# Determination of the effect of self-care based on the need for quality of life in people with AIDS

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# **Abstract**

**Introduction:** Considering the prevalence of acquired immunodeficiency virus infection and the need to strengthen programs for improving quality of life, the present study was conducted to examine the effect of self-care based on the need for quality of life in people with acquired immunodeficiency syndrome (AIDS).

**Material and methods:** In a clinical trial study, 66 human immunodeficiency virus (HIV)-positive patients referred to Navab Safavi Hospital in Isfahan were assigned to two intervention and control groups randomly. The first group was placed under the intervention of self-care program and no intervention was performed in the second group. The quality of life score of patients before and after the intervention in the two groups was examined and compared.

**Results:** The mean quality of life score in the intervention group was  $68.7 \pm 11.8$  before and reached 79.7  $\pm$  10.3 after intervention, which was statistically significant (p = 0.002). In the control group, the mean quality of life scores before and after treatment were  $65.7 \pm 11.9$  and  $60.8 \pm 11.7$ , respectively, which was not statistically significant (p = 0.053). Also, the change in the quality of life score was statistically significant (p < 0.001) between case and control groups.

**Conclusions:** Providing self-care programs in patients with HIV leads to an increase in the quality of life in them. Since these patients are at risk for various types of psychiatric disorders, they must be mentally and emotionally supported and should be encouraged to improve their quality of life by promoting their own self-care programs. Medical science and doctors may find the findings useful in their medical experience and practice.

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# Introduction

Self-care involves the ability of individuals to carry out self-care activities and is a learnable behavior that the patient is able to address somewhat depending on their care needs [1-3]. Self-care improves compliance with the disease, and patients can be involved in controlling the complications of the disease. The goal of self-care is helping patients improve their care [4]. Performing this program requires the identification of patients' needs, evaluation of the potential for self-care, acceptance of care skills education and ultimately improves the quality of life [5]. Considering the prevalence of acquired immunodeficiency virus infection and the need to strengthen programs for improving quality of life, the present study was conducted to examine the effect of self-care based on the need for quality of life in people with acquired immunodeficiency syndrome (AIDS).

Today, self-care has been considered by many researchers in the field of medicine, in which the self-care effects on the quality of life of people with certain chronic diseases, such as diabetes, have been studied [6-8]. But in patients with AIDS, unfortunately, care has not been taken seriously, given that today AIDS is a global epidemic, and with the advances in drug therapy [9]. It is still one of the leading causes of mortality in the world. Implementing and strengthening psychosocial support programs for these patients is one of the most important health priorities in many parts of the world. On the other hand, health coverage in the Eastern Mediterranean region for people with human immunodeficiency virus is low and Iran is also in this region [10]. According to a World Health Organization (WHO) report, Iran is one of the countries at high risk of human immunodeficiency virus (HIV) infection and by 2020, the rate of HIV infections in Iran will be 10% [11].

To control this hygiene, social and cultural challenge, it seems that we should seek to change the behavior of the affected individuals and those with high-risk behaviors in the community [12]. Chronic disease especially HIV has a severe negative impact on the quality of life, mental health and the economic situation of the community [13-15] and families with AIDS [16, 17] and neglecting the lives of AIDS patients, lack of proper social status, acquiring a social stigma [18], etc., makes these patients be involved in irresponsible behaviors that lead to the spread of the virus and infection of large numbers of people in the community [19]. Considering the above-mentioned issues, in order to improve the quality of life, we must seek to reduce the social, health, cultural and economic problems of AIDS patients, and this cannot be achieved except by the efforts of all people in the community, especially the healthcare team that through appropriate treatment and gaining the confidence of these patients and organizing classes and study sessions, understands their problems so that patients feel that the community values them and they are treated like other patients, they can learn and can identify their problems and get guidance. The WHO has recently highlighted self-care and quality of life in chronic patients [20]. Unfortunately, self-care has been neglected in HIV/AIDS-infected patients [10]. Therefore, the present study was conducted to determine the effect of a self-care program based on the need for quality of life in people with HIV.

# Material and methods

# Design

The population of the study consisted of HIV-positive patients referring to Navab Safavi Hospital in Isfahan. This is a clinical trial study with a control group that was conducted in Isfahan province in 2016. The study took the approval number, IR.SKUMS. Rec. 1395.44 from the Ethical Committee of Sharekord University. The inclusion criteria for the study included HIV infection, patient consent to study, age over 15, and communication power. It was also considered that withdrawal of the person during the study, the death of the participant, the occurrence of physical or psychological problems such that the person was unable to cooperate, the lack of participation in the specified sessions and failure to answer the questionnaire questions were considered as criteria for exclusion.

The method of implementation of the plan was that after obtaining permission from the university's medical ethics committee, 66 HIV-positive patients referred to the Navab Safavi in the city of Isfahan in southern Iran clinic were selected and assigned to two groups based on random allocation rule (33 people every group). Patients in the intervention group underwent self-care training sessions and the second group was under the routine care programs of the center.

### **Data gathering**

WHOQOL-BREF is a questionnaire with 26 question that measure overall and general quality of life of a person. This scale was developed by a group of experts from the WHO in 1996 and adjusted from the form of a questionnaire with 100 questions. The questionnaire has four subscales comprising physical health, mental health, social relationships, environmental health and a general score. Initially, a raw score is obtained for each subscale, which must be converted to a standard between 0 and 100 through a formula. A higher score indicates a higher quality of life. The reliability of the WHO's Quality of Life questionnaire in the Nojoomi study with Cronbach's α was 93% [21] and in the Haidari study with Cronbach's  $\alpha$  was 95% [22]. Initially, the objectives of the plan was explained to the patients, and after obtaining their consent to participate in the study, written consent was obtained from them at the first session then each patient was assigned to a group. After the sample size was completed, both groups of patients and controls were invited to perform the pre-test. It took about 20 days for us to perform the pre-test and each client who participated in the pre-test personally entered the classroom and filled out the quality of life questionnaire in the presence of the researcher, during which the questions were read and explained by the researcher and the client ticked the answer. This process continued until the pre-test was done for both the case and control groups. After completing the pretest, the control group continued to live and did not receive any pamphlets or booklet, and did not attend any class, but the intervention group after completing the pre-test based on the time they were able to attend the class were divided into five groups and they were informed that they had to attend 6 sessions of the Navab Safavi Center for behavioral disorders in order to conduct the research.

### Intervention

Intervention for participants was grouped according to the patients' literacy and comprehension (understanding) and in each group session, 6 to 7 people participated. Before the start of the first session, the medical records of all patients were studied. Some of the patients' problems were extracted through the record files. The intervention was completed during 6 sessions of 30 to 45 minutes and once every two days [23, 24]. At the first session, patients were asked to talk about their illness, and were asked to provide each person with information and an opinion on AIDS. After discussing the above questions and listening to each participant's opinion, they were given educational pamphlets tailored to their literacy and understanding about AIDS and how it was transmitted. The cases which patients felt the need for or it was seen they needed them were recorded and shared with the center's specialists. Patients were told that a solution to some of their problems was presented during the two final sessions with the help of specialists from the center for behavioral disorders of Navab Safavi. In the second to sixth sessions, nutrition topics, AIDS transmission routes, the risks to injecting drug users and sex without protection, drug treatment (medication) and AIDS drug side effects, how to deal with physical and mental health problems and coping strategies with personal problems were raised. At the end of the sessions, all participants were provided with a self-report checklist for each week and tabulated for each topic (nutrition, prevention of transmission to others, side effects of drugs, follow-up of drug orders, oral and pharyngeal care...), and cases which patients need to know were included and the group exposed to self-care, according to their needs. It should be noted that the case group was followed weekly by checklist, and each week, by referring to the Navab Safavi Center, were followed providing a checklist and emphasis on compliance, answering questions and ambiguities in some cases, and received next week's check list, and this procedure was continued completed after 6 weeks and after 6 weeks of intervention, the participants in both case and control groups were visited to assess the effect of self-care intervention, the post-test was performed and after performing the post-test, the control group received pamphlets and training manuals.

# Statistical analysis

Data are shown as means  $\pm$  SD for continuous variables and as frequency with percent for categorical variables. The  $\chi^2$  test was used for comparing categorical variables between groups and the independent t-test for continuous ones. The paired t-test was used for comparing the change of variables during the study in each group. The parametric repeated measures analysis of variance was applied to test if any change exists among variables during the study between groups. Statistical analysis was done by SPSS 23 and p-values < 0.05 were determined as statistically significant.

### Results

In this study, 66 patients were studied in two groups of 33 intervention and control subjects. During the study period, 3 patients from each group were excluded from the study due to lack of referral and data analysis was performed on 30 subjects in the case group and 30 subjects in the control group. In Table 1 the distribution of demographic

Table 1. Demographic characterization

|                        | Group        |              |      |  |  |
|------------------------|--------------|--------------|------|--|--|
| Variable               | Intervention | Control      | р    |  |  |
| Age (years)            | 38.87 ± 8.70 | 39.93 ± 7.70 | 0.65 |  |  |
| Gender                 |              |              |      |  |  |
| Male                   | 18 (60)      | 18 (60)      | 1.00 |  |  |
| Female                 | 12 (40)      | 12 (40)      |      |  |  |
| Marital status         |              |              |      |  |  |
| Single (unmarried)     | 6 (20.0)     | 9 (30.0)     | 0.18 |  |  |
| Married                | 16 (53.3)    | 18 (60.0)    |      |  |  |
| Dead wife/<br>husband  | 4 (13.3)     | 0 (0)        |      |  |  |
| Divorced               | 4 (13.3)     | 3 (10.0)     |      |  |  |
| Education level        |              |              |      |  |  |
| Elementary             | 11 (36.7)    | 6 (20.0)     | 0.55 |  |  |
| Secondary              | 11 (36.7)    | 6 (20.0)     |      |  |  |
| High school            | 8 (26.7)     | 10 (33.3)    |      |  |  |
| University             | 2 (6.7)      | 3 (10.0)     |      |  |  |
| Employment             |              |              |      |  |  |
| Worker                 | 1 (3.3)      | 2 (6.7)      | 0.39 |  |  |
| Self-employed          | 12 (40.0)    | 6 (20.0)     |      |  |  |
| Housekeeper            | 10 (33.3)    | 12 (40.0)    |      |  |  |
| Unemployed/<br>Retired | 7 (23.3)     | (10 (33.3)   |      |  |  |
| Addiction              |              |              |      |  |  |
| Yes                    | 13 (43.3)    | 14 (46.7)    | 0.8  |  |  |
| No                     | 17 (56.7)    | 16 (53.3)    |      |  |  |

**Table 2.** Mean and standard deviation of subscales for quality of life before and after studying the two groups

| Subscale/Time      | Intervention | Control    | p*         |  |
|--------------------|--------------|------------|------------|--|
| Physical health    |              |            |            |  |
| Before             | 20.5 ± 4.2   | 19.6 ± 4.2 | 0.43       |  |
| After              | 23.3 ± 3.6   | 18.1 ± 3.6 | < 0.001    |  |
| p**                | 0.026        | 0.13       | < 0.001*** |  |
| Mental health      |              |            |            |  |
| Before             | 16.4 ± 3.3   | 16.2 ± 3.6 | 0.82       |  |
| After              | 19.8 ± 2.8   | 14.3 ± 3.6 | < 0.001    |  |
| p**                | < 0.001      | 0.019      | < 0.001*** |  |
| Social health      |              |            |            |  |
| Before             | 7.8 ± 2.4    | 7.8 ± 2.5  | 0.92       |  |
| After              | 9.6 ± 2.2    | 7.7 ± 2.2  | 0.001      |  |
| p**                | 0.015        | 0.81       | 0.026***   |  |
| Environment health |              |            |            |  |
| Before             | 24 ± 4.2     | 22.1 ± 3.6 | 0.08       |  |
| After              | 27.2 ± 3.8   | 20.6 ± 3.6 | < 0.001    |  |
| p**                | 0.011        | 0.052      | < 0.001*** |  |

<sup>\*</sup>Difference between two groups based on independent t-test.

variables in both intervention and control groups is presented. Based on p-values, there was no significant difference in the demographic characteristics of the two groups.

The mean general health score from the patients' point of view before and after intervention in the intervention group was  $6.8 \pm 1.3$  and  $7.5 \pm 0.8$ , respectively, and was significant (p = 0.03). This mean score before and after intervention in the control group was  $5.9 \pm 1.3$  and  $5.8 \pm 1.2$ , respectively, and was not significant (p = 0.74). Table 2 shows the mean quality of life subscales scores before and after the study in the two groups. According to the independent t-test, there was no significant difference between the mean scores of all four subscales of quality of life before treatment between intervention and control groups, but after the intervention, the difference between the two groups was significant in all four subscales. On the other hand, according to the paired *t*-test, in the intervention group, the score of physical health, mental health, social health and environmental health subscales were significantly improved in the intervention group, but in the control group, the mental health subscale score decreased significantly. Based on repeated measures analysis of variance, the changes in the mean scores of all four subscales were significantly different between the two groups.

According to the results, in the intervention group, the quality of life score was  $68.7 \pm 11.8$  before and reached  $79.7 \pm 10.3$  after the intervention, which was statistically significant (p = 0.002). In the control group, the mean of quality

of life scores before and after treatment were 65.7  $\pm$  11.9 and 60.8  $\pm$  11.7, respectively, which was not statistically significant (p = 0.053). There was no significant difference between mean score of quality of life before the intervention between the two groups (p = 0.21); however, the difference between two groups after the intervention was significant (p < 0.001).

# **Discussion**

In this study, 60 HIV-infected patients in two groups of 30 who received self-care interventions and the control group were distributed and their quality of life status was evaluated before and after intervention. There were no significant differences between the two groups in terms of demographic characteristics such as age and sex distribution, marital status, education, and drug addiction, and there was no confounding effect of these factors on changes in the quality of life score and self-care score. Therefore, it is likely that the observed differences between the two groups can be attributed to the type of intervention performed. Regarding the impact of the demographic factors on the quality of life in the research conducted in Ethiopia in 2013, those who considered the disease to be a stigma (shame) had inadequate income and lower literacy rates, and women who had an unstable marriage or widowhood are more vulnerable than others and more likely to develop severe psychiatric disorders and schizophrenia [25]. Also the results of another study showed that elderly people with AIDS had the same conditions as non-elderly people, and getting people in a place where it is important to pay attention to the quality of life of people is more effective than a situation where they have the same age and illness conditions [26].

Based on the results, the mean general health score from the patients' point of view before and after the intervention in the intervention group was  $6.8 \pm 1.3$  and  $7.5 \pm 0.8$ , respectively. The general health status after the intervention was significantly improved but in the control group there was no significant difference in the patient's view of their health, so that the mean general health score before and after the intervention was  $5.9 \pm 1.3$  and  $5.8 \pm 1.2$ , respectively. Patients' satisfaction with their general health was also improved in the intervention group, but there was no significant difference in the control group. In this regard, Guander's study in 2012 showed that there was a direct relationship between HIV-positive patients and depression and disappointment, which led to suicides in a high percentage of patients, and the disease has an inverse relationship with life expectancy. The study by Holzemer et al. indicated that HIV stigma had a significant negative impact on quality of life for a broad sample of people living with HIV infection [27]. Therefore, the appropriate strategy to reduce this effect is very effective in these patients. According to the results of this study, interventional self-care measures were associated with improvement in the quality of life of patients [28], so that the mean of quality of life scores before and after treatment in the intervention group were  $68.7 \pm 11.8$  and  $79.7 \pm 10.3$ ,

<sup>\*\*</sup>Difference between before and after treatment in each group based on paired t-test.

<sup>\*\*\*</sup>Mean difference between the two groups based on interaction effect using repeated measures analysis of variance.

respectively, and the quality of life score in the intervention group was significantly improved, while in the control group, the mean life quality scores before and after treatment were 65.7  $\pm$  11.9 and 60.8  $\pm$  11.6, respectively, and the difference before and after intervention was not significant. Zandi's study in Tehran in 2002 showed that providing selfcare programs in patients with liver cirrhosis leads to an improvement in the quality of life of patients [23]. Shebon et al. also showed in a study conducted in the United States in 2014 that increasing the life expectancy of people with AIDS and the chronicity of the disease leads to an increase in mental disorders and substance abuse in these patients, so that the quality of life of patients is severely reduced. Patients with acquired immune deficiency virus, due to the social and cultural impacts of AIDS, face many problems in various social, cultural and moral contexts, with the exception of disease problems, and therefore psychological disorders, especially depression, are very common in these patients [19], because, on the one hand, AIDS is a life-threatening disease, and even people with HIV infection are afraid that the infection will turn out to be an obvious illness and stop them. On the other hand, patients with this infection, even if they have not received the infection through sexually transmitted infections, are subject to different charges from different people, and this will result in their rejection from the community. Ultimately, the rejection of people with acquired immunodeficiency virus causes psychological disorders, especially depression and reduced quality of life in them. Hence, mental health care is important in these people. Multivariable analysis indicated negative associations between quality of life and psychological problems, and demands for social and financial support. Interventions focused on psychosocial issues would improve the quality of life for people living with HIV [10, 29, 30].

The results of the study of Ebachi and Behroan showed that the severe stigma affects the health of the individual and the community, and with the acceptance of these patients in society, the burden of mental illness can be reduced and life satisfaction increases [31]. A study conducted in 2013 in Nigeria showed that people who are supported by the community and the family and have a family background and job have the best status, and those who are rejected from the family are in the worst situation [13]. In relation to psychiatric support there are so many different ways in which one of the best practices is the self-care approach, so that psychological components in people are strengthened so much that sick people themselves take care of their health. In fact, raising self-esteem is considered to be the most important component of self-care programs, but since HIV infection in our country is not as widespread as in other countries, serious measures have not been taken to provide the psychological support of patients with this infection, and so research in this area is limited. With the help of health professionals and educators, we can prevent mental disorders in these patients, thereby reducing the unnecessary health costs and improving the quality of life [19]. Confirming this, the study by Kim et al. showed that nursing intervention should be focused on providing interactive

communication and emotional social support to improve self-management and health-related quality of life of people living with HIV [29]. However, another study showed the relationship between housing stability and HIV self-management in women with this condition [32].

# **Conclusions**

Providing self-care programs in HIV patients has led to an increase in the quality of life in them and more satisfaction in patients. Therefore, since HIV-positive patients are at risk for various types of psychiatric disorders, especially depression, for various personal and social reasons, and the progression of these disorders will lead to suicide or refusal to be treated and even attempts to transmit the disease to others, it is necessary that the patients undergo psychological and emotional counseling during scheduled training, along with health care and treatment and by promoting self-care programs in them, for their quality of life to be improved.

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# **Conflict of interest**

The authors declare no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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