Health related quality of life: is it another comprehensive evaluation indicator of Chinese medicine on acquired immune deficiency syndrome treatment?

Liu Zhibin, Yang Jiping

Liu Zhibin, Acquired Immune Deficiency Syndrome Treatment and Research Center, the First Affiliated Hospital of Henan University of Traditional Chinese Medicine; Henan Provincial Key Laboratory of Traditional Chinese Medicine Prevention and Treatment of Viral Diseases, Zhengzhou 450000, China

Yang Jiping, the First Affiliated Hospital of Henan University of Traditional Chinese Medicine, Zhengzhou 450000, China

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Correspondence to: Associate professor Liu Zhibin, Acquired Immune Deficiency Syndrome Treatment and Research Center, the First Affiliated Hospital of Henan University of Traditional Chinese Medicine; Henan Provincial Key Laboratory of Traditional Chinese Medicine Prevention and Treatment of Viral Diseases, Zhengzhou 450000, China. drlzbcn@163.com

Telephone: +86-371-66264858; +86-13503829273

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Abstract

Health related quality of life (HRQOL) can better reflect changes in acquired immune deficiency syndrome (AIDS) patients and inform economic evaluation of AIDS treatment services, and the assessment of HRQOL can help us to detect problems that may influence the progression of the disease, hence HRQOL has become a particularly important assessment indicator for HIV comprehensive interventions. Being a multi-angle, multi-level, and diversified complex intervention, roles of Chinese medicine (CM) in AIDS treatment have been recognized and accepted by more and more patients, and HRQOL has been widely used to evaluate the comprehensive management effects of CM on AIDS. In this article, the authors analyze the definition and measurement of HRQOL, measurement of HRQOL of HIV/AIDS patients and effects of CM on AIDS, and give some reasonable advices for the usage of the scale of HRQOL. The authors hold that some new HRQOL instruments specific for CM treatment of AIDS should be developed and further prospective studies should be carried out to demonstrate the practicality, reliability and validity of HRQOL as an evaluation indicator for CM treatment of AIDS.

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Key words: Acquired immune deficiency syndrome; HIV; Quality of life; Chinese medicine, traditional; Antiretroviral therapy, highly active

INTRODUCTION

Acquired immune deficiency syndrome (AIDS) is a communicable disease recognized in the early 1980s, which is caused by the human immunodeficiency virus (HIV) infection. More than 35.0 million people were living with HIV worldwide and millions of patients died of the complex HIV related and non-related reasons in the past 30 years. To date, this global tragedy might continue to the foreseeable future because the prospect of an effective HIV vaccine to contain the pandemic remains uncertain’ and there is no cure
method for this troublesome disease. Fortunately, with the scale-up of combined antiretroviral therapy (cART), early detection and treatment, and the prevention of opportunistic infections, etc., HIV-related morbidity and mortality have been reduced dramatically. AIDS has become a chronic disease with a lifelong medication.

According to Western Medicine (WM) or convenient medicine, AIDS is caused by HIV infection. If the infection is not detected and treated, the immune system gradually weakens and AIDS develops. Thus, how to eliminate, diminish or suppress the level of plasma HIV virus loads and to improve immune system are the main goals for WM especially for cART in order to restore and preserve immunological function, prevent opportunistic diseases and reduce mortality. Now, CD4 + T cell counts and plasma HIV virus loads are recommended as a main and golden evaluation criterion and are used in researches, clinical practice, and drug screening. In addition, there are some other evaluation indexes for AIDS treatment and control such as health related quality of life (HRQOL), survival rate, HIV infection rates, etc. Especially HRQOL has become as a main concern on health for people living with HIV (PLWH) and professionals in the recent years.

In this article, after the definition and measurement of HRQOL, measurement of HRQOL of HIV/AIDS patients and effects of CM on AIDS treatment are analyzed, merits and defects of HRQOL as an evaluation indicator for CM treatment of AIDS are commented and some reasonable advices are given for the usage of the scale of HRQOL.

DEFINITION AND MEASUREMENT OF HEALTH RELATED QUALITY OF LIFE

Since 1990s, with the transformation of medical model, the definition of health has changed. Health is not only absence of disease or illness, but also the physical, psychological state and social environment maintain in a good condition. The shift of the concept promotes values of social psychological factors, life style and behavior on the health. Disease and clinical efficacy are not simply evaluated with only objective measures of disease, but a comprehensive concept of psychological, physiological and social functions, especially for chronic disease. Here, the quality of life (QOL) was introduced.

According to World Health Organization (WHO), QOL is defined as “an individual’s perception of the position in life in the culture and value systems in which they live, and in relation to their goals, expectations, standards and concerns”, being a multidimensional concept of the physical, psychological and social function status. QOL is a subjective health evaluation index and it is closely related with the specific background of culture and social circumstance.

At present, QOL is an aspect throughout the long therapeutic process of some chronic diseases. Being a subjective evaluation indicator, HRQOL has been widely used in many chronic diseases including cancer, stroke, coronary heart disease and diabetes. HRQOL focuses on QOL specifically, as it is the main concern of health care for professionals. The HRQOL also is an important indicator to detect changes in functional status overtime, evaluate intervention effects, and improve patient-provider communication and adhere to medications.

In order to assess HRQOL of patients, numerous tools have been developed. HRQOL can be measured through the two basic approaches: generic instruments, e.g. Karnofsky Performance Scale Index (KPSI), Medical Outcome Study 36-item short-form (SF-36), Nottingham Health Profile (NHP) and Quality of Life Index (QL-Index), etc.; and disease specific instruments, e.g. Minnesota Living with Heart Failure Questionnaire (MLHFQ) and Diabetes Specific Quality of Life Scale (DSQL), etc., which are not mutually exclusive. Each approach has its advantages and weaknesses, and may be suitable for different circumstances.

Currently, the generic and disease specific instruments are often used for any studies at the same time, so the instrument of HRQOL should be used appropriately and the user must follow the manual to measure HRQOL.

Briefly, to update, being a multidimensional concept, HRQOL has been commonly recognized as an important concern in patient care. A lot of tools have been developed to measure HRQOL, and researchers have used them as an important indicator in their researches and clinical practices.

HRQOL MEASUREMENT OF HIV/AIDS PATIENTS

HRQOL has become a particularly important assessment for HIV infection is a chronic and no cure disease but with the prospect of long-term survival. HRQOL can better reflect changes in HIV/AIDS patients and inform economic evaluation of HIV/AIDS treatment services, and the assessment of HRQOL can help us to detect the problems influencing the progression of the disease. The instruments of HRQOL for HIV/AIDS patients and HIV related disease or symptom are developed, including Patient Reported Outcomes Quality of Life-HIV questionnaire (PRO-QOL-HIV Questionnaire), World Health Organization Quality of Life Questionnaire for HIV/AIDS (WHOQOL-HIV), and HIV-related Fatigue Scale (HRS), etc.

It is well known that HRQOL of PLWH is significantly lower than the general population, and can be affected by many factors such as physical and clinical charac-

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teristics of HIV/AIDS patients, e.g. sex, age, education level, complication, immune status and viral load, etc., and some non-medical factors, e.g. psychological, interpersonal, environment, etc. The HRQOL related factors are so complex that some of them are the protective factors, some are risk factors, and some have a dual effect on the level of the patient’s HRQOL, i.e. eART can improve the HRQOL of patients, but the pill burden and side effects of anti-retroviral drugs would offset the beneficial effect, and even there are opposite results in different studies.

In China, HRQOL of PLWH is a major concern. The assessment of HRQOL on HIV/AIDS patients has been performed. Some instruments have been introduced and/or applied in clinical trials and clinical practice, including WHOQOL-HIV-BREF, MOS-HIV (Chinese version), Dermatology Life Quality Index (DLQI), etc., and some new scales are in development, e.g. HIV/AIDS Quality of Life Questionnaire (HIV/AIDSQOL-46), etc.

**EFFECTS OF CHINESE MEDICINE ON AIDS TREATMENT**

In China, CM has a long history and a wide mass base with a profound cultural background. AIDS has been treated with CM in the last 30 years under the guidance of CM theory. Some clinical research results show the positive roles of CM in AIDS treatment. It is reported that CM can reduce plasma HIV viral loads, promote immunity reconstitution, ameliorate symptoms and signs, improve the HRQOL, counteract against the effects of anti-retroviral drugs, even is of benefit to long-term survival of AIDS patients. Therefore, CM belongs to multi-angle, multi-level, and diversified complex intervention.

Besides the advances of CM treatment of AIDS, some Chinese herbs are screened for potential anti-HIV drugs and some active ingredients extracted from common Chinese herbs are proved to have function of anti-HIV replication in the laboratory, but very few herbal medicines show positive results for AIDS treatment so that they can not be commercially exploited. Moreover, the negative role of some herbal medicines in AIDS treatment is found. It is suggested that the efficacy, safety and mechanism of herbal medicines in AIDS treatment should be researched deeply. In short, results of some clinical observations and researches show positive action of CM on AIDS treatment, and we should provide enough evidences for supporting those effects and exploring the mechanism of CM in laboratory perfectly.

**HRQOL OF AIDS AND CHINESE MEDICINE**

There are more differences between CM and Western Medicine (WM) in explaining disease or health. According to CM theory, the patient has abnormal symptoms, signs, pulse or tongue picture caused by basic pathological factors, i.e. an abnormal status and/or outcomes of "Yin-Yang", "Qi-blood", "cold-heat" or "deficiency-excess". CM more emphasizes integrative systemic treatment and individual treatment for the patient. When CMPs give treatments to their patients, often focus on adjusting the balance of "Yin" and "Yang", and harmonizing relations between internal pathophysiological function and external natural environment changes of the patient through CM methods, e.g. strengthening body resistance and eliminating evil, replenishing Qi and detoxification, etc., combined with some humanistic concerns, e.g. assisting patient to regulate abnormal emotion, giving some advices for the abnormal changes of daily life mode, offering some general medical knowledge on disease prevention and control, etc.

For the intrinsic difference of CM and WM, assessment of CM is also different with WM. For CMPs, the efficacy evaluation is related to not only the pathological and physiological improvement such as laboratory or physical examinations developed from WM, but also the perception of the patient on the complexion, spirit, vitality and social function changes which cannot be measured by laboratory or physical examinations. Thus, based on the holistic view, CM combined with syndrome differentiation and humanistic care is likely to have positive impacts on patients’ physiological function, psychological function, independence, social relationship, personal faith and/or environment relationships; and all these positive improvements are related to the better HRQOL of patients.

In the last 30 years, CM treatment has been considered to possess the advantage of improving HRQOL of patients of some chronic diseases, and some evidences also demonstrated the improvement of the HRQOL of the patients with cancer, coronary disease or mental illnesses after the complex CM interventions. For example, a prospective and longitudinal study in Hong Kong shows that CM is associated with significant improvement of HRQOL of patients and can be used as an alternative primary care service. A systematic review shows that it is possible that oral Chinese herbal medicine used in conjunction with chemotherapy may improve QOL in non-small cell lung cancer. Furthermore, it should be pointed out that no enough evidence may prove the advantage of improving HRQOL of patients by CM intervention, and studies with better designs and longer duration should be carried out to ascertain the actual impact of CM on patients’ HRQOL with a specific HRQOL instrument for CM, etc. In brief, CM treatment can be used to improve HRQOL of patients and the assessment of HRQOL has also been used as an important outcome indicator to evaluate the CM intervention.
As a key evaluation index, HRQOL has also been used to evaluate the efficacy of the intervention on AIDS treatment, not limited to ART. Although the related researches are not many, some researchers have used HRQOL to evaluate the efficacy of CM on AIDS treatment. For example, a recent study on quality of life of the asymptomatic HIV infected person treated with CM shows that syndrome differentiation treatment can significantly improve the patient’s QOL.\textsuperscript{19} and in another one-year study using Chinese herbal medicine (CHM), researchers also find that the total score of WHO-HIV is improved after one-year therapy in 43 cases of PLWH.\textsuperscript{20} But in a prospective, placebo-controlled double-blind study, the standardized formulation of Chinese herbs for HIV infected individuals does not improve quality of life, clinical manifestations, plasma HIV virus loads, or CD4+ T cell counts.\textsuperscript{21} Therefore, there still is absent of enough systematic study on HRQOL of PLWH treated with CM.

Shortly, HRQOL has been used to evaluate the effect of CM on AIDS treatment, and it seems a good evaluation index for AIDS treatment with CM, but with few enough evidence to support. CMPs should carry out some well designed and controlled researches to demonstrate whether HRQOL is an appropriate evaluation index for CM treatment of AIDS in the future.

**DEFECTS OF EXISTING HRQOL INSTRUMENTS TO EVALUATE CM**

Despite HRQOL has been used to evaluate the effect of CM on AIDS by the existing scales introduced from WM, their validity needs to be confirmed because of the distinctive difference between Western culture and Chinese culture. Especially, the evaluation of CM should be based on its philosophy and theory so as to be sensitive and responsive to the changes brought about by CM. Therefore, we should not abandon few enough evidences to support the improvement of HRQOL by CM intervention. It still remains uncertain whether the results truly reflect those related to CM, and some new HRQOL instruments specific for AIDS CM treatment should be developed.

**CONCLUSION**

HRQOL can better reflect changes in HIV/AIDS patients and inform economic evaluation of HIV/AIDS treatment services, and the assessment of HRQOL can help us to detect the problems that may influence the progression of the disease.

To date, HRQOL has become a particularly important assessment for HIV comprehensive interventions. Being a multi-angle, multi-level, and diversified complex intervention, the roles of CM in AIDS treatment have been recognized and accepted by more and more patients, and HRQOL has been widely used to evaluate those comprehensive management effects of CM on AIDS.

But some new HRQOL instruments specific for CM in AIDS treatment should be developed, and the further prospective studies should be carried out to demonstrate the practicality, reliability and validity of HRQOL as an evaluation index for CM treatment of AIDS.

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