The Impact Of Illness Perception Among People Living With Hiv: A Scoping Review

Nida Nursaadah[1], Iqbal Pramukti[2], Hasniatisari Harun[3]
[1]Nida Nursaadah/Fakultas Keperawatan, Universitas Padjadjaran, nida21005@mail.unpad.ac.id
[2]Iqbal Pramukti/ Fakultas Keperawatan, Universitas Padjadjaran, iqbal.pramukti@unpad.ac.id
[3]Hasniatisari Harun/ Fakultas Keperawatan, Universitas Padjadjaran, hasniatisari.harun@unpad.ac.id

ABSTRACT

Illness perception is an important factor and directly affects the health outcomes of people living with HIV (PLHIV). It impacts their psychological well-being, ART adherence, and quality of life. This scoping review aims to analyze the impact of illness perception among PLHIV. A literature study with relevant keywords was conducted using Scopus, EBSCOhost, and PubMed databases. Inclusion criteria included studies involving an HIV population, published in English between 2009 and 2024 and available in free full text. The result showed that negative illness perception was consistently associated with poorer quality of life, increased psychological distress, and reduced ART adherence. Conversely, cognitive-behavioral therapy (CBT) and psychoeducation improved illness perception, enhancing health outcomes. Therefore, illness perception interventions are important in HIV care strategies because they improve mental health, quality of life, and treatment adherence, which in turn improves long-term health outcomes for people living with HIV.

Keywords: *illness perception, PLHIV, scoping review*

INTRODUCTION

HIV continues to be a significant global health concern, with millions of people worldwide affected. Within the broader framework of ending the HIV epidemic by the year 2030 (Anakwa et al., 2021). With the advancement of antiretroviral therapy (ART), the result of this illness has transformed from a fatal disease to a chronic manageable condition, significantly increasing life expectancy among people living with HIV (PLHIV) (UNAIDS, 2023). Despite these advancements, many PLHIV still encounter psychological, social, and behavioral challenges that impact their overall well-being and treatment adherence.

According to Leventhal's common-sense model of illness self-regulation, individuals can establish specific configurations of illness perceptions, which are psychological factors. Illness perception is a construct that refers to how people perceive their disease (cognitive representation) and react to it emotionally (emotional representation), influencing not only their coping but also their adherence to therapy and, to an extent, their illness outcomes (Kapetanakis et al., 2023).

In terms of HIV adaptation, research has found that the illness perceptions of PLHIV are significantly linked to a wide range of health outcomes, including coping strategies, quality of life, and antiretroviral therapy (ART) adherence, making it an important aspect of HIV care (Leventhal et al., 2016).

Furthermore, individuals with a more negative perception of their illness may experience increased distress, social withdrawal, and reduced engagement in healthcare services, ultimately affecting their quality of life (Petrie & Weinman, 2012). Therefore, illness perceptions emerge as a promising target for psychosocial interventions to improve health outcomes.

MATERIAL AND METHODS

Study Design

The literature design uses a systematic scoping review approach. The literature review uses PRISMA Guidelines for Scoping Review (PRISMA-ScR) to identify illness perception among people with HIV.

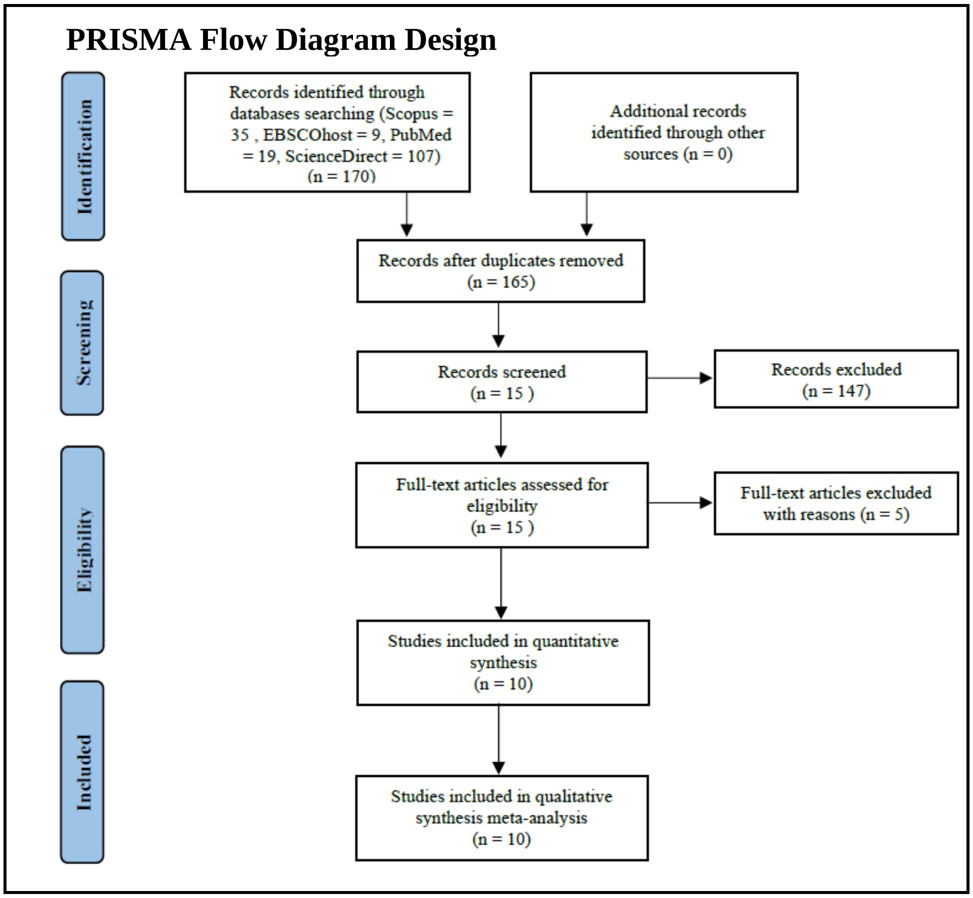

Figure 1. PRISMA Flow Diagram

Search Strategy

The search was done through four electronic databases: Scopus, EBSCOhost, PubMed, and ScienceDirect. The keywords used in the search varied using the PCC formulation, including (People Living with HIV OR HIV Patients OR PLWH) AND (Illness Perception OR Perception of Illness OR Beliefs About Illness) AND (Quality of Life OR Treatment Adherence OR Psychological Well-Being OR Health Outcomes OR Self-Management).

Inclusion and Exclusion Criteria

The selection of literature was based on predefined inclusion and exclusion criteria. The inclusion criteria were: (a) studies involving an HIV population, (b) studies published in English, (c) studies published between 2009 and 2024 to ensure a comprehensive review of the impact of illness perception on PLHIV over time and (d) free full-text availability. The exclusion criteria were (a) studies published in languages other than English, (b) studies published before

2009, and (c) studies that were not accessible in full text.

Eligibility Criteria

This scoping review investigates the impact of illness perception on health outcomes among people living with HIV. The following inclusion criteria were applied: (a) studies published between 2009 and 2024, (b) studies focusing on illness perception and its impact on PLHIV, (c) studies involving an HIV population, (d) peer-reviewed articles published in English, and (e) studies that explore the relationship between illness perception in PLHIV.

RESULTS

Description of Selection Study

From the four databases used, namely Scopus, EBSCO, PubMed, and ScienceDirect, 170 articles were obtained. Next, duplicate exclusion was carried out, which contained 5 articles, resulting in 165 suitable articles. After excluding duplicates, abstract selection was conducted, and the inclusion criteria showed 15 relevant articles. When the exclusion selection was conducted, these 15 articles were further screened into the full-text category with open access, resulting in 10 articles used in this literature review.

Study Characteristics

Of the 10 articles that met the criteria, the research was conducted on several continents: 3 articles were in Brazil, 2 articles were in China, 2 articles were in Italy, 1 article was in Greece, 1 article was in Ghana, and 1 article was in Multinational (USA, Taiwan, Norway, Puerto Rico, and Colombia).

Result Finding

No	Article Title (Country)	Writer	Objective	Method	Results
1	The impact of frailty and illness perceptions on quality of life among people living with HIV in Greece: A network analysis (**Greece**)	Kapetanakis A., Karakatsoulis G., Kyrou D., et al. (2023)	To examine the association between frailty, illness perception, and quality of life (QoL) in people living with HIV (PLHIV) in Greece.	**Research Design**: Multicenter cross-sectional study **Population & Sample**: 477 PLHIV from six HIV clinics in Greece. **Instruments**: Fried's criteria for frailty, EuroQoL (EQ-5D-5L) for QoL, Brief Illness Perception Questionnaire (BIPQ).	**Result**: Frailty and illness perception significantly impact QoL. Emotional response and illness concern were strongly correlated. Self-reported exhaustion, slow walking speed, and low physical activity affected physical QoL dimensions, while anxiety/depression was strongly associated with illness concern, leading to psychological distress. Symptom management and patient education can improve QoL.

2	Illness perception and quality of life of HIV-positive persons: Mediation effects of tenacious and flexible goal pursuit (**Brazil**)	Catunda C., Seidl E.M.F., et al. (2016)	To analyze how illness perception affects QoL in HIV-positive individuals and the mediating role of goal-pursuit strategies.	**Research Design**: Quantitative study **Population & Sample**: 196 PLHIV. **Instruments**: Brief IPQ for illness perception, WHOQOL-HIV BREF for QoL, goal pursuit questionnaire (TGP and FGA).	**Result**: Illness perception influences QoL both directly and through coping strategies. Negative illness perception was associated with lower QoL, but individuals who adopted flexible goal-pursuit strategies experienced better QoL outcomes. The study highlights the importance of psychological flexibility in adapting to illness.
3	Quality of life of people living with HIV/AIDS: Effects of illness perception and coping strategies (**Brazil**)	Seidl E.M.F., Catunda C., Lemétayer F. (2016)	To investigate the role of illness perception and coping strategies on QoL among PLHIV.	**Research Design**: Cross-sectional study **Population & Sample**: 95 PLHIV (adult Brazilian individuals) **Instruments**: Brief IPQ, Brief Cope, WHOQOL-HIV BREF.	**Result**: Illness perception directly and indirectly influences QoL through coping strategies. Patients who perceived their illness negatively had lower QoL scores, particularly in psychological and social domains. Coping strategies such as positive reframing and problem-solving improved QoL, while avoidance coping had negative effects.
4	Illness perceptions, social support, and antiretroviral medication adherence in people living with HIV in the Greater Accra region, Ghana (**Ghana**)	Anakwa N.O., Teye-Kwadjo E., Kretchy I.A. (2021)	To assess the influence of illness perceptions and social support on ART adherence in PLHIV in Ghana.	**Research Design**: Cross-sectional correlational study **Population & Sample**: 235 PLHIV from two hospitals in Ghana. **Instruments**: Illness perception scale, social support scale, adherence scale.	**Result**: Personal control and treatment control perceptions were negatively associated with adherence, whereas emotional response had a positive correlation. The study found that patients who believed they had control over their illness were less likely to adhere to ART, possibly due to overconfidence in self-management. Family support had no significant effect on adherence, but emotional support from close friends had a minor positive influence.
5	Relationships of Illness Perceptions with Depression and Anxiety in People Who Live with HIV/AIDS in a High-prevalence	Feng C., Yu B., Fu Y., et al. (2022)	To explore the relationship between illness perception and mental health outcomes (depression and anxiety) in	**Research Design**: Observational and cross-sectional study **Population & Sample**: Random sampling study, 729 PLHIV from 13 administrative units in	**Result**: Negative illness perceptions were strongly associated with higher anxiety and depression scores. Patients who perceived HIV as a severe and uncontrollable condition had significantly worse

	Ethnic Autonomous Region of Sichuan, China (**China**)		PLHIV.	Sichuan, China. **Instruments**: GAD-7 for anxiety, PHQ-9 for depression, illness perception scale.	mental health outcomes. The study emphasizes the need for psychological interventions to address illness perceptions in PLHIV.
6	Association between illness perception, treatment adherence, and emotional state in HIV/AIDS (**Brazil**)	Lima T.G., Borges L.M., Pereira F.M. (2024)	To investigate the association between illness perception, ART adherence, and emotional well-being in PLHIV.	**Research Design**: Cross-sectional study **Population & Sample**: 101 PLHIV from a university hospital. **Instruments**: Brief IPQ, ART adherence scale, Hospital Anxiety and Depression Scale.	**Result**: Strong association between illness perception and anxiety/depression. Patients with negative perceptions had significantly lower ART adherence rates, suggesting that addressing illness perception in psychological interventions could improve treatment outcomes.
7	Illness Representations of HIV-Positive Patients Are Associated with Virologic Success (**Italy**)	Leone D., Borghi L., Lamiani G., et al. (2016)	To examine whether illness representations influence ART adherence and virologic success in PLHIV.	**Research Design**: The observational study **Population & Sample**: 161 PLHIV on HAART in Italy. **Instruments**: Illness Perception Questionnaire-Revised (IPQ-R), viral load measurement.	**Result**: Patients who viewed their condition as stable and manageable had higher ART adherence and virologic success rates. The study underscores the role of illness perception in treatment engagement.
8	Dyadic Typology of Illness Perceptions in HIV Serodiscordant Couples (**China**)	Hou J., Fu R., Jiang T., Yu N.X. (2024)	To analyze illness perception among serodiscordant couples and its impact on QoL and ART adherence.	**Research Design**: Cross-sectional study **Population & Sample**: 231 HIV-serodiscordant couples in China. **Method**: Dyadic latent profile analysis.	**Result**: Three illness perception profiles were identified. Significant differences in ART adherence and QoL were observed between the profiles, highlighting the need for tailored interventions based on couple dynamics.
9	Illness perceptions and coping strategies among individuals diagnosed with HIV (**Italy**)	Norcini Pala A., Steca P. (2015)	To identify illness perception profiles and assess their impact on coping strategies and clinical biomarkers.	**Research Design**: Cross-sectional study **Population & Sample**: 248 HIV-positive patients in Italy. **Instruments**: Brief IPQ, COPE questionnaire, CD4+ count, viral load.	**Result**: Patients with high illness perception influence showed more dysfunctional coping strategies, higher viral load, and poorer treatment adherence. A high perception of control was linked to better coping and clinical outcomes.
10	HIV Illness Representation as a Predictor of Self-care	Reynolds N.R., Sanzero Eller L., Nicholas	To investigate the relationship between illness representation,	**Research Design**: Multi-site cross-cultural study **Population &**	**Result**: Illness representation impacts self-care behaviors and quality of life. Higher perceived

Management and Health Outcomes (**Multinational**)	P.K., et al. (2009)	self-care, and health outcomes across multiple countries.	**Sample**: 1,217 HIV-positive individuals from the USA, Taiwan, Norway, Puerto Rico, and Colombia. **Instruments**: IPQ, self-care management scale, HAT-QoL.	control was linked to better self-care and quality of life, while a lack of control perception led to worse outcomes.

DISCUSSION

Most reviewed studies utilized similar instruments to assess illness perception, with the Brief Illness Perception Questionnaire (Brief-IPQ) being the most commonly used tool. The consistency in measurement across studies strengthens the comparability of findings and highlights the widespread application of this instrument in evaluating illness perceptions among PLHIV. Despite minor variations in methodology, the overall trends observed across studies remain consistent, reinforcing the link between illness perception, quality of life, and treatment adherence.

The findings from the reviewed studies highlight the significant impact of illness perception on people living with HIV (PLHIV). Across various settings and populations, negative illness perceptions are consistently associated with poorer health outcomes, including reduced quality of life, lower adherence to antiretroviral therapy (ART), and increased psychological distress. Several key themes emerged from the analysis:

1. Illness Perception and Quality of Life

Studies indicate that negative illness perceptions—such as viewing HIV as a severe, uncontrollable condition—are linked to lower quality of life (Catunda et al., 2016; Feng et al., 2022). Emotional distress, heightened illness concern, and perceived lack of control contribute to worsened physical, psychological, and social well-being. Patients with stronger negative perceptions often report increased anxiety, depression, and social withdrawal, which further deteriorates their overall well-being (Leone et al., 2016). Conversely, individuals who perceive their illness as manageable and believe they have some control over their health tend to develop more adaptive coping mechanisms, leading to higher quality-of-life scores (Reynolds et al., 2009). These findings emphasize the importance of addressing illness perception in psychological interventions to improve well-being among PLHIV.

2. Illness Perception and Treatment Adherence

Research demonstrates that illness perception significantly influences ART adherence (Lima et al., 2024; Hou et al., 2024). Patients with greater control over their illness and treatment are more likely to adhere to their prescribed ART regimens, resulting in better virologic outcomes (Leone et al., 2016). In contrast, those with fatalistic views or heightened emotional distress often exhibit lower adherence rates, potentially leading to poorer health outcomes and disease progression (Norcini Pala & Steca, 2015). Furthermore, studies indicate that interventions to modify illness perception, such as psychoeducation and cognitive-behavioral therapy (CBT), can enhance adherence by reinforcing a sense of personal control and reducing treatment-related distress (Reynolds et al., 2009).

3. **Psychological and Behavioral Consequences**

   Negative illness perceptions are strongly associated with anxiety, depression, and maladaptive coping strategies, such as avoidance or substance use (Feng et al., 2022; Lima et al., 2024). Patients who perceive their illness as a severe and uncontrollable burden are more likely to experience emotional distress, which in turn can lead to ineffective coping mechanisms (Catunda et al., 2016). On the other hand, interventions that promote self-efficacy and positive illness representations have been shown to mitigate these negative effects and improve psychological resilience among PLHIV (Reynolds et al., 2009). Programs incorporating self-compassion and stress management have demonstrated the potential to help patients develop healthier perceptions of their illness, leading to better mental health outcomes and improved ART adherence (Norcini Pala & Steca, 2015).

4. **Cultural and Contextual Differences**

   Some studies indicate that illness perception varies across cultural and socioeconomic contexts (Hou et al., 2024; Leone et al., 2016). In resource-limited settings, stigma and misinformation about HIV may reinforce negative perceptions, further exacerbating non-adherence and mental health burdens (Anakwa et al., 2021). For example, in communities where HIV remains highly stigmatized, patients may internalize negative societal views, leading to increased feelings of helplessness and reluctance to seek care. Addressing these factors requires context-specific interventions, including culturally tailored psychoeducation, community-based support programs, and stigma reduction campaigns (Feng et al., 2022). Future studies should explore how sociocultural factors shape illness perception and develop strategies to improve HIV-related health behaviors within different populations.

CONCLUSION

The conclusions of this scoping review highlight the critical role of illness perception in shaping health outcomes for people living with HIV. Findings consistently demonstrate that negative illness perceptions contribute to a lower quality of life, reduced treatment adherence, and heightened psychological distress. Conversely, a more positive illness perception—characterized by a sense of control and a manageable view of the disease—is associated with better mental health, improved coping strategies, and greater adherence to ART.

This review underscores the need for HIV care models that go beyond medical treatment and actively integrate psychosocial interventions aimed at reshaping illness perceptions. Healthcare providers should consider structured counseling, psychoeducation, and behavioral therapies to help PLHIV develop a more constructive outlook on their condition. Addressing illness perception at both individual and community levels can contribute to reducing stigma, promoting self-management, and improving long-term health outcomes.

Future research should focus on developing and testing culturally tailored interventions to modify illness perception across diverse populations. Furthermore, longitudinal studies are needed to explore how illness perception impacts PLHIV. By prioritizing these efforts, healthcare systems can move towards a holistic approach that supports both the physical and psychological well-being of PLHIV and is of paramount importance to empower people living with HIV to optimize their health status.

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