

A Study on AIDS Self-Management Status and Its Influencing Factors

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Purpose: To investigate and analyse the status quo of the self-management of patients living with HIV/AIDS (PLWHA) and its influencing factors and to provide the basis for formulating intervention strategies.

Methods: In this cross-sectional study, 300 PLWHA who visited the Infection Center of Beijing Youan Hospital, Capital Medical University between September 2021 and December 2021 were enrolled using the convenience sampling method. Demographic characteristics and disease-related data were collected for each participant. The HIV/AIDS Self-Management Scale was used to evaluate the self-management ability of PLWHA.

Results: A total of 251 male and 49 female PLWHA were included in this study, with an average age of 39.08 ± 12.09 years and an average disease duration of 9.61 ± 37.04 months. Univariate analysis showed that the PLWHA's place of residence, educational level, physical condition, family relations, duration of HIV disease, receipt or not of antiviral therapy and knowledge of disease had an influence on the scores of the HIV Self-Management Scale (all $p < 0.05$). The results of the self-management scores indicated that the total score for self-management was 41.5 ± 6.4 points, with a scoring rate of 69.6%, which was at a medium level. Long-term self-management had the highest scoring rate (12.2 ± 2.5 points), followed by daily health management (22.3 ± 4.3 points), and social support for self-management had the lowest scoring (5.1 ± 0.9 points). Multivariable analysis showed that the self-management ability of PLWHA was related to educational level, duration of disease and family relations ($R^2 = 0.67$, $F = 121.7$, $p < 0.05$).

Conclusion: The self-management level of patients with AIDS, especially the social support of daily health management and self-management, needs to be further improved. Educational level, duration of disease and family relations are important factors influencing the self-management of PLWHA.

Keywords: HIV/AIDS, AIDS, self-management

Introduction

According to data from the Joint United Nations Programme on HIV/AIDS, 39.0 million people worldwide were living with HIV in 2022.¹ The latest data in China shows that 1.14 million patients are living with AIDS and that there are 111,000 new infection cases in mainland China.² At present, China implements the policy of “four immunisations and one care” for patients with AIDS, which provides free HIV testing, treatment, prevention and care services and help for infected individuals and patients. Because of the incurability, contagiousness and social discrimination of the disease,^{3–5} many factors, such as family breakdown, contribute to psychological problems, such as anxiety and depression, in the self-management of people living with HIV/AIDS (PLWHA).⁶ Depression has a particularly negative impact on treatment adherence and quality of life in PLWHA, which further impacts patient adherence to antiviral therapy. Studies have shown that adherence to antiretroviral therapy among PLWHA should exceed 95%, thus guaranteeing the effectiveness of therapy.^{7,8}

The ability of PLWHA to follow medical advice in daily life is related to their skills and knowledge of response to antiviral therapy, as well as their self-management abilities. The term “self-management” was first proposed by Creer et al⁸ in the book, *Rehabilitation of Children with Chronic Disease*, and was defined as PLWHA’s active involvement in therapy. Since then, the term “self-management” has been widely used in chronic disease studies. In the field of HIV/AIDS, Gifford et al⁹ defined it in their study on self-management health education as various behaviours, attitudes or emotions that patients actively seek to improve health outcomes. As a secondary preventive model, self-management has been recognised as the best measure to alleviate the disease and maximise health outcomes.¹⁰ As early as 1999, the Stanford University Education Research Center⁹ completed an active self-management intervention study for PLWHA. Compared with the control group, the symptom severity index of PLWHA in the experimental group was significantly reduced, and their health behaviours were significantly improved. Thereafter, scholars from the UK, Thailand and China have also applied self-management to PLWHA.^{11–13} Studies have shown that effective disease self-management of PLWHA may directly or indirectly reduce the susceptibility to comorbidities, ease the symptoms, improve the quality of life and significantly reduce the incidence of hospitalisation, thus relieving the economic burden on individuals and families.^{14,15} This suggests that effective disease self-management is the key to achieving healthy outcomes for PLWHA.

However, factors influencing the disease self-management of PLWHA are diverse and complex, and there exists a certain correlation between these influencing factors. According to existing studies, the factors influencing the self-management of PLWHA can be summarised as demographic factors, disease factors, psychological factors and social factors.^{15,16} Studies^{17,18} have shown that factors such as age, gender, marital status, whether sexual orientation is clear, education level, economic status and residence can affect the self-management level of PLWHA. Other factors, such as self-efficacy and social support, can also influence patients’ self-management of AIDS.^{19,20} However, there is no clear conclusion on how these factors affect the level of disease self-management, and the mechanism of interaction between these influencing factors is also unclear and needs to be further studied and discussed.

At present, no study has clarified the exact influencing factors of PLWHA self-management and treatment compliance or determined which aspects can be changed to reduce the symptomatic incidence of PLWHA. This study investigates and analyses the current status and influencing factors of the self-management ability of PLWHA to provide an objective basis for medical staff to provide accurate and effective self-care education for PLWHA.

Materials and Methods

Sample

For the sample size calculation, the size was estimated based on factor analysis, which indicated that the sample size should be 5–10 times the number of items. The HIV Self-Management Scale for PLWHA includes 20 items, and the sample size is increased by 20%;²¹ therefore, the sample size was 120–240, considering the possibility of fewer items and invalid responses in the questionnaire. In this study, a total of 300 questionnaires were distributed, all of which were recovered and valid, with an effective recovery rate of 100%.

This study was cross-sectional. A convenience sampling method was used to investigate 300 cases of PLWHA at the Infection Center of Beijing Youan Hospital, Capital Medical University between September 2021 and December 2021. The inclusion criteria were as follows: patients (1) diagnosed as PLWHA in compliance with the 2002 *Diagnostic Criteria and Principles of HIV/AIDS (National Standard of People’s Republic of China)*; (2) aged >18 years; (3) displaying clear consciousness and the ability to answer questions accurately; and (4) who volunteered for this study. The exclusion criteria were as follows: (1) aged <18 years; and (2) history of severe mental illness (assessed by history and clinician diagnosis). This study was approved by the Ethics Committee of Beijing Youan Hospital (No.: LL-2021-160-K), and all participants gave informed consent and signed written consent forms.

Data Collection

Data were collected through a paper-based questionnaire survey. The trained and experienced researchers explained the research purpose, procedures, potential risks and benefits to the participants before the survey and ensured their confidentiality and voluntary participation. Each participant signed the informed consent form and completed the self-

report survey, including demographics and the HIV Self-Management Scale. General demographic characteristics included the following: gender, age, ethnicity, religion and place of residence; disease-related information included the following: duration of disease, whether relatives and friends were informed, whether antiviral therapy was received and whether regular reviews followed as prescribed by the physicians.²²

Instruments

The self-management ability of PLWHA was assessed using the PLWHA Self-Management Scale. In this study, the HIV Self-Management Scale, as developed by Webel et al²³ in 2012, was used. This scale has a total of 20 items and is divided into three dimensions: daily health management, social support for self-management and the long-term nature of self-management. Each item is scored on a scale of 0–3 (0 = N/A, 1 = Never, 2 = Occasionally, 3 = Always), with a total score of 60 points. The higher the score is, the better the self-management ability of PLWHA. The total score of each dimension and scale is the sum of the scores of each item included.²⁴

Since the number of items in each dimension of the scale is different, for unified comparison, the self-management level of PLWHA was compared based on the scoring rate (scoring rate = actual score of the dimension [average score] ÷ full score of the dimension × 100%). The self-management level of PLWHA is divided into three levels – high, medium and low – by the scoring rate, as follows: high level ≥80% (48 points); medium level = 60–80% (36–48 points); low level ≤60% (36 points).²⁵ Upon authorisation by Webel, the scale was “Chineseised” and cross-culturally adapted in accordance with the guidelines for cross-cultural adaptation of the scale recommended by the Evidence-Based Medicine Committee of the American Academy of Orthopedic Surgeons,²⁶ and the Chinese version of the HIV Self-Management Scale was finally formed. According to the Chinese version of the HIV Self-Management Scale, Cronbach’s alpha reliability coefficient (α) is 0.878, the test-retest reliability is 0.933 and the content validity is 0.972.²⁵

Statistical Analysis

Statistical analysis was performed using SPSS 26.00 statistical software (IBM, Armonk, NY, USA), and the Kolmogorov–Smirnov test was used for the normality test.²⁷ Measurement data satisfying normality were expressed as mean ± standard deviation ($\bar{x} \pm s$). Means between two groups were analysed using the independent samples *t*-test, means between multiple groups were compared via one-way analysis of variance and ranked data were tested using the rank sum test. Enumeration data are presented as frequency (*n*) or rate (%).

To further explore the factors influencing the self-management of PLWHA, enter regression analysis was performed using the scores of the HIV Self-Management Scale of the respondents as the dependent variable and the variables with statistically significant differences in univariate analysis as the independent variables. The assignment of differential factors in the univariate analysis is shown in Table 1, and the original duration of the disease was entered. All variables were included, set the same prior probability and passed the collinearity test. A *p*-value of <0.05 was considered to indicate a significant difference.

Table 1 Assignment of Independent Variables in Multilinear Stepwise Regression

Independent Variable	Classification	Assignment
Place of residence	Town	1
	Country	2
Educational level	Elementary school and below	1
	Middle school/technical secondary school	2
	University/college and above	3

(Continued)

Table 1 (Continued).

Independent Variable	Classification	Assignment
Physical conditions	Poor	1
	General	2
	Good	3
Family relations	Troubled	1
	General	2
	Good	3
Antiviral therapy received or not	No	1
	Yes	2
Knowledge of disease	No	1
	Only part	2
	Yes	3

Results

Comparison of General Information and Scores of the HIV Self-Management Scale in Patients Living with HIV/AIDS

A total of 300 PLWHA were enrolled, including 251 men and 49 women, with an average age of 39.1 ± 12.1 years and an average disease duration of 9.6 ± 37.0 months. Univariate analysis showed that residence, educational level, physical condition, family relations, duration of HIV disease, receipt or not of antiviral therapy and knowledge of disease were related to the scores of the HIV Self-Management Scale (all $p < 0.05$). Gender, age, ethnicity, religion, work status, household incomes per capita, smoking status, drinking status, relatives and friends informed or not and clinical symptoms regularly checked or not did not affect the scores of the HIV Self-Management Scale (all $p > 0.05$) (Table 2).

Table 2 Comparison of PLWHA General Information and Scores of HIV Self-Management Scale Among Various Factors

Item	n	Score (\pm s)	t/F/Z value	P value
Gender			0.8	0.422
Male	251	41.3 \pm 6.8		
Female	49	40.9 \pm 7.2		
Age			-1.3	0.179
<30	81	40.4 \pm 8.4		
30~	140	40.24 \pm 7.66		
>50	79	43.13 \pm 7.34		
Nationality			0.7	0.491
Han nationality	256	40.2 \pm 7.3		
Other	44	39.4 \pm 6.4		
Place of residence			4.8	0.006
Town	246	40.7 \pm 6.5		
Country	54	37.3 \pm 7.6		
Religion			0.03	0.976
Yes	243	40.4 \pm 7.9		
No	57	40.7 \pm 7.5		

(Continued)

Table 2 (Continued).

Item	n	Score (\pm s)	t/F/Z value	P value
Educational level			17.5	<0.001
Elementary school and below	21	35.9 \pm 7.8		
Middle school/technical secondary school	113	38.6 \pm 7.8		
University/college and above	166	42.2 \pm 7.8		
Working status			0.8	0.397
Currently working	245	41.5 \pm 7.9		
Retired	21	41.6 \pm 6.9		
Unemployed	34	40.7 \pm 7.6		
Household incomes per capita (yuan)			1.1	0.275
	27	40.7 \pm 7.2		
	107	40.5 \pm 8.2		
	108	40.6 \pm 7.5		
	58	40.6 \pm 7.1		
Smoking status			1.3	0.286
Smoking	74	40.59 \pm 7.12		
Already quit smoking	21	39.3 \pm 6.5		
Never	205	39.24 \pm 6.97		
Drinking status			0.6	0.546
No	246	39.7 \pm 6.7		
Yes	54	40.4 \pm 7.2		
Physical conditions			4.5	0.008
Poor	51	38.5 \pm 7.6		
General	182	40.5 \pm 6.8		
Good	67	42.3 \pm 7.0		
Family relations			5.6	0.003
Troubled	56	38.2 \pm 8.3		
General	153	40.0 \pm 6.5		
Good	91	42.5 \pm 5.9		
Duration of HIV disease (months)			7.3	<0.001
<24	152	36.5 \pm 7.2		
24~	78	41.9 \pm 7.8		
>60	70	43.8 \pm 7.0		
Relatives and friends informed or not			0.4	0.647
No	112	39.9 \pm 7.4		
Yes	188	40.5 \pm 6.8		
Antiviral therapy received or not			-2.6	0.010
No	57	38.9 \pm 8.2		
Yes	243	41.6 \pm 7.7		
Regular physical examination done or not			0.4	0.640
No	51	39.9 \pm 7.8		
Yes	249	40.9 \pm 7.3		
Clinical symptoms			0.6	0.561
No	132	40.6 \pm 7.3		
Yes	168	40.6 \pm 7.6		
Knowledge of disease			3.5	0.032
No	52	38.4 \pm 7.2		
Only part	122	41.3 \pm 8.0		
Yes	126	43.5 \pm 7.5		

Note: PLWHA: People living with HIV/AIDS, HIVASMS: People Living with HIV/AIDS Self-Management Scale. T: T-test of two independent samples. F: One-way ANOVA. Z: Rank sum test.

Current Self-Management Scores of Patients Living with HIV/AIDS

The results showed that the total score of the HIV Self-Management Scale of all patients was 41.5 ± 6.4 , and the scoring rate was 69.6%, which was at the medium level. The scoring rates of the three dimensions of the HIV Self-Management Scale were as follows: long-term self-management had the highest scoring rate at 81.2%, with an average score of 12.2 ± 2.5 ; the scoring rate of daily health management was 65.1%, and the average score was 22.3 ± 4.3 ; the satisfaction of social support to self-management was the lowest scoring rate at 62.9%, with a with an average score of 5.1 ± 0.9 , as shown in Table 3.

Multivariable Analysis of Factors Influencing the Self-Management of Patients Living with HIV/AIDS

The results of the enter regression showed that educational level, place of residence, duration of disease and family relations can explain the scoring rate of 68.8% for the self-management of PLWHA ($F = 124.9$, $p < 0.05$), and the dependent variable – the self-management of PLWHA – and the four independent variables were well fitted. The Durbin–Watson index was 1.99, suggesting that there was no correlation between the independent variables of the model. The significance test results of the four independent variables in the model showed that $p \leq 0.05$ for all, indicating that the four independent variables were statistically significant in the model and should be retained. In addition, the variance inflation factor values of the four independent variables were all considerably <10 , meaning there was no collinear relationship between variables, and the multiple linear regression equation was as follows:

$$Y = 18.945 + 0.523X_1 + 0.332X_2 + 0.212X_3 + 0.413X_4$$

According to the partial regression coefficient in the model, it can be concluded that the influence of four independent variables on the self-management of PLWHA was as follows: educational level $>$ place of residence $>$ duration of disease $>$ family relations, as shown in Table 4.

Discussion

The results showed that the total self-management score was 41.5 ± 6.4 points and the scoring rate was 69.6%, which is at a medium level. The overall level of self-management of PLWHA is not encouraging and needs to be further improved, in agreement with the results of other studies.^{28,29} The three dimensions of self-management in this study

Table 3 Current Self-Management Scores of PLWHA

Item	Number	Scoring Range	Average Score	Scoring Rate (%)	Ranking
Long-term nature of self-management	5	0~15	12.2 ± 2.5	81.2	1
Daily health management	12	0~36	22.3 ± 4.3	65.1	2
Social support for self-management	3	0~9	5.1 ± 0.9	62.9	3
Total	20	0~60	41.5 ± 6.4	69.6	-

Abbreviation: PLWHA, People living with HIV/AIDS.

Table 4 Multivariate Analysis of PLWHA Self-Management Status

Variable	Standard error	Partial Regression Coefficient	95% CI	P value	VIF
Constant	2.167	18.945	–	<0.001	–
Educational level	1.427	0.523	0.327~0.914	<0.001	1.01
Duration of disease	1.461	0.332	0.231~0.415	<0.001	1.05
Family relations	0.754	0.212	0.159~0.339	<0.001	1.12
Place of residence	1.287	0.413	0.207~0.517	<0.001	1.04

Note: $R = 0.834$, $R^2 = 0.688$, adjusted $R^2 = 0.641$, $F = 124.9$, $P < 0.05$. 95% CI is 95% confidence interval.

were the long-term nature of self-management, daily health management and social support for self-management in descending order of scoring rate, and this result was consistent with Webel's results.³⁰ This may be because PLWHA tend to ignore daily life behaviours including diet, sleep and exercise early in antiviral therapy, and most PLWHA are reluctant to disclose their disease to family and friends and are less willing to actively seek help from others.³¹ Although discrimination is avoided to a certain extent, it also causes problems of increased physical and mental stress and insufficient social support.³² Studies have shown that the more social support PLWHA receive, the better they can adapt to the disease, the fewer related symptoms they have and the better their quality of life, mood and health.^{32,33} This signals medical staff to educate PLWHA about the importance of daily health management and inform them of the benefits of telling family, friends or trustworthy persons of their disease to help them obtain more social support and thereby improve their daily self-management ability and quality of life.

In terms of educational level, the results indicated that PLWHA with higher educational levels had higher self-management levels. This may be because they have adequate knowledge of HIV/AIDS³⁴ and have more access to relevant scientific knowledge through channels such as the internet, media and television. Active and effective health science education enables PLWHA to master disease-related knowledge. The managerial competence of PLWHA increases with the increase in knowledge.^{35,36} Therefore, in clinical work, health education should be strengthened for PLWHA with low levels of education to guide them to acquire more HIV/AIDS-related knowledge and strengthen adherence to antiviral therapy;³⁷ this will help them to better manage their symptoms and disease after leaving hospital and improve their self-management level. As far as the place of residence is concerned, patients living in cities have better self-management ability. This may be related to his more convenient medical treatment, more convenient access to disease-related knowledge and more access channels. This suggests that we should pay more attention to patients living in rural areas and give them more convenience and care.

In terms of duration of disease, the results show that the self-management ability of PLWHA with a long disease duration is better than that of those with a short disease duration, in agreement with the results of Webel et al.³⁷ Previous studies also found that as the duration of the disease increases, PLWHA become more familiar with and better at understanding their condition after more visits, have more opportunities to receive AIDS health education from medical staff and acquire more disease-related knowledge accordingly.³⁸ We suggest that, in clinical health education, targeted intervention should be provided according to different durations of disease. The PLWHA with a short duration of disease should be given more opportunities to communicate with other patients (eg "patient community" and www.120x.net) to obtain more social support, while for PLWHA with a long duration of disease, medical staff should help them establish a habitual pattern of self-management (eg as a repeated, individualised and progressively intensive health education model) to help them build confidence in controlling the disease, thereby improving their self-management ability.

In terms of family relations, the results show that PLWHA with better family relations have better self-management ability. Family members can provide patients with better home care, effectively alleviate or eliminate PLWHA's negative psychology and shift their attention to their own health, thereby improving their self-management capabilities.³⁹ This reminds medical staff that in addition to effective communication with PLWHA, they should communicate with their family members or trusted persons to help PLWHA gain understanding and help from people around them and to continuously increase their ability to adapt to the current disease by mobilising external forces, such as family and society.⁴⁰

This study has certain limitations. First, it is a cross-sectional study, which may have led to some bias, preventing causal interpretations of the results; longitudinal studies are needed to determine the causal relationship. The participants in this study have geographical limitations and the survey was only conducted in one hospital. In addition, due to the significant difference in the number of male and female patients, more female patients need to be included in future studies to verify the conclusions of this study regarding gender. It is recommended to further expand the scope of future studies to ensure its extensiveness, practicability and applicability in the Chinese population. Of course, there are still many factors affecting self-management ability that have not been measured and included in the analysis in this study. We will try to include more influencing factors in further research. This is also added to the limitations of this study.

Conclusions

The self-management status of PLWHA is relatively poor, and the social support for their daily health management and self-management needs to be further improved. Educational level, place of residence, duration of disease and family

relations are important factors influencing the self-management of PLWHA. Future practice should focus on strengthening the AIDS publicity of PLWHA, increasing the content of self-management and training the self-care skills of people infected with HIV. Pay more attention to patients living in rural areas and give them more convenience and care. At the same time, more family and social services and support for elderly patients and special groups should be strengthened. The patient's family system should be fully utilised to improve the therapeutic effect and quality of life.

Data Sharing Statement

All data generated or analyzed during this study are included in this published article.

Ethics Approval and Consent to Participate

This study was conducted in accordance with the declaration of Helsinki. The study involving human participants were reviewed and approved by the Beijing Youan Hospital of China Capital Medical University. The Ethics Committee archive number is LL-2021-160-K. The patients/participants provided their written informed consent to participate in this study.

Consent for Publication

The manuscript is not submitted for publication or consideration elsewhere.

Author Contributions

All authors made a significant contribution to the work reported, whether that is in the conception, study design, execution, acquisition of data, analysis and interpretation, or in all these areas; took part in drafting, revising or critically reviewing the article; gave final approval of the version to be published; have agreed on the journal to which the article has been submitted; and agree to be accountable for all aspects of the work.

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Disclosure

The authors declare that they have no competing interests in this work.

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