

# Analysis of online health information seeking among HIV patients in Indonesia

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## ABSTRACT

Indonesia ranks in the top three in Human immunodeficiency virus (HIV) epidemics worldwide with modest achievement in disease management. Electronic health literacy (EHL) is increasingly considered an important predictor to promote positive health behavior (e.g., knowledge, treatment adherence) in patients with chronic diseases like HIV. This study aimed to evaluate the pattern of information seeking among HIV patients, the relationship between EHL, patients' knowledge, and treatment adherence. Data were collected through a survey distributed to HIV patients during their regular monthly visits to two government-owned primary health centers in West Jakarta during August-September 2023. Spearman test was used to evaluate the relationship between EHL with patients' knowledge and EHL with treatment adherence. There were 62 study patients, with the majority male (77.4%), of productive age, secondary school graduates (77.4%) and having occupations (82.2%). Websites of healthcare providers and social media accounted for the most common online sources navigated by patients. Patients had high scores on EHL (median = 25). The majority of them had a good level of HIV-related knowledge (91.9%) and low adherence to medications (66.1%). This study found no significant relationship between EHL and knowledge (correlation = 0.081,  $p=0.529$ ) and medication adherence (correlation = -0.086,  $p=0.508$ ). In conclusion, EHL is not a significant predictor for improving patients' knowledge and medication adherence.

**Keywords:** Electronic health literacy, Medication adherence, Information seeking, Knowledge, HIV

## Introduction

Human immunodeficiency virus (HIV) is a continuing major public health concern, with an estimated 39 million people living with HIV across the world and 630,000 mortalities by the end of 2022 [1]. Indonesia -the world's fourth most populated country in South East Asia- is among the highest HIV epidemics globally, just behind China, India, and Russia. There has been an escalating trend in HIV prevalence and AIDS (*acquired immunodeficiency syndrome*) mortality rate in this country, thus requiring immediate and appropriate actions to address this public health issue [2].

Based on a report from the Indonesian Ministry of Health, as of March 2022, there were approximately 329,581 cases with a prevalence rate of 0.3% of the general population, and more than 80% of the cases were the productive ages. The report also disclosed the top five provinces with the highest HIV cases, with DKI Jakarta ranked first, followed by East Java, West Java, Central Java, and Papua [3].

The Joint United Nations Programme on HIV/AIDS (UNAIDS) in December 2020 established a new set of ambitious global targets known as "three 95s" to end the HIV epidemics. These targets warrant 95% of all people living with HIV to know their HIV status, 95% of all people with diagnosed HIV infection to receive sustained antiretroviral therapy (ART), and 95% of all people receiving antiretroviral therapy to have viral suppression by 2025 [4]. In reference to the 2022 Report from the Indonesian Ministry of Health, the performance indicators of HIV treatment success were far below the targets of three 95's in which only 72% of people living with HIV were aware of their HIV status; among those knowing their HIV status, 41% received ART; and 14% of those on ART had achieved viral suppression [3]. Modest

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achievement in HIV management, particularly the low proportion of HIV patients with adequate viral suppression, might reflect suboptimal use of ART. It has been evident that ART has represented the single most important predictor in viral suppression, leading to a decline in morbidity and mortality rates.

On the ground that HIV is a chronic disease requiring long-term treatment, treatment adherence is deemed a crucial factor facilitating optimal clinical outcomes and, subsequently, treatment success. Good adherence to ART, shown by low levels of viral load, might also reduce the rate of HIV transmission. Some studies revealed that adherence to ART was influenced by multiple factors, including demographics, health literacy, access to healthcare facilities, economy, and social factors [5-7]. One influential predictor of adherence to ART is health literacy; some studies uncovered the significant influence of health literacy on patients' knowledge and treatment adherence among HIV patients [8-10]. Poor health literacy has been underpinned as a silent epidemic impeding the patient's ability to navigate the health system effectively [8].

Internet infiltration has been considerably surging in Indonesia, and it is among the countries with the highest number of Internet users. Based on a survey from the Indonesian Association of Internet Providers, active internet users in Indonesia during the period of 2022-2023 have reached over 215 million users with a penetration rate of 78.19%, and this number is estimated to rise to more than 256 million by 2025 [11, 12]. The Internet has been used as the major information source worldwide, including in Indonesia, as it offers some advantages, including ease, rapidness, and a wide variety of available information available. One of the most searched information on the Internet is health information. Valid online information is crucial and might play an important role in influencing patients' knowledge and behavior related to their disease and treatment [13]. However, the quality of digital health information varies widely, thus signifying the importance of digital health literacy (electronic health literacy/EHL). EHL refers to the ability to critically appraise digital information and subsequently use the information in making decisions [14]. EHL is increasingly considered a prime concept to promote patients with chronic diseases like HIV.

It is true that the association between health literacy and adherence in HIV patients has been supported by robust evidence, yet there is a paucity of information on the role of digital health literacy in influencing patients' knowledge and treatment adherence [9]. In the digital era, HIV patients constitute a key population in which to intervene on EHL as digital health sources are more feasible and cost-effective modes to support the continuity of HIV care [15]. Therefore, this study aimed to explore the pattern of information-seeking among HIV patients and their EHL level. In addition, this study also analyzed the association between EHL and patients' knowledge and between EHL and treatment adherence.

## Materials and Methods

### *Study design and sample*

A cross-sectional study with purposive sampling was conducted in two government-owned primary health centers/PHCs in West Jakarta, a municipality in the capital Jakarta, during August-September 2023 (so-called *Pusat Kesehatan Masyarakat/Puskesmas*). The inclusion criteria of respondents included HIV patients aged  $\geq 18$  years, receiving antiretroviral therapy/ART a minimum of 3 months before data collection, literate in Bahasa Indonesia. The respondents were excluded if they disagreed to participate in the study. The sample size was calculated using the Slovin formula. The study was granted permission from the District Health Office and received ethical clearance from an Institutional Ethics Committee (1061/UN2.F1/ETIK/PPM.00.02/2023). Informed consent was obtained from the respondents, and participation was completely voluntary.

### *Data collection and analysis*

Respondent-administered questionnaires were used as the instruments to gather data from respondents. Each questionnaire consisted of four sections. Section 1 collected information on patients' demographic characteristics and the pattern of digital information-seeking. Section 2 comprised 8 questions to rate patients' EHL level using the Electronic Health Literacy Scale (eHEALS) with four answer choices (strongly agree, agree, slightly disagree, strongly disagree). Answers from each EHL question were totaled, and the median rate was calculated into 'good EHL' (patients' median  $\geq$  questionnaire median, i.e., 20) and 'poor EHL' (patients' median EHL  $<$  questionnaire median, i.e., 20). Section 3 contained 10 questions with 'true' and 'false' options to measure patients' knowledge of HIV/AIDS. Answer from each question was summed up using scores ranging from 0-10, and patients were categorized into three ranks: 'good knowledge' (score of 7.6-10), fair (5.6-7.5), and poor (score  $<$  5.5). Section 4 had 12 questions with 'true' and 'false' answer choices to assess patients' treatment adherence. The adherence level of patients was rated using scores ranging from 0-12, and patients were categorized into three ranks: high adherent (score of 10-12), moderate adherent (7-9), and low ( $<$ 7). The respondents were invited to participate in the study while awaiting doctor consultation. It took approximately 5-10 minutes for patients to complete the questionnaire.

Data were analyzed using IBM SPSS Statistics for Windows (version 22.0). Descriptive analysis was employed to determine patients' demographic characteristics and patterns of online health information-seeking, EHL score, HIV/AIDS knowledge, and treatment adherence. Spearman test was used to evaluate the association between EHL and patients' knowledge and EHL and treatment adherence. A p-value  $<$  0.05 was considered statistically significant.

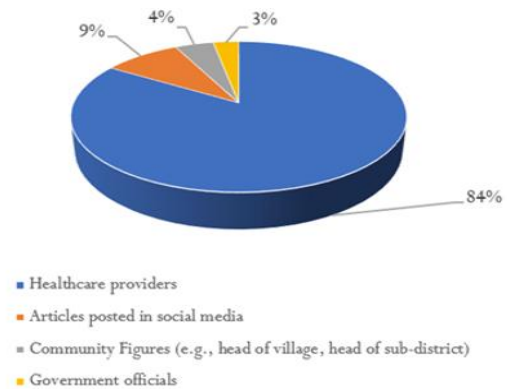
## Results and Discussion

There were 62 patients who participated in this study. The socio-demographic characteristics of the patients are detailed in **Table 1**. As described in **Table 1**, the majority of the study patients were male (77.4%), in the productive age group, secondary school graduates (77.4%), and had occupations (82.2%) with a similar proportion between self-employed and wage workers. The patients also mentioned 5-6 years as the average duration of contracting this disease since diagnosis. To some extent, the characteristics of the respondents might be the reflection of the national demographic profiles of HIV patients in Indonesia [16]. Regarding the sources of information used by the patients, unsurprisingly, healthcare providers seem to be the most trusted sources, as more than 80% of the respondents chose them when navigating information about their disease and medications. Despite the increased popularity of social media, just below 10% of the study patients were confident with the information shared through this mode (**Figure 1**). Meanwhile, government officials were not regarded as trusted sources of information related to their disease.

**Table 1. Socio-demographic Characteristics of the study patients (N=62)**

Characteristics	No. (%)
<b>Patient's age (years)</b>	
18 – 25	6 (9.7)
26 – 33	27 (43.5)
34 – 41	20 (32.3)
42 – 49	7 (11.3)
>50	2 (3.2)
<b>Gender</b>	
Male	48 (77.4)
Female	14 (22.6)
<b>Education level</b>	
Elementary	6 (9.7)
Secondary	48 (77.4)
Tertiary	8 (12.9)

Employment status	No. (%)
Unemployed	11 (17.7)
Self-employed	26 (41.9)
Employee	25 (40.3)



**Figure 1. Sources of information trusted by patients**

**Table 2** details the online information-seeking pattern among the patients. In terms of online sources used by the patients to navigate HIV-related information, most of them (30.9%) cited authorized websites of healthcare facilities, and a similar proportion of the patients referred to social media as the most frequently used online sources. Meanwhile, telemedicine platforms seem quite popular, with around 16% of the patients searching for information through this mode. **Table 2** shows a wide frequency of internet searches, which varied from ‘never’ to daily searches. With respect to the average time spent each day searching for HIV-related information, nearly three-quarters of the patients spent less than four hours per day navigating the online information. In addition, nearly all patients (89.2%) used their mobile devices, i.e., handphone/tablet, to access online information.

**Table 2. Profile of online information-seeking by the study patients**

Profile of online information-seeking	No. (%)
<b>Sources of online HIV-related information (patients can select more than one answer)</b>	
Websites of healthcare facilities (hospital, clinic, primary health center)	25 (30.9)
Social media (e.g., Instagram, Twitter)	24 (29.6)
Private providers of telemedicine (e.g., Halodoc, Alodokter)	13 (16.1)
Video-sharing websites (e.g., Youtube)	8 (9.9)
Government websites	5 (6.2)
Search engine (e.g., Google)	3 (3.7)
Online encyclopedia (e.g., Wikipedia)	2 (2.5)
News websites	1 (1.2)
<b>Frequency of internet use for searching HIV-related information (over the past 4 weeks)</b>	
Every day	3 (4.8)
3-6 times per week	19 (30.7)
1-2 times per week	17 (27.4)
Once per month	22 (35.5)
Never	1 (1.6)
<b>Daily duration of internet use for searching HIV-related information (over the past 4 weeks)</b>	
Less than 4 hours	46 (74.2)
4 – less than 8 hours	7 (11.3)
8 – less than 12 hours	5 (8.1)
More than or equal to 12 hours	4 (6.5)

**Devices used for searching online information (patients can select more than one answer)**

Handphone/tablet	58 (89.2)
Personal computer	4 (6.2)
Laptop	3 (4.6)

Assessment of EHL (**Table 3**) revealed the fact that the patients had a high score on digital health literacy (median 25 out of 20). In this case, most respondents in this study were quite confident in using internet-based media to search for HIV-related information and make informed decisions related to their disease. However, an adverse consequence of EHL was observed in a study involving HIV-infected women in which those with high

EHL were more likely to practice HIV transmission risk behavior as opposed to their less literate counterparts [17]. Following our findings, a systematic review to examine EHL in HIV patients found varying scales and scoring systems to rate EHL across the included studies, and this review unveiled high EHL scores among patients [15].

**Table 3. eHealth Literacy Scale (N=62)**

Questions	Disagree	Slightly disagree	Agree	Strongly agree
	N (%)	N (%)	N (%)	N (%)
Q1: I know how to find helpful health resources on the Internet	3 (4.8)	6 (9.7)	28 (45.2)	25 (40.3)
Q2: I know how to use the Internet to answer my health questions	6 (9.7)	4 (6.5)	35 (56.5)	17 (27.4)
Q3: I know what health resources are available on the Internet	3 (4.8)	7 (11.3)	29 (46.8)	23 (37.1)
Q4: I know where to find helpful health resources on the Internet	2 (3.2)	5 (8.1)	33 (53.2)	22 (35.5)
Q5: I know how to use the health information I find on the Internet to help me	3 (4.8)	10 (16.1)	29 (46.8)	20 (32.3)
Q6: I have the skills I need to evaluate the health resources I find on the Internet	2 (3.2)	5 (8.1)	29 (46.8)	26 (41.9)
Q7: I can tell high quality from low-quality health resources on the Internet	1 (1.6)	12 (19.4)	22 (35.5)	27 (42.5)
Q8: I feel confident in using information from the Internet to make health decisions	2 (3.2)	6 (9.7)	27 (43.5)	27 (43.5)
E-Health literacy median				25

It is interesting to note that overall, patients in our study had a good level of HIV-related knowledge, with 91.9% (n=57) having a high knowledge level, 6.5% (N=4) having a moderate level, and only one patient being categorized in a low knowledge level. As illustrated in **Table 4**, nearly all questions can be answered correctly, leaving only one question about prevention related to avoiding illicit drugs with a response rate of slightly less than 80%. However, a study conducted by Saputra *et al.* involving 60 HIV patients in an HIV referral hospital in Indonesia found a contrasting finding in which 45% of the newly diagnosed patients had a poor knowledge level [18]. It is important to note

that the nature of newly diagnosed patients recruited in Saputra *et al.* could explain the low level of knowledge as follow-up assessment six months after diagnosis showed an improvement in knowledge level resembling the level in our finding. Another Indonesian study to assess the knowledge among housewives with HIV/AIDS residing in another major city observed low knowledge levels in more than 60% of the respondents [19]. By contrast, a systematic review of studies involving HIV patients in Sub-Saharan Africa, constituting more than 70% of HIV cases globally, uncovered relatively low knowledge specifically pertinent to disease transmission and preventive measures [20].

**Table 4. HIV and AIDS-related knowledge among the study patients (N=62)**

Questions	Correct	Wrong
	N (%)	N (%)
<b>Disease etiology</b>		
1 HIV and AIDS is a transmissible disease	57 (91.9)	5 (8.1)
2 HIV and AIDS can lower the immunity system, making the body prone to infections	61 (98.4)	1 (1.6)
<b>Disease transmission</b>		
3 HIV and AIDS can be transmitted through sexual intercourse	62 (100)	0
4 HIV and AIDS can be transmitted by sharing injection equipment	57 (91.9)	5 (8.1)
5 HIV and AIDS can be transmitted from blood transfusion containing HIV	56 (90.3)	6 (9.7)
<b>Treatment</b>		
6 HIV and AIDS can be treated using voluntary counseling and testing method	53 (85.5)	9 (14.5)
7 HIV and AIDS patients should immediately receive antiretroviral therapy (ART) to slow the virus progression	61 (98.4)	1 (1.6)
<b>Prevention</b>		
8 HIV and AIDS can be prevented by avoiding free-sex relationships and having multiple sexual partners	58 (93.5)	4 (6.5)
9 Use of a condom during sexual intercourse can prevent transmission	59 (95.2)	3 (4.8)
10 Avoidance of injectable recreational drugs may prevent HIV and AIDS	49 (79.0)	13 (21.0)

In terms of ART adherence, approximately two-thirds of the patients (N=41/62) in our study had low adherence levels, leaving the remainder with moderate adherence. It is interesting to note that none of the patients reported to have high adherence to ART. However, a conflicting result was revealed by an Indonesia study in which the majority of the patients had modest to good adherence levels [18]. A high level of ART adherence (>90%) was also documented in a study by Ownby *et al.* in a county in Florida, USA. That American study used a special electronic device to record each time the patients opened the medication bottle [21]. Likewise, a study in rural Uganda documented that around 86% of the study patients reported missing a pill at most once per month, indicating optimal ART adherence [22]. This alarming fact of low-level adherence in our study should be investigated further to identify the causes and accordingly to elucidate some feasible and effective interventions to address this concern. High-level adherence, i.e., taking at least 80-90% of ART, is required to successfully suppress the viral load and reduce the risk of transmission to other persons. It should be noted adherence is a complex behaviour resulting from interactions of multiple internal (knowledge, motivation) and external factors (healthcare system, relationship with care providers), thus calling for tailored and comprehensive strategies [23].

This study also examined the relationship between EHL vs. patients' knowledge and EHL vs. medication adherence. We uncovered no relationship between EHL and knowledge (correlation coefficient = 0.081, P-value= 0.529) and between EHL and medication adherence (correlation coefficient = -0.086, p-value = 0.508). Research on the effect of internet-based health literacy on medication adherence is limited. We uncovered mixed findings when comparing our findings with other studies. Robinson and Graham conducted a study to assess the impact of a brief educational intervention on online health information evaluation among HIV-positive people. That study found EHL as a strong predictor of medication adherence, and the association remained stable three months post-intervention [24]. By contrast, an inverse association between digital literacy and ART adherence was reported by Kim *et al.* as literate HIV patients were more likely to miss doses of ART per month compared to those with low literacy [22].

Meanwhile, Krishnan uncovered that differing levels of EHL had no significant impact on medication adherence among HIV patients in Peru [25]. When expanding the context into non-HIV patients, diverse findings were also observed. Mitsutake *et al.* revealed positive health behavior (i.e., knowledge) among colorectal cancer patients in Japan was positively attributed to EHL ( $\beta = .116$ ,  $p < .001$ ) [26]. Likewise, another study by Im and Huh revealed that those with a high literacy score tend to take medications as directed [27]. Conversely, an American study involving patients with chronic diseases -not specifically HIV- aged 40 years and older found an inverse relationship between EHL and medication adherence. In this sense, patients with a high level of digital health literacy would be less likely to comply with medication recommendations [28].

Heterogeneous findings regarding the association between EHL and positive health behavior (e.g., knowledge, medication adherence) could be determined by multiple factors, e.g., social context of the study, study design, and diversity of the subjects. Promoting e-health literacy might give better opportunities for the active involvement of people with chronic diseases like HIV in self-care and for the implementation of online interventions into the existing system of care [17]. Therefore, online-based interventions targeting patients' EHL warrant further research to be validated as effective measures to improve patients' positive health behavior, including medication adherence.

These findings revealed important implications for HIV/AIDS treatment management in many countries, especially those with similar socio-economic population characteristics and governance of health systems, as the use of online health literacy and the ability to uptake the information into health decisions might play a prominent role in improving patients' knowledge and supporting adherence to their long-term medications. Our study indicates the need to develop innovative technology-based interventions to potentially improve digital health literacy among vulnerable patients. To the best of our knowledge, little research has been done, particularly in the Indonesian context, focused on EHL for HIV patients to improve their knowledge of HIV management and treatment adherence. This study has contributed to the unsettled body of knowledge on how digital health literacy might influence knowledge and medication adherence among vulnerable patients. Nonetheless, the findings of the current study should be interpreted judiciously. The relatively modest sample size and the use of two healthcare facilities from a municipality might not fully reflect the situation in Indonesia and may limit the generalizability of these findings to the broader context. Furthermore, a modest sample size in our finding might result in insufficient statistical power to measure the impact of EHL on patients' knowledge and ART adherence. Additionally, reliance on self-reported medication adherence might be affected by memory constraints, thus allowing the emergence of biased results. This self-assessment approach should be complemented with other measures, e.g., pill count history of pharmacy refills.

## Conclusion

This study provides a snapshot of health information-seeking patterns among HIV patients using digital platforms. Our findings demonstrate no significant impact of EHL on HIV-related knowledge and adherence to antiretroviral therapy among HIV patients. The findings of our study have implications for future research aimed at developing, implementing, and measuring electronically delivered interventions (e.g., mobile applications, compliance aid) to improve patients' literacy in using digital platforms to access health information.

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