

# Self-management: A comprehensive approach to improve quality of life among people living with HIV in Indonesia

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## Abstract

**Background:** People living with HIV (PLWH) today have to deal with a chronic condition that requires efficient self-management due to increased longevity. Self-management interventions have been shown to improve physical and psychological symptoms as well as clinical results in chronic diseases. However, few studies have investigated the effect of self-management on quality of life (QOL) among PLWH in Indonesia.

**Objective:** To examine the effect of a self-management program on QOL among PLWH in Indonesia.

**Methods:** This was a quasi-experimental study with a comparison group in a general hospital in Jakarta, Indonesia. Of the 114 recruited PLWH, 57 were assigned to the intervention group and 57 to the comparison group. The self-management group attended a four-week program workshop. The intervention consisted of five sessions: need assessment and goal setting, maintaining a healthy lifestyle, educational participation to increase communication and self-esteem, and evaluation. The comparison group received standard educational material throughout the leaflet regarding HIV prevention. The post-test assessment was conducted immediately after intervention (T1) and two months (T2) after the intervention in both groups. QOL was measured using the World Health Organization Quality of Life (WHOQOL)-HIV brief Bahasa version. The estimations were obtained using fixed-effect regressions. The differences between T0, T1, and T2 for the intervention and comparison groups were evaluated and compared using the DI Differences method (DID).

**Results:** The self-management program improved outcomes relative to the comparison group at T1: 1) overall QOL score increased 8.7% (95% CI 0.021–0.149), 2) physical domain saw a modest increase 8.8% (95% CI 0.017–0.125), 3) psychological domain increased 23.5% (95% CI 0.085–0.689), and 4) environmental domain showed a modest increase of 18.7% (95% CI 0.053–0.371). At T2, the total QOL score and the physical, psychological, and environmental dimensions were significantly improved compared to the comparison group.

**Conclusion:** The self-management program appears to improve the QOL of the life of PLWH. Nurses are advised to provide PLWH with self-management training. Future research on self-management intervention would need to be refined further to ensure that each community achieves consistent intervention outcomes.

## Keywords

self-management; quality of life; health-related quality of life; HIV/AIDS; nursing; Indonesia

The human immunodeficiency virus (HIV) is a major global health problem that directly impacts social growth. In Indonesia, the first case of AIDS was registered in 1987, and as of 30 March 2020, 511.955 people were living with

HIV (PLWH) and 17.210 HIV-related deaths ([Ministry of Health of Indonesia, 2020](#)). As of March 2020, HIV is a primary concern in Indonesia, notably among heterosexuals, the male who has sex with male (MSM), and

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female sex workers. In 2020, HIV transmission was primarily transmitted via sexual intercourse; 66.6% among heterosexuals and 28.2% among MSM (Ministry of Health of Indonesia, 2020).

Although the use of highly active antiretroviral therapy (HAART) in the treatment of HIV has resulted in a substantial decrease in morbidity and mortality (Nakagawa et al., 2012), psychological and social problems remain to have a devastating effect on people living with HIV (Bravo et al., 2010). PLWH are similarly vulnerable in Indonesia, as they are a sexual minority and therefore have a more severe risk of developing issues such as depression, anxiety, and stress disorder (Ghiasvand et al., 2020; Mahathir et al., 2021). Moreover, HIV is now considered a controlled infectious chronic disease (Lindayani et al., 2020). The longstanding nature of HIV infections and social discrimination are known to cause poor social adaptations to PLWH (Engelhard et al., 2018). The major problem in Indonesia is the rapid growth in the number of people living with HIV, compounded by steady growth in demand for medical services. HIV is a worldwide issue, and therefore, the management system based on HIV comprehensive care is no longer adequate to meet the needs for prevention and treatment. New management models must be developed to find better and fulfill the service needs of PLWH needs.

Quality of life (QOL) is being used increasingly to evaluate the effectiveness of medical interventions. Due to the new healthcare paradigm, medical practitioners are no longer solely focused on life expectancy as a metric (O'Brien et al., 2021). On treatment-related QOL assessments, the physiological, social, environmental, and psychological aspects can all be considered (Cooper et al., 2017). QOL is a multifaceted concept that refers to the effect of health on a person's assessment of their wellness and degree of generally functioning in essential areas of their lives (Cooper et al., 2017). Previous studies reported that the HIV population has a lower quality of life than the non-HIV group (Ghiasvand et al., 2020; Lindayani et al., 2020). HIV is a chronic and degenerative infectious disease leading to lowered QOL, not only in overall score but also in all QOL domains (Ghiasvand et al., 2020; Lindayani et al., 2020; Lindayani et al., 2018a; Handayani et al., 2019). QOL of people with HIV/AIDs depends on a variety of complex variables, including mood, social support, problem-solving abilities, and ways of dealing with problems (Engelhard et al., 2018; Lindayani et al., 2018b). In addition, the study reported that lower QOL was associated with a higher mortality rate (Portilla-Tamarit et al., 2021).

Self-management is characterized as a person's capability to handle illness and promote health in collaboration with family, society, and healthcare providers (Richard & Shea, 2011). In particular, patients are educated in self-management via a series of training programs on health education to provide relevant knowledge, management skills, and communication skills. It is particularly well-suited to the day-to-day treatment of chronic conditions that necessitate the lifelong

management of a broad range of biological, psychological, and social issues. Generally, patients are expected to rely on themselves to take care of their various medical and psychological conditions that may develop due to their illness (Nolte & Osborne, 2013). Self-management strategies thrive in various chronic conditions, including diabetes, kidney disease, chronic obstructive pulmonary disease, and chronic pain (Franek, 2013; Richardson et al., 2014; Schulman Green et al., 2016; Zhang et al., 2019).

Self-management is an essential part of HIV prevention or treatment as HIV has become chronic with successful therapy (Elzarrad et al., 2013). Both HIV infection and aging require enhanced self-management skills to live and age healthily. Individuals can improve self-management in various ways, including healthy eating behavior or regular to moderate activities (Aleri et al., 2020). Evidence has been found that self-management interventions conducted in PLWH could improve adherence to HAART and reduce symptoms burden (Nkhoma et al., 2018; Webel et al., 2018), stress and anxiety (Khumsaen & Stephenson, 2019), and mood and coping strategies (Khumsaen & Stephenson, 2019; Iribarren et al., 2018). However, few studies have been conducted to investigate the impact of self-management on the quality of life of PLWH in Indonesia (Webel et al., 2018; Cutrono et al., 2016; Jaggars et al., 2016). Those prior studies did not focus on the implementation structure of self-management intervention but instead on the influence of various lifestyle behaviors combined with exercise. Educating and caring for patients with chronic illnesses about disease self-management is a critical function of nurses. In order to inform nurses and policymakers about the self-management program, it is necessary to design appropriate self-management for PLWH in Indonesia. Thus, the current study aimed to examine the effect of a self-management intervention on QOL among PLWH in Indonesia.

## Methods

### Study Design

This study was conducted using a quasi-experimental design with a comparison group to evaluate the effect of self-management on QOL among PLWH in Indonesia.

### Participants and Setting

The participants were recruited from the two HIV clinics at general hospitals in Jakarta from January 2020 and ended in May 2020. The inclusion criteria were aged over 18 years old, diagnosed with HIV minimum of six months, and willing to voluntarily participate in the project with written informed consent. The exclusion criteria were those with major mental disorders or depression. A convenience sampling strategy was used to select potential participants.

The power estimate using G power analysis (Faul et al., 2009) was based on the results of a previous study in which the primary outcome indicator was self-efficacy for managing HIV symptoms (Khumsaen & Stephenson, 2019). Based on these results, it was calculated that the

sample size was 52 for each group, assuming a moderate to large effect size ( $d = 0.5-0.8$ ) with 80% power and a 5% significance level. The sample size was added 10% to prevent from high attrition rate during the intervention. Thus, this study recruited 114 PLWH (57 in the intervention group and 57 in the comparison group). Baseline homogeneity was ensured by taking into account factors such as age, level of education, and length of HIV infection.

**Instrument**

The questionnaires included demographic information, including birth date, gender, education level, marital status, and monthly income. Clinical data included CD4 cell counts, receiving HAART, and length of HIV infection.

The WHOQOL-HIV short Bahasa version (The WHOQOL-HIV BREF) was used to assess QOL, which contains physical, psychological, social, and environmental domains. In addition, two additional generic items assess overall QOL and general health. The WHOQOL-HIV BREF items are all assessed on a 5-point Likert scale, 1 being low perception and 5 being high perception. Cronbach's alpha was ranged from 0.71 to 0.85 (Lindayani et al., 2018a).

**Intervention**

People in the self-management group participated in a workshop for four weeks. Each session had between 18 and 17 PLWH. In summary, the curriculum was based on

Banduras' social learning theory's self-efficacy theory. The self-management model developed by Nolte et al. (2007) was adopted to enhance skills, motivation, and abilities to deal with physical-psychosocial burdens. Self-management emphasizes the importance of the person/patient in managing their condition(s) and improving their quality of life. Participants were motivated to take responsibility for their physical, social, and emotional wellness and behavioral changes to control their health better. **Table 1** provides an overview of the content self-management program for PLWH.

To monitor participant's compliance, we provided a diary book, biweekly phone calls, and monthly home visits. Every two-week nurse made a phone call during the intervention program to ensure that the participant was doing the intervention program. Then, every month nurse conducted a home visit to do data collection (diary book) and follow up related to their g program (e.g., assessment of their problems and how they encounter the problems during the process) and encourage them to continue doing an intervention.

The comparison group received standard educational material throughout the leaflet regarding HIV prevention developed by the research team. The content of educational materials was HIV basic information, treatment, and prevention.

**Table 1** Content of self-management program for PLWH

Session	Aims	Content	Strategies
First session (Step 1: need assessment and goal setting)	<ul style="list-style-type: none"> <li>- Introducing the importance of self-management for PLWH.</li> <li>- Importance of information self-management, benefits, and barriers.</li> <li>- Health goal setting</li> </ul>	<ul style="list-style-type: none"> <li>- Understanding and awareness: role self-management program for PLWH</li> </ul>	<ul style="list-style-type: none"> <li>- Lecture, questions, and answers</li> <li>- Sharing experiences</li> <li>- PowerPoint presentations</li> </ul>
Second session (Step 2: Maintaining a healthy lifestyle)	<ul style="list-style-type: none"> <li>- Improve ability and skill to manage their symptoms</li> <li>- Improve skill to maintain emotional well being</li> </ul>	<ul style="list-style-type: none"> <li>- Symptom management</li> <li>- HIV-related emotion management (stress management &amp; depression)</li> </ul>	<ul style="list-style-type: none"> <li>- Group discussion and sharing experiences</li> <li>- Educational booklet</li> <li>- Counseling and online follow-up at home.</li> </ul>
Third session (Step 3: Maintaining a healthy lifestyle)	<ul style="list-style-type: none"> <li>- Improve their knowledge about appropriate medication</li> <li>- Maintaining a healthy lifestyle</li> </ul>	<ul style="list-style-type: none"> <li>- Prompt use of appropriate medications</li> <li>- Physical exercises and workouts</li> <li>- Nutrition instructions</li> </ul>	<ul style="list-style-type: none"> <li>- Lecture, questions, and answers</li> <li>- Sharing experiences</li> <li>- Educational booklet</li> </ul>
Fourth session (Step 4: educational participation to increase communication and self-esteem)	<ul style="list-style-type: none"> <li>- Be confident about how to resolve problems and communicate with others</li> </ul>	<ul style="list-style-type: none"> <li>- Assertive communication skills</li> </ul>	<ul style="list-style-type: none"> <li>- Sharing experiences</li> <li>- Group discussion</li> </ul>
Fifth session (Step 5: evaluation)	<ul style="list-style-type: none"> <li>- To assess both the method and the final result of the program</li> </ul>	<ul style="list-style-type: none"> <li>- Wrapping up</li> </ul>	<ul style="list-style-type: none"> <li>- Sharing experiences</li> <li>- Group discussion</li> </ul>

**Data Collection**

Ethical permission was obtained from the institutional research board from the affiliated university. We presented our study objectives, benefits, inclusion and exclusion

criteria, and commitment to protecting the subjects to the head nurse and HIV case managers. Managers had previously informed participants before data collection began. Participants who meet the inclusion criteria were

scheduled for an in-person appointment to complete a consent form. They then completed the QOL assessments described below. After completing baseline (T0) assessments, participants were assigned to two groups: intervention or comparison. The research team has carried out the intervention. The intervention condition was a five-session, group intervention online teaching behavioral changes strategies and positive lifestyle education. Post-test assessments were given to both groups immediately after intervention (T1) and two months later (T2).

### Data Analysis

The demographic data and QOL scores were summarized using descriptive statistics. We compared the baseline characteristics of the two groups using independent t-tests to control the bias due to non-random sampling. Participants in the intervention and comparison groups were compared using regression models that accounted for baseline data of the dependent variable. The general linear

with a fixed-effect model was used to obtain the estimates. A significant variable resulting from comparing the two groups' baseline characteristics was put as a covariate. The differences between T0, T1, and T2 for intervention versus the comparison group were estimated calculated in the comparison of DI Differences (DID). All statistical studies were carried out using SPSS Statistics 23.0, with a significance level of 0.05 chosen to determine statistical significance.

### Results

The characteristics of the participants in the intervention group were compared to the comparison group are listed in Table 2. In terms of demographic and clinical data, there were no significant differences between the intervention and comparison groups.

**Table 2** Comparison of selected baseline characteristics of intervention and comparison participants ( $n = 114$ )

Variables	Experiment, ( $n = 57$ ) %	Comparison, ( $n = 57$ ) %	$p$ -value
<b>Demographic characteristics</b>			
Age in year (Mean $\pm$ SD)	31.56 $\pm$ 5.37	32.08 $\pm$ 4.82	0.166 <sup>a</sup>
Gender			
Male	30 (52.6)	31 (54.4)	0.377 <sup>b</sup>
Female	27 (47.3)	25 (43.8)	
Marital status			
Married	13 (22.8)	20 (35.1)	0.417 <sup>b</sup>
Single/Widow/Divorce	44 (77.2)	37 (64.9)	
Education level			
Below senior high school	35 (61.4)	40 (70.2)	0.071 <sup>b</sup>
Above senior high school	22 (38.6)	17 (29.8)	
Household income			
Below regional minimum salary	41 (71.9)	38 (66.7)	0.113 <sup>b</sup>
Above regional minimum salary	16 (28.1)	19 (33.3)	
<b>Clinical information</b>			
CD4 cell counts, cell/mm <sup>3</sup> (Mean $\pm$ SD)	385.7 $\pm$ 15.81	401.21 $\pm$ 17.39	0.103 <sup>a</sup>
Duration of living with HIV in year (Mean $\pm$ SD)	6.18 $\pm$ 2.27	6.73 $\pm$ 2.11	0.166 <sup>a</sup>
Receiving HAART			
Yes	52 (91.2)	51 (89.5)	0.127 <sup>b</sup>
No	3 (5.3)	5 (8.8)	
Drop out	2 (3.5)	1(1.7)	

Note: <sup>a</sup>  $p$ -value from independent t-test; <sup>b</sup>  $p$ -value from Chi-square test

Table 3 provides the baseline, T1, and T2 on quality of life, including total score and QOL domains by group and data collection time. In the overall QOL score, respondents showed the lower quality of life at baseline, with an average score of 2.35 ( $SD = 0.77$ ). Overall QOL scores increased over time as respondents in the intervention groups scored 4.29 ( $SD = 1.43$ ), and the comparison group scored 3.02 ( $SD = 1.78$ ) at T2. Physical domain increased at T2 in the intervention groups scored 3.1 ( $SD = 90.62$ ), and respondents in the comparison group scored 2.7 ( $SD = 0.15$ ). The psychological domain increased over time as respondents in the intervention groups scored 3.5 ( $SD = 0.92$ ), and respondents in the comparison group scored 2.1

( $SD = 0.36$ ) at T2. Social domain increased at T2 as respondents in the intervention groups scored 3.0 ( $SD = 1.19$ ), while the comparison group scored 2.1 ( $SD = 0.36$ ) at T2. Environmental domain increased as respondents in the intervention groups scored 3.19 ( $SD = 0.65$ ), and respondents in the comparison group scored 2.3 ( $SD = 0.85$ ) at T2. There was a significant difference between baseline and T2 measures in the intervention group on overall quality of life, physical, psychological, and environmental domain. While, in the comparison group, no significant difference between baseline and T2 measures was founded.

**Table 3** Studied outcomes by groups and data collection time

Variables	Experiment, (n = 57) Mean ± SD	t (baseline to T2)	p-value <sup>a</sup>	Comparison, (n = 57) Mean ± SD	t (baseline to T2)	p-value <sup>a</sup>
<b>Overall QOL score</b>		8.32	0.001		2.678	0.034
Baseline	2.35 ± 0.77			2.27 ± 1.04		
T1	3.12 ± 1.36			2.98 ± 1.33		
T2	4.29 ± 1.43			3.02 ± 1.78		
<b>Domain score</b>						
<b>Physical</b>		4.78	0.021		0.452	0.116
Baseline	2.1 ± 0.33			2.4 ± 0.32		
T1	3.6 ± 0.57			2.5 ± 0.43		
T2	3.1 ± 0.62			2.7 ± 0.15		
<b>Psychological</b>		5.11	0.010		-0.032	0.512
Baseline	2.1 ± 0.93			2.2 ± 0.13		
T1	2.7 ± 0.12			2.6 ± 0.45		
T2	3.5 ± 0.92			2.1 ± 0.36		
<b>Social</b>		1.25	0.076		-0.062	0.347
Baseline	2.7 ± 0.82			2.3 ± 0.11		
T1	2.4 ± 0.37			2.6 ± 0.84		
T2	3.0 ± 1.19			2.1 ± 1.92		
<b>Environmental</b>		4.66	0.030		1.564	0.067
Baseline	2.18 ± 0.53			1.73 ± 0.68		
T1	2.33 ± 0.28			1.9 ± 0.71		
T2	3.19 ± 0.65			2.3 ± 0.85		

Note: <sup>a</sup> p-value from Paired t-test

The change of QOL scores is shown in Table 4. The self-management program improved outcomes relative to the control at T1 across four outcomes: 1) overall QOL score increased 8.7% (95% CI 0.021–0.149), 2) physical domain saw a modest increase 8.8% (95% CI 0.017–0.125), 3) psychological domain increased 23.5% (95% CI 0.085–

0.689), environmental domain saw a modest increase of 18.7% (95% CI 0.053–0.371). At T2, improved outcomes relative to the control are still observed in the overall QOL score and physical, psychological, and environmental domains.

**Table 4** Estimated difference-in-differences (DID) with fixed effects model

Variables	T1 DID coefficient (95% CI)	T2 DID coefficient (95% CI)
Overall QOL score	0.087* (0.021–0.149)	0.418* (0.024–0.592)
Physical domain	0.088** (0.05–0.125)	0.139** (0.025–0.235)
Psychological domain	0.235** (0.085–0.689)	0.344* (0.058–0.463)
Social domain	0.051 (–0.042–0.164)	0.153 (–0.017–0.085)
Environmental domain	0.187** (0.053–0.371)	0.215** (0.052–0.485)

All models adjust for age, education level, CD4 counts, and duration of living with HIV

\*\*\* p &lt; 0.001, \*\* p &lt; 0.01, \* p &lt; 0.05

## Discussion

This study aimed to examine the effect of our self-management intervention on PLWH in all dimensions of quality of life. Overall QOL score increased by 8.7%, and the physical domain increased by 8.8% after the intervention. Similar to a study conducted in China among HIV-infected MSM, self-management has shown a significant increase in quality of life and a significant reduction in the number of anxiety symptoms (Zhang et al., 2019). Self-management could strengthen PLWH's trust in their illness, increase understanding about their health and social adaptation, assist them in building healthy habits, and teaching them to survive (Elzarrad et al., 2013). The study also reports that self-management enhances

adherence to treatment and symptoms management of PLWH (Skinner et al., 2020). A recent comprehensive review indicated that an experimental group receiving symptom management guidance skills and telephone counseling enhanced their QOL (Areri et al., 2020). Therefore, providing an education program on self-management for PLWH is needed to improve their adherence and symptoms, thus enhance their QOL

Self-management could improve the domain of psychological well-being and environmental. A recent systematic review of a specific self-management educational intervention revealed that treatments focusing on coping and symptom control increased participants' involvement in self-management programs (Areri et al., 2020). Strategies to enhance self-management practices that emphasized symptoms of psychological management



guidelines or coping skills were more successful than standard care (Millard et al., 2016). In our study, the intervention group was encouraged to participate actively in communication, which included discussing their health problems, analyzing their causes, and determining the best course of action. Self-management has helped to encourage PLWH to speak out, thus avoiding further marginalization and self-containment (Zhang et al., 2019). In addition, the self-management approach was designed as a cooperation model between the patients and the healthcare providers. During specified courses and activities, PLWH, who had received the self-management intervention, were encouraged by patients and healthcare practitioners to build healthy behaviors and enhance patients' quality of life. These findings have implications for developing interventional studies, which could benefit from an integrated evaluation to evaluate better who benefits and under what conditions.

Our study, however, had several limitations. First, the effects of the self-management program may have been affected by the team personality attributes. It is not easy to maintain consistency among the various teams regarding the organization, planning, and mobilization capacity. Second, selection bias could not be ruled out in this study since the nature of non-randomized selection—no significant difference in terms of demographic and clinical characteristics between intervention and comparison groups. Then, in baseline analysis, the score of QOL between the intervention and comparison group was not significantly different. The third problem was that standardizing the intervention program was a challenge. Future research requires further improvement in the self-management procedure to ensure that each group has a consistent response impact.

The implications for nursing practice include that self-management interventions should be implemented concerning the person, community, and healthcare settings. Peer-to-peer or lay healthcare worker-led programs might be more practical and sustained in low-resource countries with a high HIV prevalence, such as Indonesia. In addition, nurses are encouraged to provide self-management education and training to those living with HIV by providing material such as a symptom management booklet and suggesting utilizing technologies such as telehealth and online applications to access the information quickly. More importantly, the program promoted patients' communicative skills to obtain adequate support from a nurse and also helped them raise their sense of responsibility for their health.

## Conclusion

These results indicate that the self-management program might enable PLWH to gain self-specific QOL and support healthy habits while helping to establish specific capabilities. This project contributed significantly to adapting self-management of chronic conditions to

transmissible conditions, and it should be built upon and verified for further promotion.

## Declaration of Conflicting Interest

All authors declare no conflict of interest.

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## Authors' Contributions

All authors contributed equally in every step of the study and agreed with the final version to be published.

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## Data Availability Statement

The datasets generated during and/or analyzed during the current study are available from the corresponding author on reasonable request.

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