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Family Empowerment Model Based on Belief and Health-Related Quality of Life among Housewives With HIV/AIDS

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ABSTRACT

The trend of Human Immunodeficiency Virus/ Acquired Immunodeficiency Syndrome (HIV/AIDS) prevalence in Indonesia has increased significantly. This study was aimed to develop family empowerment model based on belief and analyze the effects of health-related quality of life (HRQL) in patients infected by HIV/AIDS. Mixed methods design with the first stage using quantitative research with cross sectional approach. A total 135 respondents with HIV/AIDS were determined from purposive sampling. For developing the model, we conducted focus group and expert discussion to make the model and the intervention tool for the second stage. We analyzed the collected data using Structural Equation Model Partial Least Squares (SEM-PLS) test. The outer loading value measured the sub-variable validity value of its latent variable, where the outer loading is valid if the value is >0.4. Based on the research results, nine indicators were invalid (outer loading value ≤ 0.4), and the indicator must be removed from the model. Evaluation of inner models was used to test the research hypotheses. The research hypothesis can be accepted if the value of T count >T table. The health services, patient factors, family factors and empowerment have a significant influence between some of these factors on HQRL (T >1.96). The development of a family empowerment model based on belief has a good effect in health-related quality of life among women with HIV/AIDS. From the developed model, it be seen that HRQL is related to health services, patient factors, family factors and empowerment.

Keywords: Belief, Family empowerment, Health-related quality of life, HIV/AIDS, Housewives

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INTRODUCTION

The trend of HIV/AIDS prevalence in Indonesia shows significant increment (DG of Disease Control and Environmental Health and Ministry of Health, Republic of Indonesia, 2014). In 2002, there was a new phenomenon of the HIV/AIDS spread in households (Ministry of Health, Republic of Indonesia, 2017). In addition, one of the problems in dealing with HIV-related symptoms over a long period are , social problems, stigma, poverty, depression, substance abuse and cultural beliefs, all of which have an effect on decreasing immunity (1,2) and impact on quality of life in the form of Health Related Quality of Life (HRQL) (3,4). Low HRQL can affect the immune response and make health conditions worsen (5,6).

Quality of life is an individual's perception in life, cultural context, value system of life with goals, standard expectations and interest. HRQL assessment is a subjective evaluation that is embedded in the cultural, social and environmental context. Family Empowerment is a intervention to improve the HRQL of HIV/AIDS sufferers by involving the closest people in a sufferer's life, including family (7,8). Empowerment increases the ability and independence of the community in improving living standards (9). However, the influence of belief-based family empowerment on HQRL, community stigma and immune response (CD4 and Viral Load) has not been proven.

There is a prevalence of more than 6.5 million women in Indonesia vulnerable to contracting with HIV, because infection cases appear in the household environment. Housewives with HIV/AIDS in 2017 reached the highest number of cases (12,302 housewives' infection) (Directorate General of Disease Prevention and Control, 2017). East Java, one of the areas with the greatest number of residents in Indonesia, reported HIV / AIDS infection reached 362 cases. The increasing cases create a problem in HQRL due to welfare aspects and assessing the needs of patients used as material for health promotion.

Factors affecting HQRL are depression symptoms, physical functioning, overall general health and overall quality of life (10,11). Referring to the change and maintenance of health-related behaviors, a guiding framework of health behavioral interventions is called the Health Belief Model (HBM) (12). HBM is a psychological theory predicting the emergence of a person's health behavior (13) and belief-based family empowerment has an impact on strengthening and improving the condition of HIV/ AIDS sufferers. Reviewing using HBM can increase confidence and lead to improved HQRL in housewives infected with HIV/AIDS and is assessed through the body's immune response. This study aimed to develop a family empowerment model based on belief and analyze the effects of HRQL in patients infected by HIV/AIDS.

METHODS

A mixed method study with the first stage of quantitative research design with cross -sectional approach was carried out. The study sample were 135 respondents using purposive sampling selection with inclusion criteria: women had been married; diagnosed with HIV/AIDS for at least six months; age above 20 years; and do not have psychiatric disorders. The exclusion criteria were hospitalized patients and patients in the severe category. For developing the model, we conducted the family empowerment interview instrument adopted from the family empowerment scale (FES) about quality of life and psychological fulfillment. We tested the validity of the results of the interview using a

credibility test (internal validity) with triangulation of sources from patients, families, AIDS Commissions, and medical teams focusing on HIV/AIDS patients, and analyzed used grouping of themes, sub-themes and categories. The results were summarized and then validated again. Focus group and expert discussion were conducted after collecting data to make the model and intervention tool for stage two of the research. Analysis between variables used Structural Equation Model – Partial Least Squares (SEM-PLS) T measure factors to develop the model.

RESULTS

Majority of respondents aged 38-42 years (41/135, 30.4%) and females were predominant (73/125, 54.1%). The most recent education respondents were high school graduates (69/135, 51.1%) and most respondents were married (73/135, 54.1%) with the average occupation being employee (73/135, 54.1%). From the study result, most of the HIV respondents were asymptomatic (65/135, 48.1%) and no opportunistic infection (130/135, 96.3%). Patient's conditions were independence (123/135, 91.1%) with feelings about health, both of condition and self-perception (113/135, 83.7% and 104/135, 77.0%, respectively). Some of respondents had been diagnosed HIV more than one year, first HIV test more than one monthsand had transmission from sexual activity (85/135, 63.0%; 94/135, 69.6%; 114/135, 84.4%, respectively) (Table 1)

Table 1: Characteristic of Respondents

Characteristic of respondents	Parameter	n	%
Age	10-16	1	0.7
	17-23	9	6.7
	24-30	20	14.8
	31-37	35	25.9
	38-42	41	30.4
	43-50	24	17.8
	51-57	4	3.0
	58-64	1	07
Gender	Male	62	45.9
	Female	73	54.1
Education	Elementary School	27	20.0
	Junior High School	26	19.3
	Senior High School	69	51.1
	Bachelor	13	9.6
Marital Status	Single	36	26.7
	Married	73	54.1
	Death divorced	18	13.3
	Divorced	8	5.9
Job	Civil servant	2	1.5
	Employee	73	54.1
	Enterpreneur	21	15.6
	Doesn't work	39	28.9
HIV status	Asymptomatic	65	48.1
	Symptomatic	49	36.3
	AIDS	21	15.6
Opportunistic infection	Yes	5	3.7
	No	130	96.3
Patient independence	Independence	123	91.1
	Partial care	12	8.9
	Total care	0	0
Health condition	Health	113	83.7
	Unwell	19	14.1
	Sick	3	2.2
Self Perception	Being sick	31	23.0
	Health	104	77.0
HIV diagnosed	< 1 Year	50	37.0
	> 1 Year	85	63.0

First HIV test	< 1 Month	41	30.4
	> 1 Month	94	69.6
HIV Transmission	Sexual fluid	114	84.4
	IDU	19	14.1
	MTCT	2	1.5

Variable Identification of Model Development

Support from facility (59/135, 43.7%), policy implementation (74/135, 54.8%), HIV prevention (71/135, 52.6%) and government activity (40/135, 29.6%) were sub-observational variables for policy. Health services were measured by twovariables (health facility access and health workers) and both variables gave support to patient (64/135, 47.4% and 107/135, 79.3%) (Table 2). In addition, patient factors consisted of 13 variables: age, gender, education, marital status, occupation, HIV status, opportunistic infections, patient independence, health conditions, self-perception, duration of HIV infection, first HIV test and HIV transmission (Table 1).

Family burden, social support, family stress, and family resilience were observational variables for family factors. From the results, the predominant category was they were not supported to respondents with HIV (family burden, social support, family stress, 101/135, 74.8%; 58/135, 43.0%, 111/135, 82.2%, respectively), but there was family resilience support to patients (83/135, 61.5%). The empowerment of respondents was measured from cognitive, personal threat and motivation. The majority results in the criteria of empowerment were cognitive and personal threat (113/135, 83.7% and 108/135, 80.0%, respectively) and motivation as the most dominant indicator (124/135, 91.9%) (Table 2).

HQRL was measured with physical function and overall general health. Of the three HQRL indicators, the majority of respondents felt quality of life in high condition. But there were some respondents who felt in a low condition after suffering from HIV. Respondents still needed efforts to strengthen HQRL, especially in the aspects of physical function and overall general health, where there were still respondents in the low category (102/135, 75.6% and 92/135, 68.1, respectively) (Table 2).

Table 2: Variable Identification of Model Development

Indicator	Category					
	Support		Less Support		Does not Support	
	N	%	N	%	N	%
Policy						
Facility	59	43.7	43	31.9	33	24.4
Policy Implementation	74	54.8	37	27.4	24	17.8
HIV Prevention	71	52.6	46	34.1	18	13.3
Government Activity	40	29.6	27	20.0	68	50.4
Health service						
Health facility access	64	47.4	43	31.9	28	20.7
Health workers	107	79.3	14	10.4	14	10.4
Family factors						
Family burden	8	5.9	26	19.3	101	74.8
Social support	10	7.4	67	49.6	58	43.0
Family stress	6	4.4	18	13.3	111	82.2
Family Resilience	83	61.5	32	23.7	20	14.8
Empowerment						
Cognitive	113	83.7	17	12.6	5	3.7
Personal threat	108	80.0	20	14.8	7	5.2
Motivation	124	91.9	6	4.4	5	3.7
HRQL						
Physical function	92	68.1	32	23.7	11	8.1
Overall general health	126	93.3	8	5.9	1	0.7

Evaluation of the Outer Model Analysis

The outer model was evaluated by measurement of the validity and reliability. Convergent validity was determined using loading factors and the average variance value extracted (AVE). Measurements can be categorized as having convergent validity and reliability if the loading factor value >0.6 and AVE value >0.5. Based on the research results, it can be seen that nine indicators were invalid (outer loading value was ≤ 0.4), and these must be removed from the model.

Evaluation of the Inner Model Analysis

Evaluation of inner models was used to test the research hypotheses. The research hypothesis can be accepted if the value of T count > T table. The health services, patient factors, family factors have a significant influence on empowerment (T >1.96). The results of the hypothesis test are described as follows: (1) Policies (facilities, policy implementation and government activities) improve empowerment; (2) Good health services (health workers) increase family empowerment; (3) Patient factors (age, marital status, patient independence, health conditions, self-perception, duration of HIV infection, first HIV testing, HIV transmission) influence empowerment; (4) Family factors (social support and family resilience) influence empowerment; (5) Empowerment (cognitive, personal threat, motivation) influences stigma (labeling, isolation, and discrimination); and Empowerment (cognitive, personal threat, motivation) affects HQRL (physical function and overall general health) (Table 3).

The evaluation of developing the family empowerment model based on belief with health-related quality of life was influenced by some factors: policy, health service, patient factors and family factors. Four latent variables impacted family empowerment and influenced HRQL. The novelty of this model was family empowerment based on belief; there were some components of the belief that were compared with empowering (Table 3).

Table 3. Hypotheses Test of Model Development

Varible	Path coeficient	Std Devition	T statistic	Significancy
Effect policies to HQRL	.058	.051	.615	Not significant
Effect health service to HQRL	.379	.150	1.847	Significant
Effect patient factors to HQRL	.173	.243	3.343	Significant
Effect family factors to HQRL	.042	-.414	-5.258	Significant
Effect empowerment to HQRL	.084	.473	6.383	Significant

DISCUSSION

Family empowerment is important for people with HIV/AIDS in their life. Family with empowerment integrate in social processes, recognize, promote and enhance the ability of people to find their own needs, solve their own problems and mobilize the resources needed to control their lives (Arief et al., 2018). Family empowerment has the following components of patient participation, patient knowledge and patient skills (Wilson et al., 2018), which can be useful in the care of patients infected with HIV/AIDS. The importance of family participation in the model of empowerment developed is needed by HIV/AIDS fighters; the support system of the family can increase patient motivation to improve body immunity and health (5)

Family empowerment combines with HBM, a psychological theory focused on health behavioral changes, giving effect to strengthen and change the HIV/AIDS condition based on belief so as to improve HRQL in housewives. In this research, we focused on developing a model of family empowerment based on belief; empowering was main component to increase motivation in HIV/AIDS sufferers. Empowering can make a person more confident and believe in fighting HIV/AIDS, even though the immune system may be worsening. HRQL is related to health services, patient factors, family factors and empowerment in patients with HIV. HRQL is a multi-dimensional concept that includes domains related to physical, mental, emotional, and social functioning (5). It goes beyond direct measures of population health, life expectancy, and causes of death, and focuses on the impact health status has on quality of life (4). We found in our study that health service variables (health facility access and health worker) were reported supporting to HRQL.

Improved health services for HIV/AIDS patients are needed to make sufferers healthier, more qualified and productive, so that they do not fall into the condition of AIDS and bring about many symptoms (14). Health services for people with HIV/AIDS must be provided early, especially when a patient's diagnosis is established (15). Patients will feel quality of life if the disease is at the stage of acceptance (16). Health workers are also associated with HRQL patients because they give the best service when patients go to healthcare services for medicine regularly (17).

Patients factors showed significant association to HRQL; based on this research, productive age, 38-42 years, has effect on HRQL (9). In contrast with the result of chronic disease quality of life, no significant correlations were found between age of the assessed HRQL domains or symptom scales, but the results are in line with research about older age feeling about end of life (18). They stated that age has association with quality of life, because age gives them experience to face their problems and activities during life. Females also associate with good HRQL, the reason being many women become housewives and they will accept faster than career women (5). Males with HIV/AIDS showed worse quality of life because it changes their role in family. Education and marital status have better HRQL because higher education background makes sufferer better understand and being in relationship as a couple can give them support while suffering HIV/AIDS (1). Acceptance period in HIV/AIDS patients showed variation; some sufferer just needed less than one year and others need more to accept with their condition. HIV/AIDS transmission has become the highest cause to psychological responses in patients (4).

The role of the family has high contribution to quality of life in HIV/AIDS patients. Family burden, social support, family stress and family resilience show different ways in every family. When a family cares for HIV/AIDS patients, they generally state that they feel a burden and get tired because patients are often readmitted to the hospital. This condition

make them spend their time in the hospital to support their families member (19). Supporting factors also give good contribution in HIV/AIDS quality of life, because better HRQL was show from respondents who had good support from their family, friends and society (20). Family burden in caring of HIV/AIDS patients causes stressors in family and can develop to psychological stress. Some of the family will feel burnout and give up. From this condition, family resilience becomes an important factor (21). Family resilience showed better results when the relation between family members was good. The empowerment of patients will increase patient activity and actualization, allowing the patient to develop their ability and not limit their actions. HIV sufferers can give each other support and work together. Some of the sufferers join the HIV/AIDS community and there are many events or activities to build their confidence and support each other (15,17,19).

CONCLUSION

The development of the family empowerment model based on belief has a good effect in quality of life among housewives with HIV/AIDS. The model gives new advantages to improve motivation and belief in HIV/AIDS sufferers. This model development goal was empowerment of the family role to give care to sufferers and this has good impact on patients HRQL. The evaluation of the family empowerment model based on belief in regard to health-related quality of life was influenced by some factors: influenced were policy, health service, patient factors and family factors.

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