

BMJ Open Understanding the experiences and perception of people living with HIV on integrative traditional East Asian medicine management in Korea: an interview protocol for qualitative research

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ABSTRACT

Introduction Patients with HIV/AIDS have been able to experience the average life expectancy of the general population due to medical advancements. However, they face physical, emotional and social difficulties that worsen their quality of life. The pharmacological approach is often the first choice to address these issues, but it involves some limitations. Integrative traditional East Asian medicine (ITEAM) can compensate for the limitations of drugs and can be applied to treat physiological and psychiatric problems. In Korea, ITEAM interventions are easily accessible under the government insurance. However, the experiences, perceptions and barriers to the use of ITEAM in patients with HIV/AIDS are less studied. Therefore, we will interview them to explore their experiences and examine the strengths, limitations, barriers and improvements in the use of ITEAM.

Methods and analysis This is a qualitative study using a phenomenological framework. We will conduct one-to-one interviews with 3–10 patients with HIV/AIDS who have been treated with ITEAM from March 2021 to January 2022. We will present semistructured open-ended questions and analyse them using experiential phenomenological research methods. The results will be reported in accordance with the Consolidated Criteria for Reporting Qualitative Studies.

Ethics and dissemination This research was approved by the Institutional Review Board of the National Medical Center (IRB number, NMC-2101-008). The results of this study will be disseminated through journal articles, newspapers and conference proceedings.

Trial registration number Clinical Research Information Service: KCT0005855; Pre-results.

INTRODUCTION

AIDS is an immunosuppressive disorder caused by the destruction of immune cells after infection with the HIV.¹ According to recent the The Joint United Nations Programme on HIV/AIDS (UNAIDS) data,

Strengths and limitations of this study

- The study will allow for an in-depth understanding of the experience and benefits, unmet needs and barriers to using integrative medicine in patients with HIV/AIDS.
- The results will be used as the basic data to establish policies for patients with HIV/AIDS or develop quantitative research protocols in the future.
- A multidisciplinary research team, including practitioners, clinical researchers, and counselling experts, participated in the study to increase its credibility and trustworthiness.
- As this study will be conducted in Seoul, it is possible that only metropolitan-area residents may participate, so the sample may not be representative of all patients with HIV/AIDS in Korea.
- There may be a favourable bias towards integrative East Asian medicine since there are several traditional medicine doctors on the research team.

in 2019, 1.7 million people were newly infected with HIV, 690 000 died from AIDS and 38 million were living with HIV/AIDS worldwide.² In Korea, the first HIV-infected patient was confirmed in 1985, and approximately 15 000 people were confirmed to be infected with HIV over the next 30 years.³ After the introduction of highly active antiretroviral therapy (HAART) as an effective treatment in the 1990s, the mortality rate has declined dramatically.⁴ The life expectancy of people living with HIV/AIDS (PLWHA) has increased significantly in many countries and is approaching that of the average population.⁵

Since HIV infection is not a lethal but a chronic disease,⁶ the focus is now on



improving the quality of life (QoL) in patient care. QoL is related to physical, mental and social well-being.⁷ PLWHA are often at risk of poor QoL due to underlying physical infection and mental and social problems. Symptoms frequently accompanying AIDS include pain, fatigue, breathlessness, insomnia, nausea, constipation, diarrhoea and anorexia.⁸ Moreover, HAART, a standard treatment, has adverse effects that promote biological ageing⁹ and cause skin disorders,¹⁰ lipodystrophy¹¹ and bone loss,¹² among others. Physical pain often leads to emotional depression and anxiety.¹³ Mental problems also stem from HIV-related stigma. Many PLWHA face HIV-related stigma, which is associated with depression, low self-esteem, emotional distress, shame and anxiety.¹⁴ This stigma also negatively affects the formation of relationships with people and leads to social isolation.¹⁵ Conventional medicines used to alleviate these symptoms have limitations as they increase the pharmacological burden and can lead to polypharmacy and drug interactions.¹⁶ For emotional support, technology-mediated interventions such as online social media and telephone are used in a variety of ways, but they have insignificant or negative effects in terms of improving the QoL.^{17 18} As an alternative to this situation, integrative traditional East Asian medicine (ITEAM) is being used to manage these symptoms and prevent deterioration of QoL, with some significant medical effects.¹⁹ There have been reports that acupuncture/moxibustion treatment alleviates accompanying symptoms such as peripheral neuropathy^{20–22} and digestive disorders.²³ Some studies show that herbal medicine treatment is beneficial in enhancing immunity^{24 25} or long-term survival rate.^{26 27} However, clinical evidence is still insufficient, and overall, the volume and depth of PLWHA-related studies are still lacking.

There are reports that the ITEAM approach helps manage many chronic diseases, such as cancer^{28 29} chronic pain^{30 31} and mood disorders,^{32 33} and is expected to be effective in HIV/AIDS as well. However, more clinical studies and evidence are needed to apply ITEAM to patients. According to the evidence hierarchy, we know that experimental clinical trial design is important in clinical decision-making. However, we cannot conduct clinical trials on every topic of interest in healthcare. A step-by-step approach is required for basic clinical research. First, for PLWHA, a qualitative investigation should be conducted to find out the kind of interventions necessary for various symptoms and the benefits that can be achieved through the ITEAM approach. It is also necessary to investigate the psychological, social and economic obstacles in applying ITEAM. The results of qualitative research can be used as basic data for future quantitative research. This will improve the understanding of the unmet needs and usage status of ITEAM in PLWHA. Therefore, we will conduct a qualitative research using in-depth interviews to study

the experience, barriers, advantages and limitations of ITEAM in PLWHA.

METHOD

Qualitative study design

This qualitative research explores why PLWHA choose the ITEAM approach and their overall experience with it in medical use. Among the qualitative research methods, we adopt the phenomenological method because it focuses on the lived experiences of a patient related to the research participant from the perspective of the patient.³⁴

Study sample and recruitment

The recruitment of participants in this study is a two-step process. First, we will select participants through purposive sampling focused on individuals who can provide a wealth of information in the specific field.³⁵ Recruitment notices will be posted in medical institutions treating PLWHA. In the next step, we will use snowballing sampling to recruit other participants. This sampling method is effective in recruiting target groups that are difficult to reach because participants introduce other suitable individuals.³⁶

Recruitment will be closed when the data becomes saturated. The sample size will be 3–10 people, as recommended by Dukes to ensure the validity of phenomenological research.³⁷ However, if data do not reach saturation even after 10 participants are interviewed, additional interviews can be conducted. Saturation refers to the state when a qualitative interview is no longer required because the new participant repeats previous information and no new information is obtained.

We will explain the purpose, process, and method of the study to the individuals in advance. Additionally, they will be informed that they can drop out at any time without disadvantages, and the interview will be audio or video-recorded and transcribed. Written consent will be obtained from those who voluntarily decide to participate in the study.

Inclusion criteria will consider the individuals diagnosed with HIV/AIDS and aged between 19 and 75, who received Korean medicine treatment and will agree to voluntary participation. We believe that adolescent patients have slightly different characteristics from adults. As 19 years old is the age of legal adulthood in Korea, we included participants aged 19–75 years old to focus on the deep understanding of adults. Those who are unable to participate in interviews due to hearing and speech impairments, or those who are judged to be unable to participate in interviews due to mental or cognitive impairments caused by complications or other diseases will be excluded.

Data collection

This study will be conducted from March 2021 to January 2022. Three female researchers holding a Ph.D. degree and with an experience in qualitative research will collect data through standardised open-ended interviews with

Table 1 Interview guide

Research questions	Detail questions
As a patient with HIV/AIDS, what motivated you to receive ITEAM treatment?	<ul style="list-style-type: none"> – How has your use of healthcare services changed before and after HIV infection – Have you ever received ITEAM treatment before HIV infection? – What diseases or symptoms have you received ITEAM treatment for?
As a patient with HIV/AIDS, what was your experience with ITEAM treatment?	<ul style="list-style-type: none"> – What is your perception of ITEAM treatment? – What was the effect of ITEAM treatment on your symptoms? – Are you continuously receiving ITEAM treatment?
What does medical service mean to you as a patient with HIV/AIDS?	<ul style="list-style-type: none"> – Are you willing to recommend ITEAM treatment to those around you? – Have you had any changes in your thoughts about ITEAM or yourself while receiving ITEAM treatment
What does it mean for you to choose ITEAM treatment?	<ul style="list-style-type: none"> – Are there any barriers in choosing ITEAM treatment? – What others say about their experience on ITEAM treatment?

ITEAM, integrative traditional East Asian medicine.

PLWHA (table 1). This type of interview is commonly used in qualitative research, allowing interviewees to freely express their intentions within a certain frame and involves minimal researcher bias.³⁸ Examples of questions are ‘What motivated you to receive ITEAM treatment (as an HIV/AIDS patient)?’, ‘When do you get ITEAM treatment?’, ‘What is the reason for receiving ITEAM treatment?’ and ‘Do you have any changes in your thoughts about ITEAM treatment while receiving ITEAM treatment?’ We will conduct face-to-face interviews in a quiet and private space where participants can feel comfortable. However, due to COVID-19, if required, we will conduct non-face-to-face interviews through Zoom. Each interview will take about 90–150 min, and the interview can be conducted one to five times per individual.

Since it is mandatory to compensate the participants for their time and transportation costs in any clinical research including a qualitative study, we will pay US\$88 in compensation per interview. With the consent of the participant, the interview will be audio or video recorded and transcribed after the interview is completed. Moreover, body language and gestures can be observed during the interviews, and the researcher may take field notes for this. Data collection will end when it reaches saturation.

Data analysis

When data collection is complete, the data obtained from this study will be analysed in the following steps,³⁹ using an experiential phenomenology research method.⁴⁰

First, overall, the transcribed data are bracketed, while trying to exclude the researcher’s knowledge and prejudice, and read several times to obtain the overall feeling implied by the participant’s statement.

Second, we will focus on the participant’s experience of ITEAM treatment and investigate identifying natural units centering on the unit of description that expresses his or her experience in the participant’s language. For this purpose, the part of the participant’s statement where the meaning change occurs is separated by a diagonal line and a number is placed in front of each meaning unit.

Third, by combining the divided semantic units, a theme is created, and the focal meaning contained in the theme is changed to the language of the researcher, that is, an academic term.

Fourth, we will change it into an academic term and derive constituent elements from semantic units to describe the situated structural description. The medical service experienced as a domestic patient with HIV will be explored by a general structural description of the experience, including the correlation between each component using the free change technique. In particular, for a patient with HIV living in Korea, we want to find out the meaning of life while experiencing ITEAM.

Two experts with extensive experience in qualitative research will supervise the research method and analysis process. One of them is a professor in the Department of Counseling and Psychotherapy and has been regularly counselling PLWHA, while the other is a major in pedagogy and has been counselling minority groups in the field. Furthermore, the suitability of the semantic description for the content analysis will be confirmed.

Triangulation will be performed to ensure the validity of the study, and an independent researcher will validate the coding of the main interviewer. Participants’ non-verbal communication (attitude, gaze, laughter, gestures etc) will be recorded in the participation/observation notes and will be reviewed to see if the meaning of any non-verbal expression matches the actual transcription. In addition, consensus will be reached based on the coded content within the multidisciplinary research team, so that it will not be biased towards one researcher’s point of view. To minimise researcher bias, two additional members of the research team, excluding the researcher who conducted the interview, will independently evaluate and confirm through a meeting.

The results will be reported following the Consolidated Criteria for Reporting Qualitative Studies, which are used as standard guidelines to report qualitative studies.⁴¹

Patients involvement

As our research is qualitative, we will involve patients throughout the study. Research questions will be adjusted in all interviews based on the priorities, experience and participant preferences. Patients/the public will be involved in the design and conduct of the study. They will also participate in the recruitment stage. We will communicate with the participants during the interview how we could disseminate the study result effectively to the participants' community. We will also publish the results in scientific articles. And the research results will be promoted to mass media and social media.

DISCUSSION

This qualitative study intends to explore the experience, advantages, barriers and subjective effectiveness of ITEAM through in-depth interviews of PLWHA who have received ITEAM, and determine how it can help improve the QoL of PLWHA. On the completion of this study, the status of the use of ITEAM for PLWHA, its advantages and limitations and the unmet needs of ITEAM for PLWHA will be identified.

PLWHA are at risk of a poor QoL in many aspects. Physically, they are vulnerable to infection and may suffer from chronic pain or adverse effects of medication.^{42 43} Emotionally, they often experience anxiety and depression,⁴⁴ and socially, they face discrimination and stigma.^{45 46} Although early screening and aggressive HAART have successfully saved the lives of infected people,⁴⁷ there are problems with drug toxicity, adverse effects and drug resistance.⁴⁸ PLWHA have used CAM for these complex and diverse physical, social and psychological problems. The estimates of lifelong CAM use in these patients have reached 90%. ITEAM, including herbs and acupuncture, is a commonly used CAM.⁴⁹ For PLWHA, ITEAM has been used to relieve HIV-related symptoms, improve QoL, alleviate side effects of antiviral drugs and strengthen the immune system.⁴⁸ There are many studies related to ITEAM and HIV/AIDS, such as clinical trials of acupuncture treatment,^{20 22 23 50} studies on survival rates with ITEAM^{19 26} and survey studies examining the trend in CAM (including herbs and acupuncture) use,^{16 51} but there is no clinical research focusing on the safety of ITEAM regarding interactions between antiviral drugs. Additionally, there is no in-depth exploration of unmet needs or obstacles in the use of ITEAM by PLWHA.

In particular, traditional Korean medicine and Western medicine collaborative treatment is encouraged in the Korean medical system.⁵² Moreover, as Korean medicine treatment is covered by national insurance, interventions such as acupuncture, moxibustion, *chuna* therapy and herbal medicine are available at low cost.⁵³ In this favourable situation, there is not much research on Korean medicine treatment for PLWHA.

Existing qualitative studies related to HIV-infected patients have been conducted on stigma, changes in sexual behaviour after infection, pregnancy and maternity

in HIV-positive women, feelings about HIV/AIDS diagnosis,¹⁵ and spiritual meaning. These studies did not address ITEAM.

We anticipate that the ITEAM approach might help with pain, emotion, function, social behaviour and QoL in PLWHA. However, we do not have an in-depth understanding of this issue. We do not know which intervention is the best for specific symptoms. We also lack a deep understanding of stakeholders' decision-making. We also do not know why PLWHA seek ITEAM, which is a barrier to ITEAM usage.

Therefore, in this study, we will explore the experiences and benefits, unmet needs and barriers to using integrative medicine. It is expected to be used as basic data for the development of protocols for quantitative research in the future. This will also be helpful for stakeholders. In future, we will supplement this research through a separate study targeting other stakeholders, such as medical staff and policymakers. The expected limitation of this study is that, as this study will be conducted in Seoul, the subjects residing in Seoul and the greater metropolitan area are likely to participate; hence, the sample may not be representative of all the patients with HIV/AIDS residing in Korea. Additionally, there might be a favourable bias toward ITEAM, since there are traditional medicine doctors in this research team.

Ethics and dissemination

This research was approved by the Institutional Review Board of the National Medical Center (IRB number, NMC-2101-008), and the protocol was registered in the Clinical Research Information System (registration number, KCT0005855). Before participation, an information sheet explaining the study objectives, confidentiality and anonymity, and the right to decide whether to participate or withdraw from the study will be provided to participants. Written consent will be obtained from participants. An identification code will be given to each participant, and the personal information of the research participants will be safely stored separately from other research data. Following the Bioethics Act, we will keep research-related records for 3 years after the research is finished, and destroy documents related to personal information according to the Personal Information Protection Act.

The results of this study will be disseminated through peer-reviewed journal publications, newspapers, academic seminars and conference presentations. Further dissemination will be made in health policy development meetings with policy-makers based on our research results. The results will be also presented at the annual online/offline academic seminar of traditional medicine physicians.

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Competing interests None declared.

Patient and public involvement Patients and/or the public were involved in the design, or conduct, or reporting, or dissemination plans of this research. Refer to the Methods section for further details.

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Data availability statement Data sharing not applicable as no datasets generated and/or analysed for this study.

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