

Research Progress on Online Health Information-Seeking Behavior among HIV/AIDS Patients

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Abstract

This review synthesizes the conceptual foundations, measurement tools, and current research status of online health information-seeking behavior (OHISB). It systematically examines the influencing factors of OHISB among people living with HIV/AIDS (PLWHA) from sociodemographic, cognitive, psychological, disease-related, and social perspectives. Furthermore, it proposes strategies and recommendations to enhance OHISB in this population, including addressing their specific health information needs, improving eHealth literacy, and fostering a safer and more reliable online environment. The findings aim to provide a theoretical basis for developing targeted interventions to support effective online health information seeking among PLWHA.

Keywords

HIV/AIDS, Online Health Information-Seeking Behavior, Review

1. Introduction

Acquired Immunodeficiency Syndrome (AIDS) is a chronic infectious disease caused by the Human Immunodeficiency Virus (HIV), characterized by a significant reduction in CD4⁺ T lymphocytes and severe impairment of immune function [1]. According to the latest epidemiological report released by the Joint United Nations Programme on HIV/AIDS (UNAIDS) in 2024, approximately 39.9 million (range: 36.1 - 44.6 million) people worldwide were living with HIV/AIDS by the end of 2023, underscoring the persistent severity of the epidemic [2]. To date, there is no effective preventive vaccine or definitive cure for

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HIV/AIDS [3], necessitating lifelong follow-up and treatment for affected individuals. Throughout the course of long-term disease management, people living with HIV/AIDS exhibit a strong demand for health-related information [4]. Actively seeking such information enables patients to acquire timely disease-related knowledge, fulfill informational needs, enhance self-management capabilities, and facilitate treatment and recovery [5]. Moreover, online health information-seeking behavior may help reduce dependence on medical resources and alleviate the economic burden on healthcare systems [6]. However, factors such as low eHealth literacy, stigma, privacy concerns, and social discrimination often hinder effective online health information seeking among this population [7] [8]. Therefore, this review summarizes current research on online health information-seeking behavior among HIV/AIDS patients, including its prevalence, influencing factors, and potential strategies, with the aim of informing future interventions designed to support this vulnerable group.

2. Research Status of Online Health Information-Seeking Behavior

2.1. Concept and Measurement Tools of Online Health Information-Seeking Behavior

Currently, there is no consensus on the precise definition of Online Health Information-Seeking Behavior (OHISB), with scholars offering interpretations based on their respective research perspectives. Hovick *et al.* [9] characterize OHISB as a process in which individuals utilize the internet to search, browse, select, evaluate, and apply health-related information or knowledge to address their personal health needs. Similarly, Li Yuelin [10] defines it more concisely as the act of using the internet to retrieve health information to fulfill one's health information requirements. Synthesizing these viewpoints, OHISB can be broadly defined as the process through which patients use online platforms to seek health-related information or knowledge based on their individual needs, particularly concerning disease treatment and prognosis. The instruments commonly used to investigate OHISB are primarily general-purpose scales. Notable examples include the "Online Health Information-Seeking Behavior Scale" developed by Popovac *et al.* [11] in 2022 and the scale compiled by Wang Ziyue [12] in 2017. Future research should focus on comparing the dimensional structures, reliability, validity, and target populations of these different measurement tools. Such comparative analysis will facilitate the accumulation of comparable evidence across diverse populations and regions, thereby enhancing the consistency and generalizability of research findings in this field.

2.2. Research Status of Online Health Information-Seeking Behavior in International Context

According to the literature, international scholars have conducted extensive research on online health information-seeking behavior (OHISB) from various

perspectives since 1987, achieving substantial progress in the field [13]. Research themes have evolved from initially focusing on patients' online health information needs to examining the current status and motivations behind such behavior, and further exploring its influencing factors. While numerous studies have investigated factors influencing OHISB among patients with chronic diseases, research targeting specific disease populations remains limited, with most attention directed toward diabetes patients. For instance, Jamal A *et al.* [14] conducted a cross-sectional survey involving 344 type 2 diabetes patients from two teaching hospitals in Riyadh, Saudi Arabia. The results indicated that participants who sought online health information were more proactive in diabetes self-care compared to those who did not engage in health-related information seeking. Similarly, Lee JW *et al.* [15] revealed differences in mobile-based health information-seeking behaviors between patients from high-income (Singapore) and middle-income (Malaysia) countries. Participants from Singapore were more likely to use mobile devices to access health information than their counterparts in Malaysia. Overall, international research in this area has expanded from initial analyses of search behaviors to incorporate comprehensive evaluations of information quality, contextual dependencies, and cross-cultural differences. These developments provide a valuable foundation for further studies on information behaviors among populations affected by highly sensitive diseases, such as HIV/AIDS.

2.3. Research Status of Online Health Information-Seeking Behavior in China

In China, research on online health information-seeking behavior (OHISB) is still in its early stages, with a limited number of investigative studies, most of which focus on patients with chronic non-communicable diseases. For example, Hu Meng *et al.* [16] conducted qualitative interviews with 18 elderly patients with chronic conditions and identified two key dimensions of their OHISB: motivation for seeking information and the search process itself. In a questionnaire-based study of 192 hypertension patients treated at Ganzhou People's Hospital, Qi Jiangzhen *et al.* [17] found that participants' OHISB remained underdeveloped overall. The study also revealed a significant positive correlation between patients' health behaviors, patient activation, and OHISB, highlighting the presence of a notable digital divide. Similarly, Xiong Rui *et al.* [18] surveyed 194 maintenance hemodialysis patients at West China Hospital of Sichuan University and demonstrated that eHealth literacy is a critical factor influencing patients' online health information-seeking. Another survey of 451 elderly patients with coronary heart disease in Qingdao by Zhu Yaru *et al.* [19] explored the relationships and mechanisms among patient activation, self-efficacy, social support, and OHISB. Given the long-term nature of chronic conditions, patients often exhibit a strong need for disease-related information. Healthcare providers should strive to identify the barriers these patients encounter during information seeking and offer targeted support to facilitate better self-management [20] [21]. Overall, domestic studies

have primarily focused on describing information sources, access channels, and behavioral characteristics, while in-depth exploration of the relationship between information-seeking and health outcomes remains limited. This gap is particularly evident among populations affected by highly stigmatized infectious diseases such as HIV/AIDS. Due to heightened concerns around privacy and social discrimination, people living with HIV/AIDS are more inclined to rely on anonymous online channels for information—a behavioral tendency that has not been adequately captured or studied in existing literature.

3. Factors Influencing Online Health Information-Seeking Behavior among HIV/AIDS Patients

3.1. Sociodemographic Factors

3.1.1. Gender

Women generally demonstrate a stronger preference for seeking health information, which may be attributed to their greater emphasis on healthy lifestyles and higher levels of self-efficacy. When confronted with health issues, women are more likely to acquire detailed disease-related information to address their needs [22]. It is noteworthy, however, that this gender-based difference in information-seeking behavior is less pronounced among older adult populations [23].

3.1.2. Economic Status

Individuals with different income levels exhibit distinct patterns in online health information-seeking behavior. Ghahramani *et al.* [24] demonstrated that higher-income groups are more inclined to seek health information online compared to their lower-income counterparts. Additionally, LaValley *et al.* [25] found that individuals with limited financial means often have restricted access to professional health websites or paid medical information platforms, coupled with lower awareness of such specialized resources. Consequently, they tend to rely more heavily on general search engines, which may lead to higher motivation for online health information seeking despite these constraints.

3.1.3. Age and Educational Attainment

Younger individuals demonstrate a greater propensity to utilize the internet for health information exploration [26]. In contrast, although older adults exhibit an increased demand for health-related information—particularly regarding specific medical conditions—their actual engagement in online searches tends to be more limited [27]. Meanwhile, individuals with higher educational attainment show not only better comprehension of health-related content but also greater acceptance of online health platforms, leading to more active use of digital resources to fulfill their health information needs [28].

3.2. Cognitive Factors

3.2.1. HIV/AIDS-Related Knowledge

HIV/AIDS-related knowledge encompasses understanding of the disease's

etiology, modes of transmission, clinical manifestations, and related information. Existing research has established that disease-specific knowledge significantly influences health information-seeking behavior [29]. For instance, a study by Wu Jihong *et al.* [30] involving 270 COPD patients revealed that the level of COPD-related knowledge directly affected their health information-seeking behaviors. Similarly, Hu Meng *et al.* [16] conducted semi-structured interviews with elderly chronic disease patients and found that insufficient disease knowledge often leads to information-seeking anxiety, thereby hindering patients from actively seeking health information online.

Therefore, a lack of adequate HIV/AIDS-related knowledge among patients during treatment and care can compromise their ability to manage their condition effectively and reduce their engagement in online health information-seeking activities.

3.2.2. Patient Activation

Patient activation refers to an individual's understanding of the importance of engaging in their health management, along with possessing the knowledge and confidence to do so [31]. It represents a key factor influencing health information-seeking behavior. For instance, Li Yuan *et al.* demonstrated that hospitalized stroke patients with higher activation levels were more proactive in using the internet to seek disease-related information, develop positive attitudes toward their condition, and implement behavioral changes [32]–[34]. Further supporting this relationship, another study [35] indicated that the more health information patients acquire online, the higher their level of activation becomes, suggesting a bidirectional correlation between patient activation and online health information-seeking behavior. These findings collectively indicate that enhancing patient activation not only encourages active information seeking but also plays a crucial role in fostering positive health attitudes and facilitating health behavior modification.

3.2.3. eHealth Literacy

Norman *et al.* [36] defined eHealth literacy as the ability to seek, find, comprehend, evaluate, and apply health information from electronic sources to address health problems. This competency significantly influences online health information-seeking behavior. Patients with high eHealth literacy actively utilize health information platforms, demonstrate effectiveness in discerning information quality, and successfully translate relevant information into health-promoting behaviors, thereby enhancing self-management [37] [38]. Conversely, those with limited eHealth literacy often struggle to effectively navigate digital health resources, exhibit inadequate information acquisition skills, and display poor discrimination regarding the credibility of online health information. This frequently results in failure to obtain accurate and practical disease management information, ultimately compromising treatment adherence [39] [40]. Therefore, improving eHealth literacy is essential not only for strengthening patients' capacity to access and evaluate health information but also for promoting the adoption of healthy behaviors

and improving treatment compliance.

3.3. Psychological Factors

3.3.1. Self-Efficacy

Self-efficacy refers to an individual's confidence in their ability to perform specific behaviors or overcome challenges, representing a cognitive assessment of their own capabilities [41]. It plays a significant role in disease management and health-related decision-making. Patients with high self-efficacy demonstrate greater confidence in managing their condition and believe in their capacity to seek out and select high-quality health information. Rather than passively encountering information, they engage in proactive and purposeful searches [42]. Research indicates that such individuals are more likely to actively seek health information to achieve health goals, apply this information to address health issues, and ultimately improve their quality of life [43]. Furthermore, self-efficacy has been shown to serve as a key mediating factor in the process of translating health information into tangible health outcomes or behaviors [44]. Therefore, health interventions and information services should aim to enhance patients' self-efficacy—for instance, by providing reliable information sources and skills training—to strengthen their ability to obtain and utilize health information effectively, thereby supporting positive health behavior change.

3.3.2. Stigma

Stigma refers to the experience and perception of being negatively labeled due to one's health condition, resulting in prejudice, discrimination, and unfair treatment [45] [46]. It profoundly impacts patients' psychological well-being and behavioral decisions. For example, Lee *et al.* [47] demonstrated that patients may fear exposing their condition during information seeking, which could lead to discrimination or social judgment, thereby driving them to avoid seeking information as a way to protect themselves from potential psychological harm. Therefore, health interventions and information services should focus on mitigating stigma—for instance, by creating supportive environments, providing anonymous information channels, and implementing anti-stigma education—to reduce psychological barriers to information seeking and promote active engagement in health management.

3.4. Disease-Related Factors

Existing evidence clearly indicates that a patient's health status significantly influences their health information-seeking behavior. Specifically, declines in physical function and associated health issues—such as visual impairment and limited mobility—pose substantial barriers to accessing health information [48]. Supporting this relationship, a study by Nikoloudakis *et al.* [49] among Australian adults confirmed a positive correlation between health status and information-seeking behavior, indicating that poorer health often motivates individuals to seek health-related information more actively.

Furthermore, the number of chronic conditions a patient has serves as a significant predictor of information-seeking behavior. Ducrot *et al.* [50] demonstrated that individuals with two or more chronic diseases are more likely to engage in active health information seeking compared to those with a single condition or no chronic diseases, revealing a significant positive relationship between disease burden and information-seeking behavior. These findings collectively highlight that both the severity and complexity of an individual's health conditions are closely associated with their initiative in seeking health information.

3.5. Social Factors

Social support refers to the material, emotional, and informational assistance provided by significant members of an individual's social network [51]. It is widely recognized as an important factor influencing health information-seeking behavior [52]. Through resources and support from family, friends, and non-professional contacts [53], social support can enhance patients' engagement in health information seeking and improve their ability to manage their condition effectively. For example, Wang Jingjing *et al.* [54] demonstrated that older adults with higher levels of social support are more likely to actively and effectively utilize online medical resources to obtain health-related information, thereby facilitating better disease self-management. Similarly, Sun *et al.* [55] found that strong social support alleviates psychological distress among elderly patients with coronary heart disease and strengthens their motivation to seek health information.

However, some studies also suggest that excessive social support may lead to over-reliance on family and friends, reducing patients' initiative in managing their own health [56], which can in turn negatively affect their online health information-seeking behavior. Therefore, improving communication between healthcare providers and patients, as well as enhancing patients' sense of efficacy in obtaining information through formal medical channels, are crucial steps in mitigating unnecessary information-related risks and promoting appropriate use of online health information.

4. Strategies and Recommendations to Enhance Online Health Information-Seeking Behavior among HIV/AIDS Patients

4.1. Addressing Health Information Needs and Protecting Patient Privacy

Given the particular sensitivity of HIV/AIDS, associated social stigma, and strong concerns around privacy, affected individuals have especially urgent needs for reliable health information. The anonymity, accessibility, and low cost of online health resources have led many people living with HIV/AIDS to seek information via the internet [57]. In the era of digital health, healthcare providers should pay close attention to these patients' information needs, understand the current state of their online health information-seeking behaviors, and identify key barriers

they encounter. Such understanding is essential for carrying out targeted and effective health education [58]. Due to the high levels of stigma and discrimination in offline settings, people with HIV/AIDS often rely heavily on anonymous online environments. However, this also makes them more vulnerable to misinformation. It is therefore recommended to develop secure and reliable health information platforms specifically designed for this population, with strong emphasis on privacy protection, to facilitate better disease self-management.

4.2. Improving eHealth Literacy to Reduce Health Anxiety

eHealth literacy is a critical competency that encompasses the ability to seek, understand, evaluate, and apply health information obtained through digital channels to address health issues [59]. Currently, online health information varies widely in quality and reliability. Patients with low eHealth literacy are often unable to process such information appropriately—especially in the absence of professional guidance—which may lead to cognitive biases and subsequently increase health anxiety [60] [61]. Research has shown that health anxiety can severely affect both physical and psychological well-being, reduce quality of life, and even contribute to the onset of additional health problems [62]. Therefore, government and health institutions should implement specialized eHealth literacy training programs, combining community workshops and online courses, to help patients develop skills in retrieving information from authoritative sources and critically evaluating online health content. These efforts can enhance self-management capabilities and mitigate health anxiety induced by confusing or conflicting information.

4.3. Purifying the Online Environment and Providing Accurate Disease Knowledge

With the rapid development of technology, digital media has become a major channel for disseminating health information, and the public increasingly relies on the internet to access knowledge about diseases [63]. However, health information is often distorted during dissemination, and the internet can amplify the spread and scope of inaccurate information, making it difficult for patients to obtain reliable knowledge and adversely affecting their online health information-seeking behaviors [64] [65]. To counter this, online health platforms should leverage big data technologies to enable accurate content recommendation, thereby improving the accuracy and timeliness of health information. Furthermore, relevant regulatory bodies should strengthen oversight of online health information platforms to ensure that professional and trustworthy disease knowledge is provided, ultimately promoting more informed and effective health information seeking among patients.

5. Summary and Outlook

Based on a comprehensive review of the literature, current research gaps are

summarized below, along with corresponding recommendations for future work: 1) There is a scarcity of studies within the nursing science field focusing specifically on online health information-seeking behavior (OHISB) among people living with HIV/AIDS. Future research should prioritize this vulnerable population to better understand their unique information needs and behaviors. 2) Internationally, there is a lack of validated and reliable scales designed to measure OHISB in HIV/AIDS patients. The development and psychometric evaluation of such tools are urgently needed to facilitate comparative and high-quality research. 3) Current studies on OHISB are predominantly qualitative in nature. Future investigations would benefit from adopting mixed-methods approaches, incorporating quantitative and longitudinal designs, to enable more comprehensive and in-depth analyses. 4) There is a notable absence of intervention programs aimed at improving OHISB among HIV/AIDS patients in China. It is recommended that future research explore the influencing factors of OHISB from diverse perspectives and develop culturally adapted intervention strategies tailored to this population.

In summary, stigma and other negative psychosocial factors often lead people living with HIV/AIDS to turn to the internet for disease-related information. OHISB can play a positive role in promoting self-management, improving health outcomes, enhancing patient activation, and ultimately elevating quality of life. It is therefore essential to leverage existing empirical evidence, raise awareness and understanding of OHISB among patients and providers, conduct thorough analyses of current behavior patterns and determinants, and develop effective intervention and guidance strategies. Such efforts will contribute significantly to the advancement of healthcare services for people living with HIV/AIDS.

Conflicts of Interest

The authors declare no conflicts of interest regarding the publication of this paper.

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