Usefulness of Patient-Generated Index for HIV to Measure Individual Quality of Life: A Study from Thailand

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A B S T R A C T

Objectives: To measure health-related quality of life (HRQOL) in Thai HIV patients using the patient-generated index for HIV (PGI-HIV) and to compare the psychometric properties of the PGI-HIV with those of the EuroQol five-dimensional (EQ-5D) questionnaire and the Medical Outcome Study HIV Health Survey in terms of practicality, reliability, validity, and responsiveness. **Methods:** In this study, two rounds of interviews were carried out in HIV outpatients who met the eligibility criteria and attended the HIV Clinic of Warinchamrap Hospital between January and March 2010. The patients were interviewed using a data collection form and three HRQOL measures (the PGI-HIV, the EQ-5D questionnaire, and the Medical Outcome Study HIV Health Survey) to assess the practicality and validity. The second interview was performed to check the test-retest reliability and responsiveness. **Results:** A total of 210 patients completed the study. They were mostly women (69.5%), with a mean age of 39.2 ± 11.1 years. The majority with the US Centers for Disease Control and Prevention clinical stage C took the current antiretroviral drugs within

1 year. The average PGI score was about 0.60, implying HIV/AIDS and antiretroviral drug therapy decreased the patients' quality of life by 40% from their healthy life. Three mostly cited impact domains were hyperlipidemia, lipid maldistribution and lipodystrophy, and hepatitis. The PGI-HIV was considered as practical, with a mean difficulty score of 3.7 ± 0.8, highly reliable (intraclass correlation coefficient = 0.75; $P < 0.001$), and responsive to HRQOL changes (effect size = 0.81; standardized response mean = 0.99), but not valid when compared with CD4 levels and viral loads (all Pearson' $r < 0.2$; $P > 0.05$). **Conclusions:** The PGI-HIV was used to measure the individual HRQOL in a Thai sample of HIV-positive patients. It proves to be practical, highly reliable, and very responsive to changes in patients' HRQOL.
Keywords: HIV/AIDS, individual quality of life, patient-generated index, psychometric properties, Thailand.

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Introduction

Human immunodeficiency virus (HIV) infection is a major public health problem in Thailand and worldwide. The World Health Organization in 2010 estimated that 3.3 million people live with HIV and 1.8 million die from AIDS each year [1]. In Thailand, the Minister of Public Health reported 372,874 patients diagnosed with HIV/AIDS and 98,153 deaths of people from the disease up to March 2011 [2]. HIV infection and its management have many effects on not only patients' survival but also their health-related quality of life (HRQOL). Although Highly Active Antiretroviral Therapy has a high potency to prolong HIV patients' life expectancy and decrease the number of deaths, it tends to cause various adverse effects (i.e., adverse drug reactions and drug interactions) and partly affect the daily activities, thereby reducing their quality of life [3]. Because patients need to rely on the Highly Active Antiretroviral Therapy lifelong, the assessment of HRQOL in this patient group is of paramount importance.

HRQOL assessments are usually carried out by applying standardized or individualized measures. In the case of HIV, most HRQOL

evaluations make use of the standardized method in forms of generic or disease-specific questionnaires. Some standardized HRQOL instruments for HIV disease include the Medical Outcome Study HIV Health Survey (MOS-HIV) [4], Quality of Well-Being [5], human immunodeficiency virus-quality of life 31 questions [6], HIV/AIDS-targeted quality of life [7], AIDS Health Assessment Questionnaire [8], HIV Overview of Problems Evaluation System [9], Multidimensional Quality of Life Questionnaire for HIV/AIDS [10], Functional Assessment of Human Immunodeficiency Virus Infection [11], Euro-QoL [12], and World Health Organization's Quality of Life HIV instrument [13]. The Schedule for Evaluation of Individual Quality of Life [14] is one of two individualized tools that have been used. The other is the "patient-generated index (PGI)" [15], which is widely used in many diseases and yet to be explored in HIV/AIDS.

In general, individualized HRQOL tools help individual patients to identify their own impact domains and give a weight to each domain themselves, whereas most standardized instruments provide predetermined items, each of which carries the same weight for all patients. This is consistent with the definition of the World Health Organization that "quality of life" is "the individuals' perception of

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their position in life within the context of the culture and value systems in which they live, and in relation to their goals, expectations, standards, and concerns" [16]. Accordingly, an individualized tool should be more appropriate than a standardized measure to assess patients' quality of life from their own perspectives.

From an extensive information search, only one study in Ireland reported an individualized quality of life tool (Schedule for Evaluation of Individual Quality of Life-Direct Weight) to monitor HIV patients [14]. To date, no study in this area has used the PGI, although it is more specific than the Schedule for Evaluation of Individual Quality of Life-Direct Weight in terms of assessing the effects of disease and treatment [15]. The former asks patients to identify the five domains most affected by their disease and treatment, but the latter just requests them to write down the five most important things in life, which are quite general. In addition, the PGI's psychometric properties were still unclear, especially its responsiveness to HRQOL changes, and no data on the psychometric properties of the PGI in HIV/AIDS were available [17]. This study therefore aimed to measure the individual quality of life in Thai patients with HIV/AIDS using the patient-generated index for HIV (PGI-HIV) and to compare the psychometric properties of the PGI-HIV with those of the EuroQol five-dimensional (EQ-5D) questionnaire and the MOS-HIV in terms of its practicality, reliability, validity, and responsiveness. The MOS-HIV was chosen because it proves to be reliable and valid for measuring the quality of life in Thai HIV patients [18]. The EQ-5D questionnaire was also selected owing to the recommended health utility method in Thailand [19] and its high validity in measuring health utility in Thai HIV patients [20].

Methods

This study was ethically approved by Warinchamrap Hospital in Ubon Ratchathani Province. The hospital was selected in the study because it is a specialized center for HIV referral in the northeast region of Thailand. The study with two rounds of interviews (1 month apart) with HIV/AIDS outpatients was conducted. Details of the methodology are elaborated below.

Patients and Eligibility Criteria

All 315 HIV patients attending the HIV clinic of the hospital from January to March 2010, the time period of data collection, were approached. Two hundred ten patients (67%), however, were eligible for the study. The eligibility criteria were adults older than 18 years, able to communicate in Thai, taking Highly Active Antiretroviral Therapy regimens, and willing to participate in the study with written informed consent. Regarding the sample size, it was determined on the basis of the criterion validity test [21], with the minimum correlation coefficient (r) between MOS-HIV scores and other variables of 0.25 or more, two-sided significance level ($\alpha/2 = 0.25$), and $\beta = 0.10$. When taking the loss to follow-up and withdrawal from the study (20%) into consideration, at least 200 patients were required.

Instruments

A data collection form was specially designed to gather data relating to patients' characteristics, HIV infection, medication use, medication adherence (i.e., simple questions plus pill counts), and relevant data. Three HRQOL tools were also included as follows:

The PGI-HIV that embraced a three-column table and a predetermined list of 30 health-related and 6 nonhealth domains was devised from 20 HIV patients in the pilot test, along with clinical experiences of the researcher (K.C.) and then checked for content validity by two experts. To complete this HRQOL instrument, patients were requested to go through three steps: 1) select

A 19-year-old college student was diagnosed as HIV infection at the age of 10. His parents passed away due to HIV 5 years ago and he now lives with his grandparents. He does not smoke, drink alcohol, or use narcotic drugs. His CDC clinical stage prior to the ARV treatment was identified as B3 and he has been taking GPO-VIR®Z (zidovudine+lamivudine+nevirapine). The current CD4 cell count and viral load were reported as 316 cells/µL and 50 copies/mL, respectively. His six domains together with ratings and weights were recorded and PGI-HIV scores calculated as shown in the table below.

Six domains affected by HIV/AIDS and taking antiretroviral drugs (both positive and negative impacts)	**Domain ratings** on the scale of 0 (the worst status) to 100 (the best status)	**Domain weights** for preferred improvement with a maximum of 12 points
1. Anemia	70/100	2/12 (= 0.167)
2. Nightmare	50/100	2/12 (= 0.167)
3. Feeling bored with taking many medicines	50/100	3/12 (= 0.25)
4. Leg wounds taking long time to heal	40/100	3/12 (= 0.25)
5. Being healthier	70/100	0/12 (= 0)
6. Cannot go to school (miss classes to go to hospital)	80/100	2/12 (= 0.167)

PGI-HIV score = $(0.7 \times 0.167) + (0.5 \times 0.167) + (0.5 \times 0.25) + (0.4 \times 0.25) + (0.7 \times 0) + (0.8 \times 0.167) =$ **0.56**

Fig. 1 – An example of the patient-generated index for HIV (PGI-HIV) score found in a Thai outpatient with HIV/AIDS.

Table 1 – Characteristics of HIV patients (N = 210).		
Characteristic	Attribute	Value
Age (y)	Mean ± SD	39.2 ± 11.1
	Range (min–max)	19–68
Sex, n (%)	Male	64 (30.5)
	Female	146 (69.5)
Marital status, n (%)	Married	75 (35.7)
	Single	8 (3.8)
	Widowed	73 (34.8)
	Divorced	54 (25.7)
Education, n (%)	Elementary school	160 (76.2)
	Secondary and high school	38 (18.1)
	University/college and higher	12 (5.7)
Income (baht/mo), n (%)	≤2000	20 (9.5)
	2001–4000	109 (51.9)
	4001–6000	73 (34.8)
	6001–8000	8 (3.8)
CDC clinical stage before ARV therapy, n (%)	A (asymptomatic, acute HIV or PGL)	17 (8.1)
	B (symptomatic condition)	72 (34.3)
	C (AIDS-indicator condition)	121 (57.6)
Time since HIV diagnosis (y)	Mean ± SD	4.7 ± 2.4
Type of ARV drugs, n (%)	Stavudine + lamivudine + nevirapine (GPO-VIRS)	122 (58.1)
	Zidovudine + lamivudine + nevirapine (GPO-VIRZ)	40 (19.1)
	Stavudine + lamivudine + efavirenz	33 (15.7)
	Zidovudine + tenofovir + lopinavir + ritonavir	15 (7.1)
Use of current ARV drugs (mo)	Mean ± SD	4.3 ± 2.3
Number of ARV tablets	Mean ± SD	3.3 ± 2.1
Medication adherence by pill count	Mean ± SD	96.4 ± 2.6
CD4 cell counts (cells/μL)	Mean ± SD	457.6 ± 246.4
Viral load (copies/mL)	Mean ± SD	0.09 ± 0.29

ARV, antiretroviral; CDC, Centers for Disease Control and Prevention; PGL, persistent generalized lymphadenopathy.

five health-related domains and one nonhealth domain affected by HIV/AIDS and antiretroviral (ARV) drug therapy from the list or their own choices, and put them in column 1; 2) rate each of the six domains on a scale of 0 (the worst status) to 100 (the best status) in column 2 using a visual analogue scale as appropriate; and 3) weigh each domain for preferred improvement in column 3 and total them up with a maximum of 12 points. There is no need for patients to allocate points to every domain, but the total points must be 12. The PGI-HIV score, which is the sum of the multiplication products of domain ratings and weights, is detailed in Fig. 1. The score ranges from 0 to 1; the higher the score, the better patient's quality of life.

The MOS-HIV is a 35-item disease-specific questionnaire [22] that consists of 11 domains, which can be further summarized as Physical Health Summary score or Mental Health Summary score. The 11 domain scores are within the range of 0 to 100, and the two summary scores are 50 ± 10. A higher score of the MOS-HIV reflects better quality of life.

The EQ-5D questionnaire tool comprises five domains (i.e., mobility, self-care, usual activity, pain/discomfort, and anxiety/depression), each of which has three levels: no problems, some problems, and major problems. To answer this questionnaire, patients were requested to pick a level that best describes their current health for each domain. It should be noted that the weights confirmed in Thai people [23] were used in this study to calculate EQ-5D questionnaire health utility index scores. These scores normally range from −0.45 to 1.00, where 1.00 and 0 represent perfect health and death, respectively; negative values indicate health status worse than death. It should be noted that the Thai version of the MOS-HIV and the EQ-5D questionnaire were available from Dr. Albert Wu and the EuroQol Group, respectively.

Data Collection

The 210 outpatients who met the eligibility criteria were interviewed two times during two hospital visits. They were interviewed by the researcher (K.C.) using three HRQOL tools for both visits in the pharmacy counseling room. Each interview was audiotaped with permission and subsequently transcribed to cross-check all answers. This first interview was intended to measure the patients' quality of life and to assess the tool's practicality and validity. For the second hospital visit, they were interviewed by the same researcher so as to evaluate its test-retest reliability and responsiveness. In this second interview, patients were asked to answer the query, "Compared with the previous visit, how would you rate your health in general now?" with 5-point Likert scale answers: (1) much better, (2) slightly better, (3) the same as before, (4) slightly worse, and (5) much worse. If they picked answer (3), their three HRQOL scores would be used to compute the test-retest reliability. For answers with any changes in the health status (i.e., 1, 2, 4, or 5), their scores would be analyzed for the responsiveness.

Data Analysis

All data from two rounds of the interviews were entered into PASW Statistics 18 (SPSS-IBM Co., Chicago, IL) and analyzed by using descriptive statistics for patients' characteristics and psychometric properties. The practicality of the PGI-HIV, the EQ-5D questionnaire, and the MOS-HIV was assessed in terms of the interview time, refusal rate, and difficulty scores by a five-point Likert scale, with lower scores indicating more difficulty. To evaluate the test-retest reliability of the three HRQOL tools, an intraclass correlation coefficient (ICC) was calculated. Regarding the criterion validity, Pearson's correlation coefficients (r) between the PGI scores, the PHS or MHS scores of the MOS-HIV, the EQ-5D questionnaire index scores, and clinical variables including CD4 levels and viral loads were used.

The responsiveness of the three HRQOL tools was presented as an effect size (ES) and standardized response means (SRMs). The ES was computed using the mean change scores of the three HRQOL tools between the first and second visits divided by the SD of the first visit (or baseline data). If the mean change scores were divided by the SD of the mean change, it would yield the SRM. A significance level in this study was determined at α = 0.05.

Table 2 – Descriptive statistics of three HRQOL tools (N = 210).

Quality-of-life tool	Mean ± SD	Range	% Floor	% Ceiling
PGI-HIV	0.61 ± 0.16	0.06–0.95	0	0
EQ-5D questionnaire	0.56 ± 0.26	−0.45 to 1.00	1.0	11.9
MOS-HIV with 11 domains				
General Health Perception	44.7 ± 7.9	25.0–75.0	0	0
Physical Functioning	75.6 ± 13.9	16.7–100.0	0	5.7
Role Functioning	84.3 ± 26.2	0–100.0	2.0	71.4
Social Functioning	72.2 ± 21.3	20.0–100.0	0	21.4
Cognitive Functioning	73.5 ± 15.5	25.0–100.0	0	3.8
Pain	59.5 ± 9.1	33.3–100.0	0	0.5
Mental Health	50.8 ± 7.5	36.0–72.0	0	0.5
Energy/Vitality	50.9 ± 8.5	30.0–80.0	0	0
Health Distress	59.4 ± 21.1	15.0–100.0	0	1.0
Quality of Life	34.4 ± 22.9	0–100.0	16.2	1.0
Health Transition	35.8 ± 23.7	0–100.0	16.7	0.5
Physical Health Summary Score	48.4 ± 4.6	30.6–56.9	0	0
Mental Health Summary Score	39.3 ± 4.5	29.8–55.3	0	0

EQ-5D, EuroQol five-dimensional; HRQOL, health-related quality of life; MOS-HIV, Medical Outcome Study HIV Health Survey; PGI-HIV, patient-generated index for HIV.

Results

A total of 210 HIV outpatients were enrolled in this study, and all of them completed two rounds of the interviews. Most patients were women (69.5%), and the mean age was 39.2 ± 11.1 years. Other patient characteristics and clinical details are given in Table 1.

Individual Quality of Life

Table 2 presents the descriptive statistics of the PGI-HIV, the EQ-5D questionnaire, and the MOS-HIV. The mean PGI-HIV and EQ-5D scores were equal to 0.61 ± 0.16 and 0.56 ± 0.26, respectively. When considering high ceiling or floor effects by HRQOL scores greater than 15% [24], neither was found in the EQ-5D questionnaire and the PGI-HIV measure. For the MOS-HIV, the mean PHS and MHS scores were 48.4 ± 4.6 and 39.3 ± 4.5, respectively. The high ceiling effects were detected in two domains, that is, Role Function (71.4%) and Social Functioning (21.4%), and floor effects in two domains, that is, Quality of Life (16.2%) and Health Transition (16.7%). The mean PHS and MHS score was lower than the norm scores of 50 ±10. Based on the first visit, 30 health-related domains impacted by HIV/AIDS and ARV drug therapy were reported by patients (Table 3). Top 5 major impact domains included hyperlipidemia (31.4%); lipid maldistribution and lipodystrophy (28.1%); hepatitis (26.2%); chronic fever, fatigue, weight loss, or chronic diarrhea (25.7%); and severe drug allergy and shock (25.2%). Moreover, six nonhealth impact domains were identified. Examples were travel expenses for visiting the hospital, social unacceptance of HIV patients, and the dissemination of HIV infection to their partner or family members.

Psychometric Properties of the PGI-HIV

As shown in Table 4, for practicality among the three HRQOL tools, the EQ-5D questionnaire had the shortest interviewing time, followed by the PGI-HIV and the MOS-HIV, respectively. No patient declined to be interviewed with the three HRQOL tools. Most of them agreed that the PGI-HIV and the EQ-5D questionnaire were easy to answer, compared with the MOS-HIV. The test-retest reliability in 109 patients with the same health status indicated that the EQ-5D questionnaire, the PHS of

the MOS-HIV, and the PGI-HIV had high agreement, whereas the MHS of the MOS-HIV had fair agreement (all P < 0.01).

When looking at the criterion validity, only the PHS of the MOS-HIV was significantly correlated with CD4 levels and viral loads (P < 0.01), while the MHS of the MOS-HIV was significantly associated with viral loads (P < 0.05). Both the PGI-HIV and the EQ-5D questionnaire were not significantly related to both CD4 levels and viral loads. As for the responsiveness, 101 patients responded some alterations to their health during the second visit, but two answered "slightly worse" and no one opted for "much worse." Thus, the HRQOL scores of 99 patients were used to compute "positive" responsiveness. It was found that the PGI-HIV and the MHS of the MOS-HIV were highly responsive whereas the EQ-5D questionnaire was small to medium responsive, and the PHS of the MOS-HIV was very low responsive.

Discussion

This is the first study that reported the individual quality of life using the PGI-HIV. The overall study mirrored the quality of life in Thai HIV outpatients who were mostly female, middle-aged, and less educated with low income. They largely suffered from full-blown AIDS for a period of time, but just received the current ARV drugs within 1 year, which was recent enough to elicit their views on the quality of life. Although most patients had to take 28 tablets daily, they still adhered to their multiple drug usage, therefore leading to increased CD4 cell counts and undetectable viral load.

In this HIV patient group, the average PGI score was about 0.60. This implied that HIV/AIDS and ARV drug therapy probably decreased the patients' quality of life by 40% from their healthy life. More than one quarter of the patients described that their lives were mainly affected by adverse drug effects. A possible explanation was that half of them were taking GPO-VIRS according to the previous national guidelines as discussed by Phanuphak et al. [25]. The drug containing stavudine, lamivudine, and nevirapine is likely to cause both hyperlipidemia and lipodystrophy, especially for stavudine, and nevirapine has the highest incidence of hepatitis [26]. This combined ARV drug should be replaced by GPO-VIRZ or tenofovir-containing regimens based on the Thai National Guidelines 2010 [27], but profound anemia caused by ziduvudine is still a matter of great concern. Apart

Table 3 – All domains impacted by HIV/AIDS and ARV drug therapy reported by HIV patients during the first visit (N = 210).

Domain	Number of reports (%)
Health-related domains	
1. High blood lipid levels (hyperlipidemia)	66 (31.4)
2. Lipid maldistribution and lipodystrophy—fat deposits around the abdomen and neck, and thinning arms, legs, face, and bum	59 (28.1)
3. Liver inflammation (hepatitis)	55 (26.2)
4. Chronic fever, fatigue, weight loss, or chronic diarrhea	54 (25.7)
5. Severe drug allergies and shock with hospitalization	53 (25.2)
6. Taking many medicines or difficulty in swallowing big tablets	52 (24.8)
7. Increased immunity or CD4 cell counts	51 (24.3)
8. Weight gain almost or near to normal	49 (23.3)
9. Being healthier	47 (22.4)
10. Numbness of hands and feet	44 (21.0)
11. Lung infection (pneumonia)	41 (19.5)
12. Feeling to be a patient with no value in life and easily tired	40 (19.1)
13. Fungal infection in the brain with severe headache, stiff neck, and tuberculosis (TB)	39 (18.6)
14. Decreased viral load until undetectable	38 (18.1)
15. Low red blood cells and hemoglobin (anemia)	37 (17.6)
16. Feeling disheartened to be HIV infected and need take medicines for life	37 (17.2)
17. Difficulty in seeping (insomnia) and nightmare	35 (16.7)
18. Oral thrush, sore throat, and painful swallowing	32 (15.2)
19. Itchy skin	30 (14.3)
20. Dizziness	27 (12.9)
21. Nausea, vomiting, or loss of appetite	19 (9.1)
22. Diarrhea or boasting	17 (8.1)
23. Hope to live on	17 (8.1)
24. Happiness for having sex	17 (8.1)
25. Medicines with bad taste, feeling bitter, or unpalatable eating	15 (7.1)
26. Herpes simplex or herpes zoster	13 (6.2)
27. Swollen lymph nodes in the neck, armpit, or groin	11 (5.2)
28. Headache	7 (3.3)
29. Skin disease or wounds taking long time to heal	5 (2.4)
30. Viral infection in the eyes causing vision problems	4 (1.9)
Nonhealth domains	
1. Travel expenses for visiting the hospital and cost of living	39 (18.6)
2. Social unacceptance of HIV patients	37 (17.6)
3. Passing on HIV to the couple or family members	36 (17.1)
4. Responsible for taking care of the family and want to live with them as long as possible	35 (16.7)
5. Job loss, less productivity, or cannot go to school	34 (16.2)
6. Do not get help and support from the family	29 (13.8)

ARV, antiretroviral.

from the adverse effects, HIV symptoms, psychological problems, and a large number of medicines had considerable effects on patients' quality of life.

With the result of 30 health-related domains, it was consistent with the study of Hickey et al. [14] that applied the Schedule for Evaluation of Individual Quality of Life to measure individual quality of life in Ireland. They pointed out that most HIV patients put the areas of health (71%) as a major impact, followed by family (69%) and financial issues (59%). Nevertheless, in the present study, Thai patients were mostly worried about numerous health-related problems and concerned about economic and social aspects, possibly due to their low socioeconomic status with monthly income lower than household nationwide earned on average (20,903 baht or US $697) [28].

As regards the practicality, the PGI-HIV was construed as difficult and time-consuming, but second after the EQ-5D questionnaire; the MOS-HIV was the hardest. The reason might be that patients needed to make a decision on six impact domains with related ratings, and this cognitive skill was not normally

practiced in their daily life. Regarding the test-retest reliability of the PGI-HIV, the ICC of 0.75 was considered as highly reliable (ICC = 0.70–0.85) [17], consistent with the results of the EQ-5D questionnaire and the PHS of the MOS-HIV. This result was also aligned with Haywood et al.'s study [29], which affirmed the high reliability of the PGI (ICC $>$ 0.80) in patients with ankylosing spondylitis. As with the study, Martin et al. [17] reviewed the psychometric properties of the PGI methods in 18 studies and concluded that the PGI is markedly reliable and valid (i.e., Pearson's or Spearman rank correlation coefficients = 0.30–0.49). The findings of this present study were therefore corresponding to their review in terms of high reliability but not for the validity.

As for the criterion validity of the PGI, our study found no associations between the PGI and CD4 levels and viral loads, and neither did the EQ-5D questionnaire. Only the MOS-HIV had associations with these HIV clinical variables. A possible explanation for this is that the PGI measured concepts different from those of the MOS-HIV. For example, from the PGI results, most HIV patients were concerned about their adverse drug effects of

Table 4 – Psychometric properties of the PGI-HIV compared with those of the EQ-5D questionnaire and the MOS-HIV.				
Psychometric property	PGI-HIV	EQ-5D questionnaire	PHS	MHS
Practicality (N = 210)				
Interview time (min), mean ± SD	14.6 ± 4.4	5.9 ± 1.7	20.9 ± 5.3	
Refusal rate, %	0	0	0	
Ease of use, n (%)	84 (40.0)	83 (39.5)	10 (4.8)	
Difficulty rating scores, mean ± SD	3.7 ± 0.8	4.2 ± 0.9	2.4 ± 0.7	
Reliability (N = 109)				
Intraclass correlation coefficients	0.75[†]	0.89[†]	0.87[†]	0.37[†]
Criterion validity (N = 210)				
CD4 levels, r	−0.07	0.06	0.31[†]	0.08
Viral loads, r	−0.08	−0.04	−0.38[†]	−0.14[*]
Responsiveness in patients with "much better" or "slightly better" health status (N = 99)				
Scores on visit 1, mean ± SD	0.61 ± 0.14	0.56 ± 0.27	46.67 ± 5.10	38.72 ± 4.93
Scores on visit 2, mean ± SD	0.73 (0.12)	0.61 ± 0.26	46.74 ± 4.40	42.42 ± 4.27
Mean change, mean ± SD	0.12 ± 0.12)	0.05 ± 0.12	0.07 ± 2.71	3.70 ± 4.54
Effect size (ES)[‡]	0.81	0.21	0.01	0.75
Standardized response mean (SRM)[§]	0.99	0.48	0.03	0.81

EQ-5D, EuroQol five-dimensional; MOS-HIV, Medical Outcome Study HIV Health Survey; PGI-HIV, patient-generated index for HIV; MHS, Mental Health Summary; PHS, Physical Health Summary.
[*] Statistically significant, $P < 0.05$.
[†] Statistically significant, $P < 0.01$.
[‡] ES = Mean change ± SD of PGI-HIV scores on visit 1.
[§] SRM = Mean change ± SD of the mean change.

ARV drugs and HIV symptoms, while the MOS-HIV measured general health in HIV patients. These patient concerns may not be reflected from the values of CD4 levels and viral loads. The PGI approach also measures nonhealth domains, which may not be captured by the HIV clinical variables.

With respect to the responsiveness, the PGI-HIV was clearly responsive to quality-of-life changes, as evidenced by the high values of ES and SRM. The result also supported a PGI study in patients with obstructive sleep apnea [30]. In the review of Martin et al. [17], they reported that 13 of 18 studies reported that the PGI was highly responsive (ES and SRM = 0.5–0.8), but three articles [31–33] disclosed no responsiveness (ES and SRM < 0.20); two studies did not present the data. This present study hence provided evidence for the high responsiveness.

Like the PGI-HIV, the MHS of the MOS-HIV were highly responsive. The responsiveness indexes of the PHS of the MOS-HIV and the EQ-5D questionnaire, however, were small. A possible explanation is that the HIV patients who reported improvement in their health were better in terms of mental health. They were less fearful or concerned about their HIV symptoms and adverse drug effects of ARV drugs, whereas their physical health was still not much improved because the follow-up visit was just 1 month. This duration may be too short to assess the responsiveness of physical health in HIV patients. The EQ-5D questionnaire also has four items related to physical health (mobility, self-care, usual activity, and pain/discomfort).

This study had some limitations. Most patients did not get used to the decision-making process and judgment in the PGI-HIV. They felt uncomfortable with the selection of impact domains and could rarely come up with a new set of domains. As a result, this study could not provide an exhaustive list of domains for the PGI-HIV. In addition, they found it difficult to use a visual analogue scale of 0 to 100 or choose one number from the range. This made it challenging for rating and giving weights to a particular domain.

In conclusion, the PGI-HIV was used to measure the individual quality of life in a Thai sample of HIV-positive patients for the first time. Their quality of life was mostly affected by the adverse effects of ARV drugs, HIV symptoms, psychological problems, and multiple drug therapy. In addition, patients were concerned about financial and social effects. It is the first time that this study reported the psychometric properties of the PGI-HIV, which proves to be practical, highly reliable, and very responsive to changes in patients' quality of life, but not valid when compared with HIV clinical variables. Further research is needed to confirm the psychometric properties of the PGI-HIV in other HIV patient groups.

Acknowledgments

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