

Brief Communication



Identifying the Unmet Medical Needs of HIV-Positive Subjects in Korea: Results of a Nationwide Online Survey

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ABSTRACT

An online survey was conducted in Korea to identify the unmet medical needs of people living with human immunodeficiency virus (HIV) (PLWH). Participants (n = 105) were mostly male (93.3%), aged >40 years (75.2%), and treated for ≥6 years post-diagnosis (61.9%). Most PLWH (71.4%) were very satisfied/satisfied with their HIV management. Areas of concern were quality of life (QoL) and mental health. Characteristics of a long-term therapeutic agent were 'low risk of resistance', 'high long-term viral suppression efficacy', and 'high degree of safety'. Pre-consultation QoL and mental health screening would be beneficial for the long-term success of HIV management.

Keywords: Mental health; Psychological health; Quality of life; Surveys and questionnaires; HIV

Since the first report of human immunodeficiency virus (HIV) infection in Korea in 1985, more than 12,500 individuals were infected over the next 30 years, of whom over 2,000 died [1]. Universal access to antiretroviral therapy (ART) for people living with HIV (PLWH) in Korea has been guaranteed through the health insurance system since 1997. Although the prognosis for PLWH has improved dramatically in recent years, some questions remain about the optimal treatment and management of HIV and how these are perceived by PLWH.

A nationwide online survey was conducted in Korea from 21 - 25 March 2022 to identify the unmet medical needs

of PLWH. Participants were recruited via a pop-up link on the 'LOVE4ONE' homepage [2]. In addition to collecting demographic information, the questionnaire consisted of five sections (Medications Patterns and Adherence; Satisfaction with Hospital Visits and Medical Care; Information Channels and Cognitive Information about HIV; Disease Awareness and Long-Term Management Considerations; Analytical Life Understanding) and took approximately 30 minutes to complete (**Supplementary File 1**).

Of 105 PLWH who completed the survey, most were male (93.3%), aged over 40 years (75.2%), were infected by homosexual and/or heterosexual intercourse

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(72.4%/15.2%) and treated for ≥ 6 years after diagnosis (61.9%). The most common comorbidity was cardiovascular disease (45.7%). Participants were mainly from the Seoul/Gyeonggi/Incheon (61.9%), Gwangju/Jeonnam/Jeonbuk (14.3%) and Daegu/Gyeongbuk (13.3%) regions of Korea; were mostly educated to college/university (52.4%), high school (31.4%), or postgraduate (12.4%) level; many were unemployed (31.4%) or permanently employed (23.8%); and monthly income was relatively low - most earned ≤ 1.99 million Korean Republic won (KRW; 41.0%) or 2 - 2.99 million KRW (18.1%). Lifestyle and dietary pattern were highly regular/regular in 40.9% and 43.8% of participants, respectively (Table 1). The proportion of subjects with highly regular/regular lifestyle and dietary pattern increased with age: by age group, participants with highly regular/regular lifestyle were 20 - 39 (26.9%),

40 - 49 (42.2%), and >50 years (50.0%); and results for dietary pattern were 20 - 39 (34.6%), 40 - 49 (40.0%), and >50 years (55.9%).

Most PLWH visited tertiary hospitals (91.4%) followed by secondary hospitals (7.6%), and clinics (1.0%). Nearly half (45.7%) visited hospital once every 3 months and the time between visits was longer than 6 months for 31.4%. The mean frequency of hospital visits during the last 12 months was 3.6.

Table 1. Demographics and clinical characteristics of participants (N = 105)

Parameter	n (%)
Gender	
Male	98 (93.3)
Female	6 (5.7)
Did not respond	1 (1.0)
Age group, years	
20 - 29	8 (7.6)
30 - 39	18 (17.1)
40 - 49	45 (42.9)
≥ 50	34 (32.4)
Area	
Seoul/Gyeonggi/Incheon	65 (61.9)
Gwangju/Jeonnam/Jeonbuk	15 (14.3)
Daegu/Gyeongbuk	14 (13.3)
Busan/Gyeongnam	5 (4.8)
Daejeon/Chungnam/Chungbuk	4 (3.8)
Jeju	2 (1.9)
Educational level	
Graduate school	13 (12.4)
College/university	55 (52.4)
High school	33 (31.4)
Middle school	3 (2.9)
Elementary school	1 (1.0)
Employment status	
Permanent	25 (23.8)
Contract/irregular work	18 (17.1)
Self-employment without employee/freelancer	14 (13.3)
Self-employment with employee/businessman	2 (1.9)
Unemployed	33 (31.4)
Other	13 (12.4)
Monthly income, Korean Republic won (KRW)	
<1.99 million	43 (41.0)
2 - 2.99 million	19 (18.1)
3 - 3.99 million	15 (14.3)
4 - 4.99 million	3 (2.9)
>5 million	2 (1.9)
Did not respond	23 (21.9)

(continued to the next page)

Table 1. (Continued) Demographics and clinical characteristics of participants (N = 105)

Parameter	n (%)
Year of HIV diagnosis	
1990 - 2000	12 (11.4)
2001 - 2005	12 (11.4)
2006 - 2010	16 (15.2)
2011 - 2015	11 (10.5)
2016 - 2021	40 (38.1)
Don't remember	14 (13.3)
Treatment period after diagnosis (years)	
1 - <2	8 (7.6)
2 - <3	3 (2.9)
3 - <4	10 (9.5)
4 - <5	9 (8.6)
5 - <6	10 (9.5)
≥ 6	65 (61.9)
Route of HIV infection ^a	
Homosexual intercourse	76 (72.4)
Heterosexual intercourse	16 (15.2)
Contaminated needle	2 (1.9)
Infected blood transfusion	2 (1.9)
Vertical transmission	2 (1.9)
Don't know	16 (15.2)
Lifestyle	
Highly irregular	9 (8.6)
Irregular	20 (19.0)
Medium	33 (31.4)
Regular	33 (31.4)
Highly regular	10 (9.5)
Dietary pattern	
Highly irregular	9 (8.6)
Irregular	22 (21.0)
Medium	28 (26.7)
Regular	40 (38.1)
Highly regular	6 (5.7)
Comorbidity ^b	
Cardiovascular disease	48 (45.7)
Endocrine disorder	19 (18.1)
Gastrointestinal disorder	17 (16.2)
Musculoskeletal disorder	15 (14.3)
Respiratory disease	6 (5.7)
Kidney disease	4 (3.8)
Other	5 (4.8)
No comorbidity	34 (32.4)

^aSubjects may have more than one route of infection.

^bSubjects may have more than one comorbidity.

Most PLWH were very satisfied/satisfied (71.4%) with their HIV management, 25.7% were neither satisfied or unsatisfied and 2.9% were unsatisfied. On a scale of 5 (very satisfied) to 1 (very unsatisfied), the mean score was 3.9. PLWH considered that checking medication adherence, and explanation of the disease course, disease management and patient disease status, were generally well delivered by health care professionals (HCPs). However, quality of life (QoL) considerations, side effects, and psychological health were scored less favorably by PLWH (Fig. 1). These results show that HCPs need to pay closer attention to QoL and mental health in PLWH, as psychological issues (such as depression and suicide) are critically important in PLWH. Mental health, such as anxiety and depression problems, has a higher prevalence in PLWH than in the general population [3-5].

Most PLWH had a once-daily, single-tablet regimen for anti-HIV medication which improves adherence due to a lower pill burden [6]. Overall, 99% took their medication once daily and 89.5% had a single-tablet ART regimen. Adherence was high with 82.9% taking their medication regularly, either with (51.4%) or without (31.4%) a meal. Overall, 55.2% reported missing/skipping their medication occasionally. The main reasons were forgetting (70.7%) or not carrying their medicine when going out (20.7%).

Most PLWH (86.7%) switched drugs and one-third requested the drug switch. Reasons for switching were a preference for an easy-to-take medicine (33.3%), wanting a new drug (33.3%), and side effect(s) with their existing

medication (24.1%).

Many symptoms experienced by PLWH were under-reported. Individuals who were not satisfied with their hospital visits for HIV care reported that they experienced symptoms more than PLWH who were satisfied with their hospital visits but reported their symptoms less to HCPs. Fig. 2 shows the discrepancy between experienced and reported symptoms during the last 4-week period. The most common symptoms were tiredness and lack of energy (experienced by 42.9%, reported by 25.3%), changes in the appearance of the body (39% vs. 26.7%) and sleep disturbance (38.1% vs. 26.7%). Rates of experienced and reported symptoms were similar for some symptoms, notably skin disorders (21% vs. 18.7%), nausea and vomiting (13.3% vs. 13%), and dizziness (10.5% vs. 9.3%) which are known reported adverse events associated with ART. Common adverse effects for anti-HIV drugs include gastrointestinal effects (nausea, diarrhea), neuropsychiatric effects such as dizziness, sleep disturbance, headache and depression; and skin disorders such as rash. However, the frequency of these adverse effects is dependent on anti-HIV drug type [7, 8].

Previous research has highlighted the importance and benefits of routinely using an HIV symptom questionnaire among PLWH to identify and address common and bothersome symptoms associated with HIV and its treatment [9]. Appropriate use of an HIV symptom index can allow HCPs to carefully consider individual symptoms, their patterns of distribution in clinically relevant groupings, and their individual impact on the patient's

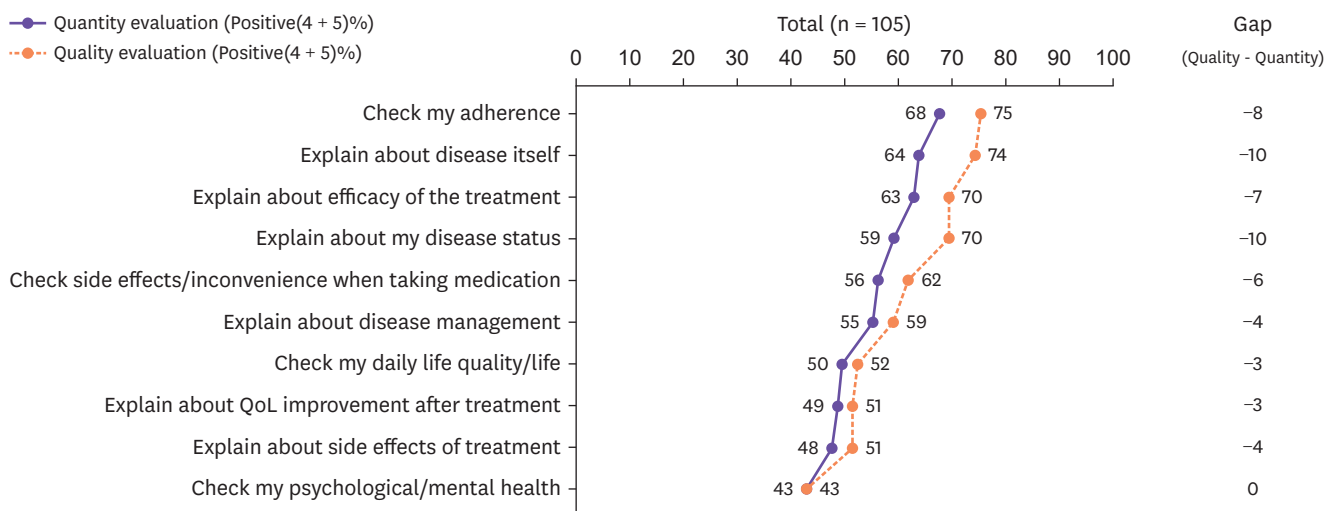
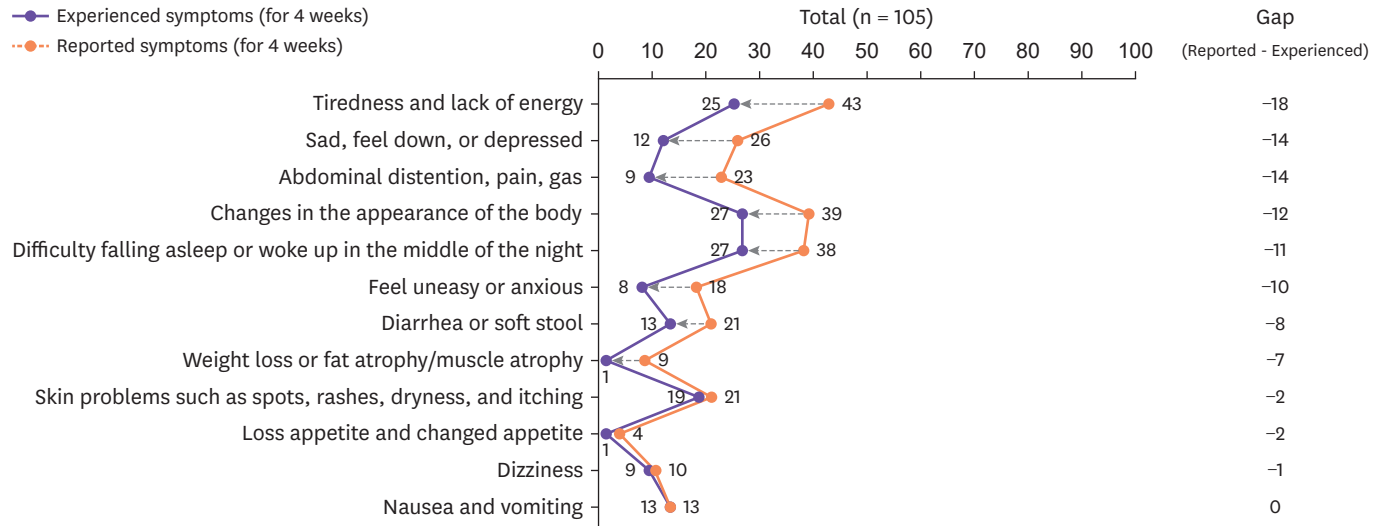


Figure 1. Assessment of care by people living with HIV (n = 105). For quantity and quality evaluations, participants were asked to rate each on a scale of 1 - 5. The proportion of subjects who were very satisfied/satisfied (score 5/4) are shown. HIV, human immunodeficiency virus; QoL, quality of life.



Note: "No experienced symptoms of the above over the past 4 weeks" 29%,
 "No reported symptoms of the above over the past 4 weeks" 24%

[Base: All, (N = 105) Unit: %]

Figure 2. Discrepancy between symptoms experienced and reported by people living with HIV during the last 4-week period. HIV, human immunodeficiency virus.

health-related QoL [9]. In the current study, most PLWH (81.9%) considered that a preliminary survey to check major symptoms would be helpful and 85.7% intended to answer such a survey. Of those, nearly half (40/90; 44.4%) preferred completing an online survey prior to their hospital visit and 26.7% wanted their symptoms checked by a doctor during consultation. This pre-consultation screening would also be helpful to check the physical and mental health of PLWH.

As a result of advances in HIV diagnosis, linkage to care, and treatment, the life expectancy of PLWH has improved significantly in recent decades. However, these advances have created a new set of challenges that must be addressed to ensure the long-term success (LTS) of PLWH [10]. Consequently, an LTS framework which offers a comprehensive and person-centric approach has been developed that includes five outcome pillars: sustained undetectable viral load, minimal impact of treatment and clinical monitoring, optimized health-related QoL, lifelong integration of healthcare, and freedom from stigma and discrimination [11].

PLWH regarded that the key characteristics of an agent to be long-term therapy were 'low risk of resistance' (70.5%), 'high long-term viral suppression efficacy' (63.8%), and 'high degree of safety' (63.8%). The main concerns about long-term HIV management were 'treatment failure due to drug resistance' (53.3%),

'interaction with other drugs' (53.3%) and 'influence on the management of other diseases' (47.6%). PLWH aged >40 years and those treated for >6 years after diagnosis were particularly concerned about treatment failure due to drug resistance. Most PLWH considered that 'improvement of negative social awareness' (88.6%), 'more effective drug development' (65.7%), and 'my effort to take medication consistently' (63.8%) were essential for successful long-term HIV management.

The main sources for information about the disease were HIV-related community websites (39.0%) and portal sites (21.0%), while HCPs such as doctors and nurses accounted for 17.1%. PLWH considered that HIV-related community websites were the most trustworthy information resource (33.3%), although the proportion was slightly lower than for the question about the main source of information. 30.5% of PLWH considered that HCPs such as doctors and nurses were the most trustworthy source of information.

The degree of knowledge about HIV and AIDS was variable. A high proportion of PLWH correctly agreed with the statements: 'if uninfected can eat food with HIV-infected people' (96.2%), 'if the number of viruses in the blood is not detected, the possibility of infection to others decreases' (91.4%), and 'even if infected with HIV, I can have children who are not infected with HIV' (86.7%); and correctly disagreed with 'condoms are not required for

sexual intercourse between HIV-infected people' (90.5%), and 'if I have red spots on the body, it's AIDS' (81.9%). A lower number of correct responses were recorded for correctly disagreeing with 'if using a condom just before ejaculating, there is no risk of HIV infection' (67.6%), and 'if someone does not ejaculate semen within the partner's anus or vagina, the partner has no risk of HIV infection' (62.9%). Clearly, more communication is required to correct these misperceptions. Effective communication channels, such as HIV-related community websites, are needed to inform and educate PLWH.

This study had several limitations. Recruitment of participants via a website may not have provided a representative cross-section of PLWH in Korea, as subjects without access to the internet or who were digitally illiterate would be excluded. Secondly, as the sample size was relatively small, conclusions from subgroup analyses (e.g., age group) are tentative and need to be confirmed in a larger study.

In conclusion, QoL and psychological/mental health of PLWH are less well managed than their physical health. A pre-consultation screening would be helpful to check the physical and mental health of PLWH.


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Ethics statement

Inclusion criteria included participants receiving ART for at least 1 year and providing informed consent. The study was approved

by the Institutional Review Board of the Korean National Institute for Bioethics Policy (KONIBP; 2021-3693-003).

Conflict of Interest

JYC is editorial board of *Infect Chemother*; however, he did not involve in the peer reviewer selection, evaluation, and decision process of this article. Otherwise, no potential conflicts of interest relevant to this article was reported. JAL, YK and JYL are employees of Gilead Sciences Korea Ltd. SP have no relevant disclosures to declare.

Author Contributions

Conceptualization: JAL, YK, JYL; Data curation: JAL, YK, SP; Formal analysis: JAL, YK; Investigation: JAL, YK, JYL, JYC; Supervision: JYL, JYC; Writing - original draft: JAL; Writing - review & editing: JAL, YK, JYL, SP, JYC.

SUPPLEMENTARY MATERIAL

Supplementary File 1

Nationwide online survey used to conduct research on understanding the perceptions and needs of people living with HIV.

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REFERENCES

- Kim JM, Kim NJ, Choi JY, Chin BS. History of acquired immune deficiency syndrome in Korea. *Infect Chemother* 2020;52:234-44. [PUBMED](#) | [CROSSREF](#)
- Love4one. Love4one. Available at: <https://love4one.com>. Accessed 7 December 2022.
- Song JY, Lee JS, Seo YB, Kim IS, Noh JY, Baek JH, Cheong HJ, Kim WJ. Depression among HIV-infected patients in Korea: assessment of clinical significance and risk factors. *Infect Chemother* 2013;45:211-6. [PUBMED](#) | [CROSSREF](#)
- Kee MK, Lee SY, Kim NY, Lee JS, Kim JM, Choi JY, Ku NS, Kang MW, Kim MJ, Woo JH, Kim SW, Song JY, Baek JH, Choi BY, Kim SS. Anxiety and depressive symptoms among patients infected with human immunodeficiency virus in South Korea. *AIDS Care* 2015;27:1174-82. [PUBMED](#) | [CROSSREF](#)
- Gooden TE, Gardner M, Wang J, Chandan JS, Beane A, Haniffa R, Taylor S, Greenfield S, Manaseki-Holland S, Thomas GN, Nirantharakumar K. The risk of mental illness in people living with HIV in the UK: a propensity score-matched cohort study. *Lancet HIV* 2022;9:e172-81. [PUBMED](#) | [CROSSREF](#)
- Truong WR, Schafer JJ, Short WR. Once-daily, single-tablet regimens for the treatment of HIV-1 infection. *P T* 2015;40:44-55. [PUBMED](#)
- Clinical Info HIV. gov. Guidelines for the use of antiretroviral agents in adults and adolescents living with HIV. Available at: <https://clinicalinfo.hiv.gov/en/guidelines/adult-and-adolescent-arv>. Accessed 15 November 2022.

8. European AIDS Clinical Society (EACS). Guidelines version 9.0. October 2017. Available at: http://www.eacsociety.org/files/guidelines_9.0-english.pdf. Accessed 15 November 2022.
9. Justice AC, Holmes W, Gifford AL, Rabeneck L, Zackin R, Sinclair G, Weissman S, Neidig J, Marcus C, Chesney M, Cohn SE, Wu AW; Adult AIDS clinical trials unit outcomes committee. Development and validation of a self-completed HIV symptom index. *J Clin Epidemiol* 2001;54(Suppl 1):S77-90.
[PUBMED](#) | [CROSSREF](#)
10. Fuster-RuizdeApodaca MJ, Wohl DA, Cascio M, Guaraldi G, Rockstroh J, Hodson M, Richman B, Brown G, Anderson J, Lazarus JV; Fuster-RuizdeApodaca MJ. Why we need to re-define long-term success for people living with HIV. *HIV Med* 2023;24(Suppl 2):3-7.
[CROSSREF](#)
11. Lazarus JV, Wohl DA, Cascio M, Guaraldi G, Rockstroh J, Hodson M, Richman B, Brown G, Anderson J, Fuster-RuizdeApodaca MJ. Long-term success for people living with HIV: a framework to guide practice. *HIV Med* 2023;24(Suppl 2):8-19.
[PUBMED](#) | [CROSSREF](#)