



Knowledge and Awareness about HIV Among People Living with HIV: A Cross-Sectional Survey Study

HIV ile Yaşayan Bireylerin HIV Hakkındaki Bilgi Düzeyleri ve Farkındalıkları: Kesitsel Bir Anket Çalışması

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ABSTRACT

Introduction: The impact of human immunodeficiency virus (HIV) extends beyond physical health, affecting social, sexual, and psychological well-being. This study aimed to evaluate the knowledge and awareness levels of people living with HIV (PLWH), including the sources of their knowledge and influencing factors.

Materials and Methods: This prospective, cross-sectional survey study included 150 PLWH over 18 years of age, who attended the Infectious Diseases outpatient clinic of Sivas Cumhuriyet University Hospital between January and May 2024. Participants completed a 24-item self-administered questionnaire, comprising 12 demographic questions and 12 items assessing knowledge of HIV transmission, treatment, and prevention. Knowledge was scored on a scale from 0 to 12, with scores ≥ 7 classified as demonstrating sufficient knowledge.

Results: Of the 150 participants, 127 (84.7%) were male, with a mean age of 37 (inter quantile range= 31-46) years. The majority of participants were heterosexual ($n= 83$, 55.3%), single ($n= 97$, 64.6%), and had a high level of education ($n= 85$, 56.6%). A total of 70 participants (46.6%) had disclosed their HIV status to at least one person. Sufficient knowledge was significantly associated with being single ($p < 0.001$), identifying as homosexual ($p < 0.001$), being employed ($p = 0.007$), having a university education ($p < 0.001$), and membership in a PLWH association ($p < 0.001$).

Conclusion: Although the participants had relatively sufficient HIV knowledge, disclosure rates were low. Members of PLWH associations demonstrated significantly better awareness. The results emphasize the need for supportive, stigma-reducing interventions that promote behavior change alongside knowledge dissemination.

Key Words: HIV; AIDS; Knowledge; Awareness; People living with HIV

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ÖZ

HIV ile Yaşayan Bireylerin HIV Hakkındaki Bilgi Düzeyleri ve Farkındalıkları: Kesitsel Bir Anket Çalışması

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Giriş: İnsan immünyetmezlik virüsü (HIV)'nün etkisi fiziksel sağlığın ötesine geçerek sosyal, cinsel ve psikolojik iyilik halini de etkileyebilmektedir. Bu çalışmanın amacı, HIV ile yaşayan bireylerin (HİVB) HIV hakkındaki bilgi ve farkındalık düzeylerinin ve onları etkileyen faktörlerin değerlendirilmesidir.

Materyal ve Metod: Bu prospektif kesitsel anket çalışmasına Ocak-Mayıs 2024 tarihleri arasında Sivas Cumhuriyet Üniversitesi Hastanesi Enfeksiyon Hastalıkları Polikliniğine başvuran, 18 yaş üstü 150 HIV pozitif birey dahil edilmiştir. Katılımcılar, 12 demografik soru ve HIV'in bulaşma, tedavi ve korunma yollarına ilişkin bilgi düzeyini ölçen 12 maddeden oluşan toplam 24 soruluk, kendi kendine doldurulan bir anketi tamamlamıştır. Bilgi düzeyi 0 ile 12 arasında puanlanmış; ≥ 7 puan "yeterli bilgi düzeyi" olarak kabul edilmiştir.

Bulgular: Çalışmaya 150 katılımcı dahil edildi ve bunların 127 (%84.7)'si erkek, yaş ortalaması ise 37 (çeyrekler arası aralık= 31-46) yılıdır. Katılımcıların çoğu heteroseksüel ($n= 83$, %55.3), bekar ($n= 97$, %64.6) ve yüksek eğitim düzeyine sahiptir ($n= 85$, %56.6). Katılımcıların 70 (%46.6)'i HIV durumunu en az bir kişiye açıklamıştı. Yeterli bilgi düzeyi bekar olmak ($p< 0.001$), homoseksüel olmak ($p< 0.001$), çalışıyor olmak ($p= 0.007$), üniversite mezunu olmak ($p< 0.001$) ve HIV pozitif birey derneklerine üye olmak ($p< 0.001$) ile anlamlı şekilde ilişkiliydi.

Sonuç: Katılımcıların HIV konusunda göreceli olarak yeterli bilgiye sahip oldukları görülmekle birlikte, HIV durumunu açıklama oranı düşüktü. HIV pozitif birey derneklerine üye olanlar belirgin şekilde daha yüksek farkındalık göstermiştir. Bu sonuçlar, bilgi yayılımının yanında davranış değişikliğini teşvik eden, destekleyici ve damgalamayı azaltıcı müdahalelere duyulan ihtiyacı vurgulamaktadır.

Anahtar Kelimeler: HIV; AIDS; Bilgi; Farkındalık; HIV ile yaşayan bireyler

INTRODUCTION

Human immunodeficiency virus (HIV) continues to be a major global public health concern, especially in developing countries, with approximately 39 million people living with HIV (PLWH) worldwide and 1.5 million new infections each year^[1]. In recent years, Türkiye witnessed a concerning rise in HIV incidence. In 2023 alone, 5591 new cases were reported^[2].

While HIV was initially recognized as a fatal disease, the widespread use of antiretroviral therapy (ART) has transformed it into a manageable chronic condition by significantly reducing morbidity and mortality^[3]. However, the impact of HIV/acquired immune deficiency syndrome (AIDS) is not limited to physical health; it also disrupts social, sexual, and psychological dimensions of life^[4-6]. Therefore, the follow-up of PLWH should go beyond medical treatment to include efforts that improve their knowledge, reduce stigma, and support disclosure and preventive behaviors^[7].

Although previous studies have extensively evaluated the knowledge and attitudes of healthcare workers or HIV-negative individuals, data on the knowledge and awareness among PLWH themselves are scarce^[7-12]. The present study aims to assess the HIV-related knowledge, awareness, and disclosure patterns of PLWH and identify factors that influence their level of knowledge.

MATERIALS and METHODS

Ethical Approval

This study was approved by the Sivas Cumhuriyet University Non-Interventional Clinical Research Ethics Committee (2023-12/40, 21.12.2023).

Study Design, Sampling

This prospective, cross-sectional survey study included 150 PLWH over 18 years of age, who attended the infectious diseases outpatient clinic of Sivas Cumhuriyet University Hospital between January and May 2024. Elderly, infirm, or mentally retarded individuals, illiterate individuals,

individuals with severe psychiatric conditions (such as exacerbation periods of schizophrenia or other psychotic disorders, bipolar manic episodes), and those under 18 years of age were excluded. Written informed consent was obtained from all participants prior to participation.

Survey Questionnaire

The questionnaire consisted of 24 items, including 12 questions on demographic information (such as age, gender, occupation, and education level) and 12 questions addressing clinical manifestations, transmission routes, treatment, and prevention of HIV. Participants filled in the questionnaire anonymously and privately in a designated area. Healthcare staff were present to assist if needed, but they did not influence responses.

HIV knowledge was assessed using binary (yes/no) questions. One point was awarded for each correct response, resulting in a possible total score ranging from 0 to 12. A score of 0-6 was classified as “insufficient knowledge,” while a score of 7-12 indicated “sufficient knowledge.” Demographic and clinical variables-such as age, gender, marital status, sexual orientation, education level, duration of HIV infection, and support from associations-were compared between the insufficient and sufficient knowledge groups.

Statistical Analyses

Statistical analyses were performed using IBM SPSS for Windows, version 23.00 (Armonk, New York, United States of America), and visualizations were created with GraphPad Prism, version 8.3.0 (San Diego, California, USA). The distribution of the data was assessed using the Shapiro-Wilk test. Descriptive statistics included categorical data presented as frequencies and percentages, parametric data as means and standard deviations, and non-parametric data as medians and quartiles (Q1-Q3). Categorical data were analyzed using the Chi-square test or Fisher’s exact test, parametric data with the independent samples t-test, and non-parametric data with the Mann-Whitney U test. A p-value of less than 0.05 was considered statistically significant.

RESULTS

A total of 150 PLWH were enrolled in the study. The majority of participants were male (84.7%, $n=127$), with a mean age of 37 years [inter quantile range (IQR)= 31-46]. Most identified as heterosexual (55.3%, $n=83$), were single (64.6%, $n=97$), and had a high level of education (56.6%, $n=85$). The median time since HIV diagnosis was four years (IQR= 2-8). Overall, 46.6% of participants reported having disclosed their HIV status to at least one individual. The sociodemographic and clinical characteristics of the participants are summarized in Table 1.

Among the participants, 35.3% ($n=63$) were married, and 66% ($n=99$) reported having at least one sexual partner. Of these, 51% ($n=34$) stated they currently did not have a sexual partner, while 20.7% ($n=31$) reported having more than one. Disclosure of HIV status was most commonly made to friends. Among the 99 individuals with a spouse or sexual partner, only 10 had disclosed their status to their partner(s). Male participants were significantly more likely to disclose their HIV status than females (91.4% vs. 8.6%, $p=0.032$). Disclosure rates were also higher among employed individuals compared to those unemployed or homemakers (95.7% vs. 4.3%, $p=0.002$), among university graduates compared to those with only primary or secondary education (70% vs. 30%, $p<0.001$), and among single participants compared to married ones (75.7% vs. 24.3%). No significant associations were observed between disclosure of HIV status and HIV knowledge level, adequacy of HIV-related information provided by a physician, or duration of HIV diagnosis.

As detailed in Table 2, a high proportion of participants demonstrated sufficient knowledge of HIV/AIDS and its transmission routes. Each item in the HIV knowledge scale was scored as 1 point, with a maximum possible score of 12. The mean knowledge score was 7 ± 2.6 , and 70.7% ($n=106$) of participants were categorized as having sufficient HIV knowledge. Single participants had significantly higher knowledge levels compared to married participants (73.6%

Table 1. Characteristics of patients and factors associated with sufficient knowledge of HIV

Variables	Total	Insufficient Knowledge (Score 0-6) n (%)	Sufficient Knowledge (Score 7-12) n (%)	P value
Age in years (mean, Q1-Q3)	37.0 (31-46)	42 (32.2-54.7)	35.5 (29.7-45)	0.030
Gender (Male)	127 (84.7)	34 (77.3)	93 (87.7)	0.105
Sexual orientation				
Heterosexual	83 (55.3)	35 (79.5)	48 (45.3)	<0.001*
Homosexual	59 (39.3)	6 (13.6)	53 (50)	
Bisexual	8 (5.3)	3 (6.8)	5 (4.7)	
Marital status				
Single	97 (64.6)	19 (43.2)	78 (73.6)	<0.001
Married	63 (35.3)	25 (56.8)	28 (26.4)	
Educational level				
Primary-High school	65 (43.3)	30 (68.2)	35 (33.0)	<0.001
University-Master's	85 (56.6)	14 (31.8)	71 (67.0)	
Number of sexual partners				
No sexual partner	51 (34)	13 (29.5)	38 (35.8)	0.331
Single partner	68 (45.3)	24 (54.5)	44 (41.5)	
More than one	31 (20.7)	7 (15.9)	24 (22.6)	
Employment status				
Unemployed or homemaker	20 (13.3)	11 (25)	9 (8.5)	0.007
Employed	130 (86.6)	33 (75)	97 (91.5)	
Disclosure of HIV status				
Yes	70 (46.6)	16 (36.4)	54 (50.9)	0.103
No	80 (53.4)	28 (63.6)	52 (49.1)	
Duration of HIV				
5 years	107 (64.6)	24 (55.8)	58 (54.7)	0.905
>5 years	53 (35.3)	19 (44.2)	48 (45.3)	
HIV information from the physician				
Sufficient	34 (77.3)	34 (77.3)	79 (74.5)	0.720
Insufficient	10 (22.7)	10 (22.7)	27 (25.5)	
Member of PLWH association				
Yes	63 (42)	3 (6.8)	60 (56.6)	<0.001
No	87 (58)	41 (93.2)	46 (43.4)	

Q1-Q3: Quartiles, HIV: Human immunodeficiency virus, PLWH: People living with HIV.

*The groups contributing to the observed differences were the homosexual and heterosexual participants.

vs. 26.4%, $p < 0.001$). Participants identifying as homosexual had higher HIV knowledge levels compared to heterosexual participants (50% vs. 45.3%, $p < 0.001$). Similarly, employed individuals demonstrated greater HIV knowledge compared to those unemployed or homemakers (91.5% vs. 8.5%, $p = 0.007$). Those receiving support from PLWH associations had significantly higher knowledge scores than those who did not (56.6% vs. 43.4%, $p < 0.001$) (Table 1). In multivariate linear regression analysis, being single and receiving support from a PLWH association were independently associated with higher HIV knowledge (Table 3).

Regarding condom use, 82.7% ($n = 124$) of participants reported current use, with 26% ($n = 39$) indicating they began using condoms after receiving their HIV diagnosis. Condom use was negatively associated with increasing age ($p = 0.01$) and positively associated with higher educational attainment ($p < 0.001$). However, no significant associations were found between condom use and gender, marital status, sexual orientation, physician-provided HIV information, duration since diagnosis, or overall HIV knowledge level.

DISCUSSION

In this study, we aimed to examine the HIV knowledge levels and awareness among PLWH.

Table 2. Assessment of HIV knowledge in people living with HIV

Question and Answers*	n (%)
Does a positive HIV test mean that you have AIDS?	113 (75.3)
Is HIV transmitted only through unprotected sexual intercourse?	106 (70.7)
Can HIV be transmitted by using the pool, jacuzzi, or toilet used by PLWH?	115 (76.7)
Can HIV be transmitted through kissing?	120 (80)
Can HIV be transmitted by sharing common plates, spoons, and cups with PLWH?	122 (81.3)
Does HIV cause infertility?	102 (68)
Is HIV a fatal infection with no cure?	106 (70.7)
Can a pregnant woman living with HIV give birth to an HIV-negative baby?	103 (68.7)
Does alcohol and smoking negatively affect HIV prognosis and treatment?	83 (55.3)
Does food change the effect of HIV medicines?	88 (58.6)
Can condoms prevent HIV transmission?	125 (83.3)
Is it possible to protect against HIV infection with vaccination?	97 (64.7)

HIV: Human immunodeficiency virus, AIDS: Acquired immunodeficiency syndrome, PLWH: People living with HIV.

*Results are expressed as number (n) and percentage (%) of patients with correct answers.

Table 3. Univariate and multivariate logistic regression of variables for HIV knowledge level

Variables	Univariate Analyze			Multivariate Analyze		
	OR	95% CI	p	OR	95% CI	p
Age	0.95	0.92-0.98	0.030	-	-	-
Sexual orientation	6.44	2.49-16.6	<0.001	-	-	-
Marital status	3.50	1.64-7.48	<0.001	2.60	1.10-6.07	0.02
Education level	5.14	2.30-11.50	<0.001	-	-	-
Current employed	3.74	1.41-9.91	0.007	-	-	-
Member of PLWH association	25.2	5.78-110.3	<0.001	22.0	5-97.1	<0.001

Our findings indicate that while a significant proportion of participants demonstrated sufficient knowledge of HIV/AIDS and its transmission routes, this knowledge did not consistently translate into safer sexual practices or disclosure behaviors. Notably, disclosure of HIV status was more prevalent among males, single individuals, those with higher education levels, and employed participants. However, overall disclosure rates remain suboptimal, highlighting ongoing challenges in addressing stigma and promoting open communication. Additionally, although the majority reported current condom use, factors such as increasing age were associated with decreased usage, suggesting the need for targeted interventions to reinforce safe sex practices across all age groups.

HIV remains a global public health concern, making it essential to prevent transmission and

protect vulnerable populations. Enhancing individuals' knowledge regarding HIV transmission and preventive strategies is a crucial component in curbing the spread of the virus. Awareness of both transmission risks and effective preventive measures can promote behavior change, thereby contributing to the reduction of new infections^[13].

In a study by Nachega et al., misconceptions about HIV transmission were prevalent among PLWH, with 13.3% believing it could be transmitted through kissing, 17.5% through sharing food and drinks, and 16.3% through coughing^[14]. Similarly, although 76.6% of participants in the present study demonstrated a sufficient level of HIV knowledge, misconceptions persisted: A total of 29.3% of participants believed that HIV is transmitted only through unprotected

sexual intercourse, while 23.3% cited shared jacuzzis, towels, or toilets, 20% cited kissing, and 18.7% believed transmission could occur via shared utensils. These findings underscore the persistence of misinformation, despite generally high levels of knowledge. We attribute the relatively high knowledge levels observed in our study to the information provided by physicians and the support of PLWH associations.

Non-disclosure of HIV status to sexual partners significantly contributes to the continued transmission of HIV^[15]. However, fear of negative partner reactions remains a major barrier. In a study by Maman et al., conducted at a voluntary counseling and testing center in Dar es Salaam, key barriers to disclosure included fear of adverse reactions, poor communication between partners, and negative attitudes toward HIV testing^[16]. In our study, while 53.4% of participants disclosed their HIV status to at least one person, a considerable proportion refrained from disclosure. Among the 99 participants with a spouse or sexual partner, only 10 had disclosed their HIV status to their partner(s), which is relatively promising. Nevertheless, overall disclosure rates remain suboptimal and may be reflective of the persistent stigma surrounding HIV in Türkiye.

Disclosure was significantly higher among males, single individuals, university graduates, and those who were employed. These findings may be explained by gender-related disparities in perceived stigma, with women potentially facing greater social repercussions upon disclosure. Additionally, married individuals may fear negative reactions from their spouses, further deterring disclosure. Higher disclosure rates among employed and more educated participants may be attributed to greater HIV-related knowledge and empowerment through access to health information.

A previous study assessing knowledge about mother-to-child transmission among women living with HIV found that higher educational attainment was associated with better understanding of transmission risks^[17]. Similarly, our study found that university graduates demonstrated higher levels of HIV knowledge compared to

those with only primary or secondary education. This supports existing literature indicating that individuals with higher education are more likely to seek out and comprehend health-related information^[18].

Raberahona et al. reported that PLWH who were members of support associations had significantly greater knowledge about antiretroviral therapy than non-members^[19]. Consistent with these findings, our study also demonstrated significantly higher HIV knowledge levels among participants who received support from PLWH associations. This suggests that such organizations play an important role in disseminating accurate information and empowering individuals living with HIV.

Previous studies have reported condom use rates among PLWH to be around 80%, which aligns with our finding that 82.7% of participants reported condom use^[20,21]. Among them, 26% stated that they began using condoms after their HIV diagnosis. Condom use declined with increasing and rose with higher educational attainment. However, there was no significant association between condom use and gender, marital status, sexual orientation, the adequacy of HIV-related information received from physicians, duration since diagnosis, or overall HIV knowledge. Notably, the absence of a relationship between HIV knowledge and condom use is striking and warrants further investigation.

In conclusion, this study demonstrates that while a large proportion of PLWH possess good knowledge of HIV/AIDS and its transmission routes, this knowledge does not consistently lead to disclosure or safer sexual behavior. PLWH who are members of support associations tend to have better knowledge, yet this knowledge alone does not appear to influence condom use or status disclosure. These findings underscore the complexity of HIV-related behaviors and the necessity for multifaceted strategies to enhance both knowledge and its practical application among PLWH.

This study has several limitations that should be acknowledged. First, its cross-sectional design limits the ability to infer causal relationships

between HIV knowledge, disclosure behavior, and condom use. Second, the data were collected through self-reported questionnaires, which may be subject to recall bias and social desirability bias, particularly concerning sensitive topics such as sexual behavior and HIV status disclosure. Third, the study was conducted at a single center with a relatively small, convenience-based sample, which may limit the generalizability of the findings to the broader population of PLWH in Türkiye. Furthermore, although HIV knowledge was assessed using a structured scale, the sources and means by which participants acquired this knowledge were not thoroughly explored. Additionally, because the study did not evaluate participants' level of HIV knowledge prior to their diagnosis, no comparison could be made regarding changes in knowledge over time.

ETHICS COMMITTEE APPROVAL

This study was approved by the Sivas Cumhuriyet University Non-Interventional Clinical Research Ethics Committee (Decision no: 2023-12/40, Date: 21.12.2023).

CONFLICT of INTEREST

The authors have no conflicts of interest to declare that are relevant to the content of this article.

AUTHORSHIP CONTRIBUTIONS

Concept and Design: YÇK

Analysis/Interpretation: YÇK, SAB

Data Collection or Processing: YÇK

Writing: YÇK, SAB

Review and Correction: YÇK, SAB

Final Approval: YÇK, SAB

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