant and postpartum women? A pilot mixed methods study. *JAIDS J Acquir Immune Defic Syndr.* 2020; Publish Ahead of Print.
11. UNAIDS. Global HIV and AIDS statistics. Avert [Internet]. 2019;1:1–6. Available from: [https://www.unaids.org/sites/default/files/media\\_asset/UNAIDS\\_FactSheet\\_en.pdf](https://www.unaids.org/sites/default/files/media_asset/UNAIDS_FactSheet_en.pdf)
12. Ministry of Health of Republic Indonesia. Indonesia Health Profile 2018. Profil Kesehatan Provinsi Bali. 2019.
13. Faturiyele IO, Appolinare T, Ngorima-Mabhena N, Fatti G, Tshabalala I, Tukei VJ, et al. Outcomes of community-based differentiated models of multi-month dispensing of antiretroviral medication among stable HIV-infected patients in Lesotho: A cluster randomised non-inferiority trial protocol. *BMC Public Health.* 2018;18(1).
14. Roy M, Bolton Moore C, Sikazwe I, Holmes CB. A Review of Differentiated Service Delivery for HIV Treatment: Effectiveness, Mechanisms, Targeting, and Scale. Vol. 16, *Current HIV/AIDS Reports.* 2019. p. 324–34.
15. Beres LK, Narasimhan M, Robinson J, Welbourn A, Kennedy CE. Non-specialist psychosocial support interventions for women living with HIV: A systematic review. *AIDS Care - Psychol Socio-Medical Asp AIDS/HIV.* 2017;29(9):1079–87.
16. Anderson, E. T. and McFarlan, J. (2011) *Community As Partner Theory and Practice in Nursing.* Sixth Edit. Lippincott Williams.
17. Bryant-Lukosius D, Valaitis R, Martin-Misener R, Donald F, Peña LM, Brousseau L. Advanced practice nursing: A strategy for achieving universal health coverage and universal access to health. *Rev Lat Am Enfermagem.* 2017;25.
18. Richardson RA. Measuring Women's Empowerment: A Critical Review of Current Practices and Recommendations for Researchers. *Soc Indic Res.* 2018;137(2):539–57.
19. Crawford Shearer NB. Health Empowerment Theory as a Guide for Practice. *Geriatr Nurs (Minneap).* 2009;30(2 SUPPL. 1):4–10.
20. Juanamasta IG, Nursalam N, Efendi F, Erwanyah RA. Stigma of People Living with HIV/AIDS. *NurseLine J.* 2020;4(2):154.
21. Nursalam, Efendi F, Tristiana RRD, Primasari NA. Determinants of stigma attitude among people living with HIV. *J Glob Pharma Technol.* 2019;11(8):274–9.