

A qualitative study on the illness identity experience of newly diagnosed HIV/AIDS patients

Mengya Wang

Nanjing University of Chinese Medicine

Rui Huang

Nanjing University of Chinese Medicine

Wenwen Yang

Nanjing University of Chinese Medicine

Yuhan Wu

Nanjing University of Chinese Medicine

Yan Song

njyy037@njucm.edu.cn

The Second Hospital of Nanjing, Affiliated to Nanjing University of Chinese Medicine

Research Article

Keywords: HIV, AIDS, newly diagnosed, illness identity, qualitative study

Posted Date: October 7th, 2026

DOI: <https://doi.org/10.21203/rs.3.rs-10685708/v1>

License: © ⓘ This work is licensed under a Creative Commons Attribution 4.0 International License.

[Read Full License](#)

Additional Declarations: No competing interests reported.

A qualitative study on the illness identity experience of newly diagnosed HIV/AIDS patients

Mengya Wang¹, Rui Huang¹, Wenwen Yang^{1*}, Yuhao Wu^{1*}, Yan Song²

1. School of Nursing, Nanjing University of Chinese Medicine, Nanjing, Jiangsu 210023, P.R. China; 2. Department of Nursing, The Second Hospital of Nanjing, Affiliated to Nanjing University of Chinese Medicine, Nanjing, Jiangsu 210003, P. R. China

*Mengya Wang and Rui Huang have contributed equally to this work.

Corresponding author: Yan Song, Department of Nursing, The Second Hospital of Nanjing, Affiliated to Nanjing University of Chinese Medicine, Nanjing, Jiangsu 210003, P. R. China.

Email: njyy037@njucm.edu.cn

Abstract: Objective To explore the illness identity experience of newly diagnosed HIV/AIDS patients and provide reference for formulating targeted clinical nursing interventions. **Methods** A descriptive phenomenological research method was used. Purposeful sampling was applied to select newly diagnosed HIV/AIDS patients who initiated antiviral treatment at the Infectious Disease Outpatient Department of Nanjing Second Hospital from December 2025 to March 2026. Semi-structured interviews were conducted, and the data were analyzed using the Colaizzi's phenomenological research method. **Results** A total of 21 newly diagnosed HIV/AIDS patients were included as the research subjects. 4 themes and 12 subthemes were extracted: Experience and perception of stigma related to HIV disease identity (experienced stigma, anticipated stigma, internalized stigma); Disruption of the life process (worries about living with the disease, treatment burden); Struggles with adapting to the illness identity (ruminative thinking, resistance to HIV/AIDS identity, social isolation, refusal to disclose); Perception of illness identity through social comparison (upward comparison, horizontal comparison, downward comparison). **Conclusions** Newly diagnosed HIV/AIDS patients face complex challenges in illness identity recognition. Medical staff should intervene in aspects such as psychological support, education guidance, social

integration, and treatment assistance, to help patients achieve positive self-identity and social adaptation.

Key words: HIV, AIDS, newly diagnosed, illness identity, qualitative study

HIV remains a major global public health issue, having claimed an estimated 44.1 million lives to date. There were an estimated 40.8 million people living with HIV at the end of 2024. In 2024, an estimated 630 000 people died from HIV-related causes and an estimated 1.3 million people acquired HIV. Of all people living with HIV, 87% knew their status, 77% were receiving antiretroviral therapy and 73% had suppressed viral loads. It can be seen that there is still a certain gap between the current situation and achieving the three 95% goals (95% of all people living with HIV should have a diagnosis, 95% of whom should be taking lifesaving antiretroviral treatment, and 95% of people living with HIV on treatment should achieve a suppressed viral load)^[1]. In China, overall HIV prevalence is relatively low globally, yet the epidemic situation remains severe. Sexual transmission dominates, with increasing attention to men who have sex with men, mobile populations, and younger groups ^[2].

The achievement of the first 95% target depends on large-scale HIV testing, while the key to achieving the latter two goals lies in how to maximize the number of HIV/AIDS patients who receive ART and retain viral suppression in care ^[3]. A newly diagnosed HIV infection is a major

life stress event for an individual. Newly diagnosed patients often experience shock, denial, shame, fear, helplessness, and anxiety about the future and social relationships, with notable risks of depression and even suicidal ideation. They not only have to confront the potential threat to health posed by the disease itself, but also bear the tremendous psychological pressure brought about by the stigmatization of HIV from society and culture. This makes the psychological adaptation period of newly diagnosed patients full of challenges, and their mental health status directly affects subsequent compliance with medical advice, the timeliness of treatment initiation, and the long-term quality of life, even lead to no further treatment ^[4~6], and this group of confirmed but uncared infected individuals can result in 43% of new infections ^[7].

When confronted with illness, patients need to understand what it means for their identity and attempt to create or regain a consistent sense of self-awareness. This process was initially conceptualized in the field of sociology as disease identity recognition ^[8]. Oris from the perspective of diabetic patients, hold that disease identity is the degree to which diabetes is integrated into an individual's self-awareness.^[9] The disease identity framework proposed by Oris includes four identity dimensions: engulfment, rejection, acceptance and enrichment. Up to now, this illness identity framework has been validated in various chronic illness populations including type 1 diabetes ^[10], inflammatory bowel disease ^[11],

refractory epilepsy ^[12]. In these prior studies, illness identity was associated with important patient-reported outcomes such as treatment adherence, life satisfaction, depressive feelings, feelings of anxiety and so on.

At present, studies on newly diagnosed HIV/AIDS patients mostly focus on clinical efficacy ^{[13][14]} and disease self-management ^{[15][16]}, while less exploration is conducted on the experience of illness identity among newly diagnosed HIV/AIDS patients. How newly diagnosed patients construct an illness identity during the early diagnostic stage remains underexplored. Therefore, this study adopts the descriptive phenomenological method, starting from the perspective of patients, to deeply explore the experience of illness identity of newly diagnosed HIV/AIDS patients. The aim of this study is to introduce the theoretical framework of illness identity into the research on the psychological adaptation of newly diagnosed HIV/AIDS patients, providing a more profound and dynamic theoretical perspective for understanding the psychological adjustment process of this group and explaining the underlying mechanisms of psychological and behavioral responses after diagnosis. Provide a direct basis for clinical workers and psychological counselors to develop targeted psychological counseling and support programs centered on identity construction.

1. Methods

99 **1.1 Recruit patients**

100 By using the purple-sampling method, HIV/AIDS patients who
101 established medical records at the outpatient department of Infectious
102 Diseases of Nanjing Second Hospital from December 2025 to March
103 2026 and initiated antiviral treatment for the first time were selected as
104 the research subjects. The sample size was based on the principle of data
105 information saturation. Inclusion criteria: 1) Hold an HIV positive
106 diagnosis report issued by the Center for Disease Control and Prevention;
107 2) Age ≥ 18 years old; 3) Establish a medical record at the infectious
108 disease outpatient department and start antiviral treatment for the first
109 time; 4) Informed consent and voluntary participation in this study.
110 Exclusion criteria: 1) Severe illness that prevents participation in the
111 investigation; 2) People with hearing or cognitive impairments. This
112 study has been approved by the hospital Ethics committee (Ethics
113 Number: 2024-LS-ky-094), and all respondents signed the informed
114 consent form.

115 **1.2 Design the interview outline**

116 Based on a review of the literature, this study initially drafted an
117 interview outline in accordance with the theoretical framework of illness
118 identity. Before the formal interview, two newly diagnosed HIV/AIDS
119 patients were selected for a pre-interview. Based on the results of the

pre-interview, the initial interview outline was revised and improved to form the final interview outline, mainly including the following contents:

- 1) What was your first reaction after being diagnosed with HIV infection?
- 2) How much do you know about this disease? What do you think HIV is?
- 3) What's your opinion on the identity of an infected person? 4) Have you ever disclosed the identity of the infected person after being diagnosed? If it has not been made public, what is the reason for your unwillingness to do so? If you have made it public, have you received any support or help from others? 5) Does being infected with HIV have any impact on your work, life, social interactions and other aspects? 6) Do you need any help or guidance to assist you in adapting to your new identity as an AIDS patient? 7) What are your plans for your future life?

1.3 Data Collection

Descriptive phenomenological research methods were adopted, and data were collected through face-to-face semi-structured interviews. The interview was conducted in a quiet and private outpatient room and was carried out by two postgraduate students who had received qualitative research training and mastered interview skills. Before starting the interview, the researcher introduces themselves, explains the research purpose and content to the respondents, builds a trusting relationship with them, and conducts the interview in accordance with the interview outline after obtaining the respondents' consent, with the entire process recorded.

One researcher led the interview, while the other recorded the respondents' expressions, actions and other non-verbal expressions. The interview time should be controlled between 15 and 30 minutes.

1.4 Data Analysis

Two researchers converted the audio recordings into text word for word within 24 hours after the interview and used Nvivo12 software to organize the text data. The Colaizzi 7-step analysis method was adopted to analyze the text, which included: repeatedly reading the interview materials, identifying the sentences related to the research, encoding the recurring and meaningful expressions, summarizing, encoding and categorizing to form the theme, narrating the research phenomena associated with the theme, constructing the theme structure and returning the research results to the respondents for verification and validation.

2 Results

2.1 Demographic characteristics

A total of 21 newly diagnosed HIV/AIDS patients were included in this study (Table 1). To protect the privacy of participants, they were numbered P1-P21.

Table 1 Demographic characteristics of newly diagnosed HIV/AIDS patients (n=21)

Number	Age	Gender	Educational	Marital	Payment	Employment	Monthly
	(Years)		Level	Status	Type for	Status	Income

					Antiviral Treatment	(Yuan)	
P1	44	Male	Senior High School	Divorced	Self- payment	Employed	3000-5000
P2	18	Male	Bachelor's Degree	Unmarried	College Student Medical Insurance	Student	≤3000
P3	33	Male	Bachelor's Degree	Married	Self- payment	Employed	≥5000
P4	43	Male	Bachelor's Degree	Unmarried	Employee Medical Insurance	Employed	≥5000
P5	50	Male	Senior High School	Married	Employee Medical Insurance	Employed	≥5000
P6	19	Male	Bachelor's Degree	Unmarried	College Student Medical Insurance	Student	≤3000
P7	42	Male	Senior High School	Divorced	Employee Medical	Employed	3000-5000

P8	27	Male	Junior College	Unmarried	Insurance		
					Employee	Employed	≥ 5000
					Medical		
P9	43	Male	Junior High School	Divorced	Insurance		
					Self-	Unemployed	≤ 3000
					payment		
P10	30	Male	Bachelor's Degree	Unmarried	Self-		
					Employee	Employed	≥ 5000
					payment		
P11	22	Male	Bachelor's Degree	Unmarried	Employee		
					Employee	Employed	≥ 5000
					Medical		
P12	21	Male	Technical Secondary School	Unmarried	Insurance		
					Employee	Employed	3000-5000
					Medical		
P13	24	Male	Master's Degree	Unmarried	College		
					Student	Student	≤ 3000
					Medical		
P14	22	Male	Bachelor's Degree	Unmarried	Insurance		
					Employee	Employed	≥ 5000
					Medical		
P15	20	Male	Bachelor's	Unmarried	Insurance		
					College	Employed	≤ 3000

			Degree		Student		
					Medical		
					Insurance		
P16	52	Male	Junior High	Married	Employee	Employed	≤3000
			School		Medical		
					Insurance		
P17	48	Female	Technical	Married	Employee	Employed	3000-5000
			Secondary		Medical		
			School		Insurance		
P18	33	Male	Bachelor's	Unmarried	Self-	Employed	≥5000
			Degree		payment		
P19	56	Male	Senior High	Married	Self-	Employed	≤3000
			School		payment		
P20	37	男	Master's	Unmarried	Employee	Employed	≥5000
			Degree		Medical		
					Insurance		
P21	55	男	Senior High	Married	Employee	Employed	3000-5000
			School		e Medical		
					Insurance		

2.2 Disease Identity Experience

Through sorting and analyzing the interview data, the disease identity experience of newly diagnosed HIV/AIDS patients can be

summarized into 4 themes and 12 subthemes.

2.2.1 Experience and Perception of Stigma Related to HIV

Disease Identity

Three subthemes were summarized under this theme: experienced stigma, anticipated stigma, and internalized stigma. The interview content and corresponding subthemes are shown in Table 2.

Table 2 Experience and Perception of Stigma Related to HIV Disease Identity

Subtheme	Interview Content
Experienced Stigma	P9: "When I went to the CDC for registration, the people there looked at me strangely, with discriminatory eyes. The doctor who drew my blood even walked around me." P14: "I went to the CDC and said I wanted to get tested for HIV. As soon as I said that, they immediately reacted differently (smiling helplessly). Their attitude was okay, but they just wanted to keep a certain distance from me." P16: "That staff member kept asking me when I did this (had sexual intercourse). I didn't do it, so how could I explain? It was really frustrating... I'm over 50 years old. If I had done it, I would admit it; if not, I wouldn't lie... Having this disease makes me feel like I'm being judged, as if I got it from being promiscuous."
Anticipated Stigma	P4: "Some people may think that contact can lead to infection, so they avoid contact." P8: "To talk about HIV openly, many cases are related to men who have sex

with men. Because the rectum is relatively fragile and prone to infection, I think the discrimination is against homosexuality, which may be associated with HIV, leading people to think it's promiscuous—a double discrimination."

P14: "Others will think that people who get this disease deserve it because they fool around outside."

P17: "Some people think that those infected with this disease will pass the virus on to others."

P18: "The way you get this disease isn't good. Some people will think you're promiscuous or something."

Internalized Stigma P9: "Well, how should I put it? Can normal people be like this? Normal people wouldn't get this disease."

2.2.2 Disruption of the Life Process

Two subthemes were summarized under this theme: worries about living with the disease and treatment burden. The interview content and corresponding subthemes are shown in Table 3.

Table 3 Disruption of Life Process

Subtheme		Interview Content
Worries about Living with the Disease	Lifespan	P9: "Is this disease divided into early, middle, and late stages? Am I hopeless? Which stage am I in now? I should still be saved, right?" P14: "I want to know how this disease affects lifespan. Many people online say you can only live three to five months."

	P20: "I searched a lot online about how long you can live with this disease, and the internet told me 6-12 months."
Academic Pursuits	P15: "I originally wanted to pursue further studies, but now I'm not sure. I'm worried that the school will reject me because of this."
Work	P11: "After being diagnosed, I thought a lot. I felt like my life was over, and my job too."
Medical Care	P5: "If I need surgery somewhere in the future, can I have it in other regular hospitals instead of yours? Because as I get older, I'll definitely have more health problems, and I have to consider this. I don't want to come to an infectious disease hospital. If I do without telling my family, they will wonder why I'm having surgery in an infectious disease hospital." P9: "If I get other diseases, do I have to come to the infectious disease hospital for checks? Can I go to other hospitals?" P13: "Has my access to medical care narrowed down? Do I have to come to the infectious disease hospital for treatment? It's so troublesome."
Marriage and Childbirth	P10: "I'm worried about getting married and having children. I think it's possible to have children as long as the blocking measures are proper, but there are still some difficulties now." P18: "I want to have children, but I don't know what to do next."

		The main issue now is the child. I can't prepare for pregnancy and have children anytime I want like before."
Medication		P8: "It feels a bit difficult to take medicine on time every day. I have to take it 365 days a year, and it's impossible to be on time every day. People are social beings, and sometimes I forget to take it because of social events. I will definitely miss doses." P13: "I don't know much about medication contraindications now. Should dietary restrictions have no effect?"
Infectivity		P9: "I want to ask how to protect my child. Will eating together with my child infect them? Can we wash clothes together?" P17: "My only worry is infecting my daughter."
Fear of		P14: "I'm also worried that people in my hometown will find
Privacy		out. Because many hospital systems are connected, it seems that
Leakage		many township management systems can access the
		information."
Treatment	Medication	P8: "It feels a bit difficult to take medicine on time every day. I
Burden	Burden	have to take it 365 days a year, and it's impossible to be on time
		every day. People are social beings, and sometimes I forget to
		take it because of social events. I will definitely miss doses." P10: "Now I'm a bit worried about the side effects of the medicine. I read online that the side effects are quite serious, so I'm a bit concerned."

P15: "What I'm most afraid of is the side effects of the medicine. That's my biggest worry."

Economic Burden P7: "Yesterday, I spent over 900 yuan on various checks, and today I spent over 2,000 yuan on blood tests. Although it's reimbursed, over 2,000 yuan is not a small amount for me. My monthly salary is only 3,000 to 5,000 yuan."

P9: "The main pressure is economic. I don't have a job now. After being diagnosed with low platelets, I couldn't do heavy work, so I resigned. I'm from a rural family, and the burden is heavy. The doctor told me I can't use medical insurance, so I have to pay for everything myself. I have a lot of pressure to support my children, who need money, and my parents are over 70 and need me to take care of them. Plus, I have to take medicine every day in the future—the burden is really heavy... I can only find a job when my health improves a bit. I have no choice; I have to live (wiping tears)."

P13: "Treatment is a burden for me. Even with medical insurance, it adds nearly 400 yuan to my monthly expenses."

Psychological Burden P7: "I suddenly break down and cry for no reason. This emotion is uncontrollable. It's not that I don't want to get better or face life, but when something like this happens to you or someone else, only people in the same situation can understand. If you're

not an infected person, you can never feel our pain. Only we know in our hearts that our pain is twofold—psychological and physical from the disease."

2.2.3 Struggles with Adapting to the Illness Identity

Four subthemes were summarized under this theme: ruminative thinking, resistance to HIV identity, social isolation, and refusal to disclose. The interview content and corresponding subthemes are shown in Table 4.

Table 4 Struggles with Adapting to the Illness Identity

Subtheme	Interview Content
Ruminative Thinking	P1: "If I had known more about it before, I might not have gotten this disease." P6: "Actually, I've only had sexual intercourse once in my life, and I never thought I would get infected with HIV from that one time. I used a condom the entire time, and I don't know why I got infected. Maybe it's because I went to a bar once at the beginning of the year and got pricked by a needle. At that time, a little blood came out, but I didn't care. I just thought I was unlucky." P17: "It must be him (the patient's husband) who infected me, 100% him (slamming the table angrily). I never had sexual

	contact with anyone outside... Now that I think about it, if I had divorced him earlier, I wouldn't have gotten AIDS. I really regret it. If I had divorced him, I wouldn't have been infected with this disease (choking up)." P21: "If it weren't for this, my family would be really good. Although business hasn't been easy these two years, the family was still good. But then I got infected with this virus."
Resistance to HIV	P2: "For now, I can't accept this identity. I can't accept that I'm an HIV-infected person."
Identity	P13: "Actually, I can't really accept the identity of an infected person, but I have to, because people are very resistant to AIDS." P8: "Now I'm a bit like having AIDS phobia, but not exactly. I just haven't gotten used to it yet." P11: "Now I don't want to read anything about AIDS. I'm quite resistant." P13: "The Blued app sometimes pops up windows about post-exposure prophylaxis, test strips, etc. Now I'm resistant to that app, the pop-up windows, and even myself."
Social Isolation	P13: "I don't really want to interact with people. I'm resistant. I used to have a very good personality, but now I'm not as outgoing as before."

		P14: "Now I may not have the confidence to interact with others. I feel like I have to keep a little distance from them and don't want to communicate with them."
Refusal to Disclose	Disclosure Affects Survival	P7: "I have to keep it hidden. There's no other way. If I disclose that I'm an infected person, others will be afraid, and I might lose the chance to survive—meaning it will be difficult to survive in society."
		P10: "I saw many people online saying that infected people are exposed publicly. I think that's too exaggerated. If that happens, we won't be able to survive in this society, in this world."
	Disclosure Leads to Discrimination	P12: "I dare not say it. I'm afraid of being discriminated against, and I'm also afraid that others will say I'm promiscuous."
		P16: "I'm over 50 years old; how many years do I have left to live? Telling others will only get me discriminated against."
		P19: "I won't tell anyone I'm infected. I must keep it a secret. My family and friends will look down on me, and people will talk about me."

2.2.4 Perception of Disease Identity Through Social Comparison

Three subthemes were summarized under this theme: upward

comparison, horizontal comparison, and downward comparison. The interview content and corresponding subthemes are shown in Table 5.

Table 5 Perception of Disease Identity Through Social Comparison

Subtheme		Interview Content
Upward Comparison	Positive Aspects	P3: "I feel my body is quite normal, just like ordinary people. I don't feel any discomfort." P10: "I think I'm the same as ordinary people. As long as the viral load is controlled within the normal range, I am a normal person." P15: "I think as long as I manage myself well and don't maliciously spread the virus like the person who infected me, I'm actually the same as ordinary people."
	Negative Aspects	P7: "Our bodies are weaker. For example, when others catch a cold, they get better quickly with some medicine or even without it, but we definitely can't. Our resistance is weaker because we're sick, so we're definitely different from ordinary people in many ways." P8: "I feel like I have the virus in my body. I have the virus, so I'm not a normal person."
	Horizontal Comparison	P7: "It's like hypertension—you have to take medicine for life. This is the same; one pill a day, every day." P10: "If people knew that this disease is like diabetes or hypertension, they would only accept it as a chronic disease, not a fatal one."

P15: "Because my sister didn't know much about this, she searched a lot of information and then comforted me, saying it's not that scary. It's similar to diabetes or hepatitis B—you have to take medicine every day."

Downward

P15: "I'm glad I didn't get a directly life-threatening disease like cancer."

Comparison

3 Discussion

The first theme obtained in this study is the stigma brought about by the experience and perception of illness identity, which includes three sub-themes: experience stigma, expected stigma and internalized stigma. This study found that newly diagnosed HIV/AIDS patients are vulnerable to discrimination from medical institution staff during the process from HIV testing to initiating antiviral treatment. The reason is that some medical staff lack knowledge of the disease and worry about contracting AIDS through contact with HIV/AIDS patients. The worry leads to discrimination, and they thus keep a distance from HIV/AIDS patients ^[17]. Their inadvertent avoidance makes patients feel discriminated against. In addition, past HIV health education adopted a fear-driven model. Although this model enhanced people's understanding of the severity of HIV, influenced by traditional concepts, it also led people to invisibly attach moral labels to infected individuals, believing that AIDS is caused by immoral behavior. Therefore, the general public, including medical

205 staff, holds strong social discrimination against AIDS patients ^[17~19].
206 HIV/AIDS patients may also anticipate the stigma associated with the
207 AIDS identity due to past stereotypes about AIDS, and even internalize
208 this stigma because they accept and agree with negative social
209 evaluations ^[20]. For newly diagnosed HIV/AIDS patients, receiving the
210 diagnosis is itself a traumatic event. Experiencing and anticipating the
211 stigma and discrimination associated with the AIDS identity can
212 exacerbate the trauma ^[21]. Compared with the HIV virus, HIV/AIDS
213 patients are more afraid of social discrimination. Such discrimination and
214 stigmatization predict poor antiviral treatment adherence and emotional
215 states, causing great harm to the physical and mental health of HIV/AIDS
216 patients ^{[18][22][23]}. Therefore, relevant institutions and organizations should
217 strengthen social publicity to reduce or eliminate AIDS-related stigma.
218 For example, popularize knowledge about HIV transmission routes and
219 U=U (Undetectable = Untransmittable) on a large scale through online
220 platforms, videos, or animations ^[24], update and improve the public's
221 understanding of HIV, reduce AIDS-related fear, and provide a loving,
222 equal, and inclusive social living environment for HIV/AIDS patients. At
223 the same time, medical staff engaged in AIDS prevention and control
224 should receive training on disease knowledge and empathy to improve
225 their professional quality. As an important part of social support for the
226 AIDS population, medical staff's non-discriminatory care and support can

227 help patients better cope with negative emotional distress such as anxiety
228 and depression, reduce their sense of isolation and psychological burden
229 in society, and thus assist patients in better managing the disease and
230 adapting to the AIDS identity.

231 The second theme is the disruption of the life process, which
232 includes two sub-themes: the anxiety of living with illness and the burden
233 of treatment. Being infected with AIDS makes newly diagnosed
234 HIV/AIDS patients realize that their life process is hindered and disrupted,
235 and this group has to re-examine and reflect on their lives ^[25]. Due to the
236 lack of understanding of the disease in the early stage and the huge blow
237 to their lives and personal cognition caused by the diagnosis, newly
238 diagnosed HIV/AIDS patients have many worries about how to live with
239 the disease in the future, including aspects of life, work, and medical care.
240 They also worry about the upcoming medication, economic, and
241 psychological burdens of antiviral treatment, resulting in insufficient
242 motivation for self-management ^{[26][27]}. Cheng ^[15] found that one-on-one
243 interviews with newly diagnosed HIV/AIDS patients to understand their
244 problems and needs, online dissemination of disease-related knowledge,
245 and offline correction of incorrect behaviors can encourage patients to
246 actively participate in disease self-management. Zhou ^[28] also showed
247 that personalized and targeted health education can mobilize the
248 enthusiasm of newly diagnosed HIV/AIDS patients to acquire knowledge,

thereby forming healthy attitudes. It is evident that health popularization for newly diagnosed HIV/AIDS patients is of great significance for promoting their adaptation to the disease identity. Therefore, medical personnel should assess the existing or potential cognitive misunderstandings and blind spots of newly diagnosed HIV/AIDS patients, use models such as remote continuous care via medical mobile apps to popularize disease-related knowledge and lifestyle during treatment, and promptly correct patients' incorrect perceptions. To a certain extent, this can also reduce the level of internalized stigma among patients ^[29]. However, the trauma caused by AIDS to patients is irreversible. Liu ^[30] believes that only the complete cure of AIDS can completely change the survival mode of HIV/AIDS patients, help them get rid of the shackles of lifelong treatment, and restore their life process to its original state. However, HIV cure research is accompanied by many complex ethical issues, and the road to HIV cure is long and arduous.

The third theme is the pain of disease identity adaptation, which includes four sub-themes: ruminative thinking, resistance to HIV/AIDS identity, social alienation, and refusal to disclose. In the early stage of the disease, the dual characteristics of infectious disease and chronic disease also greatly impact the disease adaptation process of newly diagnosed HIV/AIDS patients ^[31]. This group usually experiences adaptive struggles related to the disease identity, which manifest in forms such as ruminative

271 thinking, resistance to HIV/AIDS identity, social isolation, and refusal to
272 disclose. Newly diagnosed HIV/AIDS patients find it difficult to accept
273 the fact of being infected with AIDS for a while. They repeatedly think
274 about and over-analyze possible exposure sources and infection routes,
275 often unable to extricate themselves from these thoughts. Such excessive
276 ruminative thinking not only exacerbates patients' psychological distress
277 but also hinders their acceptance of the illness and cooperation with
278 treatment, and affects the achievement of post-traumatic growth ^{[32][33]}.
279 Therefore, medical staff should patiently listen to the emotions and
280 confusions of newly diagnosed HIV/AIDS patients, help them relieve
281 anxiety through empathy, and encourage them to shift their attention from
282 unchangeable facts to controllable matters such as actively cooperating
283 with treatment and improving quality of life. Traditional Chinese
284 Medicine emotional therapy has been proven to have a certain improving
285 effect on the ruminative thinking of HIV/AIDS patients, which can
286 provide a reference for clinical medical staff to implement interventions
287 ^[33]. Some patients resist accepting the HIV/AIDS identity, not only
288 avoiding contact with AIDS-related knowledge but also rejecting
289 themselves. This reduced level of self-acceptance affects social
290 adaptability to a certain extent ^[34]. For such patients, medical staff can
291 help them learn to accept themselves and reality through psychological
292 counseling, promote the adaptation to the disease identity, and thereby

improve their social adaptability. There are also some newly diagnosed HIV/AIDS patients who reduce social interaction to avoid exposing their infection status and transmitting the virus to others, resulting in social isolation. They also refuse to disclose their infection status to avoid discrimination, which leads to emotional and social isolation of this group. Emotional and social isolation can increase the levels of anxiety and depression among HIV/AIDS patients ^[35]. Studies have found that when HIV/AIDS patients disclose their infection status to family, friends, or partners, their social support level can be improved, and their stress and high-risk behaviors can be reduced ^[36]. Therefore, medical staff should assess the interpersonal network of newly diagnosed HIV/AIDS patients and encourage them to disclose their infection status to trusted family, friends, and peers as appropriate, or regularly organize peer exchange meetings to help patients expand their social support system and reduce the sense of social isolation.

The fourth theme is to view disease identity through social comparison, including three sub-themes: upward comparison, parallel comparison and downward comparison. This study found that when dealing with the disease identity, newly diagnosed HIV/AIDS patients often adjust their emotions and cognition through social comparison with others. Newly diagnosed HIV/AIDS patients conduct upward comparisons with healthy people, evaluating their own conditions by

315 measuring the physical, psychological, and resource differences between
316 themselves and healthy people. To achieve a state of parity with healthy
317 people, newly diagnosed HIV/AIDS patients take viral load control as a
318 personal progress standard or motivation to promote self-improvement ^[37].
319 These patients often have good treatment adherence. However, such
320 upward comparisons can also cause negative cognitions in patients. When
321 newly diagnosed HIV/AIDS patients realize that their situation is worse
322 than that of healthy people, they experience relative deprivation. Relative
323 deprivation is an unpleasant experience of wanting, deserving, and
324 resenting not having something, mainly arising from a sense of injustice
325 after comparison. It affects patients' motivation to adhere to antiviral
326 treatment and leads to varying degrees of negative psychological impacts
327 on patients ^[37 ~ 39]. There are also some newly diagnosed HIV/AIDS
328 patients who choose to compare themselves with people in similar
329 situations to assess their own status, with reference objects mostly being
330 patients with chronic diseases such as hypertension and diabetes who
331 need to take medicine daily. Through horizontal comparison, newly
332 diagnosed HIV/AIDS patients understand the nature of the disease and
333 collect information for self-evaluation, thereby coping with the
334 uncertainty and anxiety caused by the disease and enhancing self-efficacy
335 ^[40]. In addition, to cope with the psychological stress caused by the
336 diagnosis of AIDS, some newly diagnosed HIV/AIDS patients tend to

compare themselves with individuals in worse situations, such as those with cancer. Downward comparison can not only temporarily reduce anxiety but also enhance self-esteem and meet self-actualization needs by identifying personal strengths, ultimately leading to the gradual acceptance of the new identity of AIDS ^[37]. In summary, social comparison can help newly diagnosed HIV/AIDS patients adjust their negative emotional states, but such comparisons may also lead to negative consequences, such as inferiority or further solidification of negative cognitions about the disease identity. Therefore, medical staff should guide and help newly diagnosed HIV/AIDS patients find positive and appropriate ways of social comparison. For example, let HIV/AIDS patients who have received antiviral treatment with good therapeutic effects serve as navigators to provide emotional and care support for newly diagnosed patients. Peer navigators share treatment experiences to set an example and provide references for newly diagnosed HIV/AIDS patients, guiding them to conduct positive social comparisons, thereby regulating negative emotions and promoting the adaptation to the disease identity ^{[41][42]}.

4 Conclusion

In summary, constructing a disease identity among newly diagnosed HIV/AIDS patients is a complex psychosocial adaptation process fraught with internal conflicts and external pressures. Patients not only passively

bear the heavy stigma associated with an HIV identity from socio-cultural sources but also profoundly experience the disease as a disruptive force that shatters their life trajectory. The diagnosis acts as a sudden fissure, cleaving their familiar lives, triggering a deep existential crisis concerning their future life plans, intimate relationships, social roles, and self-worth. During this uncertain transitional period, patients internally grapple with significant pain, loss, and a sense of injustice. To cope with this crisis, patients spontaneously activate a series of psychological adjustment mechanisms, among which social comparison is particularly crucial. They engage in downward comparison (comparing themselves to others perceived as worse off, such as those with more advanced disease or less social support) to gain temporary psychological comfort and a sense of superiority, or in upward comparison (seeking out stories of successful patients who have reintegrated into society) to draw hope and motivation. However, this comparative strategy is inherently double-edged, potentially reinforcing internalized stigma or creating new pressures. Thus, it is evident that newly diagnosed patients are situated within a predicament composed of stigma, biographical disruption, and complex social comparisons, making the construction of their disease identity full of tension and challenge.

Confronted with such complex dilemmas, a purely biomedical intervention model is insufficient. To effectively help patients navigate

this difficult period and achieve an identity transition from “being defined by the disease” to “living with the disease”, healthcare providers must deliver comprehensive humanistic care that goes beyond routine treatment. This firstly involves creating a safe, non-judgmental communication environment and providing empathetic psychological support to alleviate patients’ sense of isolation. Secondly, it requires systematic, individualized education about the disease and its management, empowering patients to become active self-managers. Finally, in terms of treatment assistance, there should be a keen awareness to identify and address psychosocial barriers affecting identity formation, seamlessly integrating psychological assessment and support into routine follow-up care. Through these multi-dimensional interventions, the ultimate goal is to guide patients toward constructing a well-integrated illness identity, thereby facilitating positive social adaptation and a high quality of life.

The limitation of this study lies in the fact that the research subjects are only from the same hospital, and the sample representation is limited. In the future, hybrid research methods can be adopted to conduct follow-up interviews with newly diagnosed patients for a period of one year or longer, dynamically mapping the evolution of their disease identity, identifying key turning points, core challenges, and facilitating factors at different stages.

403

404 **Supplementary information**

405 **Abbreviations**

406 HIV-human immunodeficiency virus

407 AIDS-acquired immune deficiency syndrome

408 **Declarations**

409 No applicable.

410 **Ethics approval and consent to participate**

411 This study had been approved by the hospital Ethics committee
412 (Ethics Number: 2025-LS-ky-119), and all respondents signed the
413 informed consent form.

414 **Consent for publication**

415 All presentations of the data have consent for publication.

416 **Availability of the data and materials**

417 The datasets used and/or analyzed during the current study are
418 available from the first author on reasonable request.

419 **Conflict of interests (Competing interests)**

420 The authors declare that they have no competing interests.

421 **Fundings**

422 No applicable.

423 **Author's contribution**

Mengya Wang and Rui Huang developed the semi-structured interview guide and provided scientific oversight, and they contributed to the design of the measures and interpretation of findings. Moreover, they are responsible for recruiting patients. Wenwen Yang and Yu han Wu conducted informed consent and data analysis, Yan Song provided guidance for the research and reviewed the articles. All authors provided critical review and edits. The final manuscript for submission was approved by all authors.

Acknowledgements

No applicable.

References

- [1] HIV and AIDS. <https://www.who.int/news-room/fact-sheets/detail/hiv-aids>.
- [2] Lu Fan, Liu Zhongfu, Liu Yufen, et al. Anchor the target improve ability to promote the development of HIV/AIDS prevention and control of high quality [J]. Chinese Journal of AIDS & STD, 2024, 30 (4) : 335-338. DOI: 10.13419 / j.carol carroll nki AIDS. 2024.04.01.
- [3] Mizuno Y, Higa DH, Leighton CA, et al. Is HIV patient navigation associated with HIV care continuum outcomes? AIDS. 2018 Nov 13;32(17):2557-2571. doi: 10.1097/QAD.0000000000001987.
- [4] Baumgartner LM, David KN. Accepting being poz: the incorporation of the HIV identity into the self[J]. Qual Health Res, 2009, 19(12):1730-43. DOI: 10.1177/1049732309352907.
- [5] Lai Longfang. Correlation of Psychological Distress with Stigma and Quality of Life in Newly Diagnosed Persons Living with HIV/AIDS[J]. Medical Journal of Liaoning, 2020, 39(01):62-65.
- [6] Tang Xiaoyu. Factors Influencing the Identity of People Live With HIV in the Internet Age [D]. Shantou University, 2022.
- [7] Li Z, Purcell DW, Sansom SL, Hayes D, et al. Vital Signs: HIV Transmission Along the Continuum of Care - United States, 2016. MMWR Morb Mortal Wkly Rep. 2019 Mar 22;68(11):267-272. doi: 10.15585/mmwr.mm6811e1.
- [8] Dong Wenwen, Guo Yongpan, Zhang Chunhui, et al. Illness identity in adolescents with type 1 diabetes mellitus: a review[J]. Journal of Nursing Science, 2024, 39(18):125-129.
- [9] Oris L, Luyckx K, Rassart J, et al. Illness Identity in Adults with a Chronic Illness. J Clin Psychol Med Settings. 2018 Dec;25(4):429-440. doi:

10.1007/s10880-018-9552-0. [4]Baumgartner LM. The incorporation of the HIV/AIDS identity into the self over time[J]. Qual Health Res,2007,17(7):919-31. DOI: 10.1177/1049732307305881.

[10]Commissariat PV, Volkening LK, Weinzimer SA, et al. Assessing Incorporation of Type 1 Diabetes Into Identity: Validation of the Accepting Diabetes and Personal Treatment (ADAPT) Survey in Teens and Young Adults. Can J Diabetes. 2023 Feb;47(1):66-72. doi: 10.1016/j.jcjd.2022.08.007.

[11]Rassart J, Van Wanseele C, Debrun L, et al. Illness Identity in Inflammatory Bowel Disease. Int J Behav Med. 2023 Feb;30(1):77-88. doi: 10.1007/s12529-022-10072-y.

[12]Luyckx K, Oris L, Raymaekers K, et al. Illness identity in young adults with refractory epilepsy. Epilepsy Behav. 2018 Mar;80:48-55. doi: 10.1016/j.yebeh.2017.12.036.

[13]Ma Shujing, Fu Yanhua, Xie Xiaoxin, et al. Efficacy and safety analysis of Ainoovirine combined with Tenofovir disoproxil and Lamivudine in newly treated HIV/AIDS patients[J]. Chinese Journal of AIDS & STD, 2023, 29 (8) : 872-876. The DOI: 10.13419 / j.carol carroll nki AIDS. 2023.08.06.

[14]Xia Yuchao, Yang Xuan, Gan Yuan, et al. Renal function changes in patients with HIV/AIDS receiving tenofovir treatment for 3 years in Zhengzhou City[J]. Chinese Journal of AIDS & STD, 2024, 30 (10) : 1025-1029. The DOI: 10.13419 / j.carol carroll nki AIDS. 2024.10.04.

[15]Cheng Shujin, Zhong Meirong, Wu Guofeng, et al. Effects of follow-up management based on the Behavior Change Wheel theory for newly treated HIV-infected patients [J]. Medical Journal of Liaoning,2023,38(16):107-111.

[16]Jia Xiaofeng, Wang Huiqun, Shi Min, et al. Mediating role of self-efficacy between illness perception and quality of life in newly treated HIV patients[J]. Chinese Journal of AIDS & STD, 2023, 29 (10) : 1120-1124. The DOI: 10.13419 / j.carol carroll nki AIDS. 2023.10.10.

[17]Xie Peng, Zeng Yan, Zhao Xia, et al. Experiences and Perceptions of HIV-Infected Individuals Facing Discrimination from Healthcare Providers [J]. Medicine & Philosophy,2023,44(21):59-64.

[18]Lopez CM, Baker NL, Moreland AD, et al. Development and feasibility testing of an integrated PTSD and adherence intervention cognitive processing therapy-life steps (CPT-L) to improve HIV outcomes: Trial protocol[J]. Contemp Clin Trials Commun,2023, 20;33:101150. DOI: 10.1016/j.conctc.2023.101150.

[19]Yang Hao, Guan Yujia, Wang Ying, et al. A Qualitative Study of Refusal of Antiretroviral Drug Treatment Among HIV-Positive Men Who Have Sex with Men in Chengdu[J]. The Chinese Journal of Dermatovenereology, 2023 5 (7) : 808-814. The DOI: 10.13735 / j.carol carroll JDV. 1001-7089.202210016.

[20]O'Donnell AT, Habenicht AE. Stigma is associated with illness self-concept in individuals with concealable chronic illnesses[J]. Br J Health Psychol, 2022, 27(1):136-158. DOI: 10.1111/bjhp.12534.

[21]Lai Xinyi, Wang Honghong, Tang Chulei. Qualitative study of life experiences of patients with AIDS-related post-traumatic stress disorder[J]. Chinese Journal of AIDS & STD, 2024, 30 (6) : 618-622. The DOI: 10.13419 / j.carol carroll nki. AIDS. 2024.06.11.

[22]Bunn JY, Solomon SE, Miller C, et al. Measurement of stigma in people with HIV: a reexamination of the HIV Stigma Scale[J]. AIDS Educ Prev,2007,19(3):198-208.DOI: 10.1521/aeap.2007.19.3.198.

[23]Yu Yong, Sun Yinmeng, Chang Zijue, et al. Self-stigma and Perceived Social Support

among HIV/AIDS Patients: The Mediating Role of HIV Notification[J]. Chinese Journal of Social Medicine,2022,39(05):548-553.

[24]Yang Hao, Guan Yujia, Feng Xianqiong. Analysis of Homosexual Cognition and Attitude among Medical Students in Chengdu [J]. Chinese Journal of School Health,2017,38(7):1086-1088.

[25]Dai Suhui, Living with Illness: A Study on the Survival of AIDS Patients Based on the Theory of Life Process Disruption and Social Support [D] Shenzhen university, 2022. DOI: 10.27321 /, dc nki. Gszdu. 2022.002408.

[26]Liao Hui, Xie Chaoying, Xiang Fang, et al. Qualitative study on self-management experience and needs of newly treated HIV patients[J]. Psychological Monthly,2023,18(16):1-5.

[27]Ma Haiqi, Zhai Huimin, Li Bing, et al. Analysis of current situation and influencing factors of HIV-related psychological distress for HIV/AIDS patients who received antiretroviral therapy[J]. Journal of Wenzhou Medical University,2023,53(04):298-304.

[28]Zhou Zhihui, Sun Qiulan, Wu Guixiang.Effect of knowledge-belief-behavior nursing intervention on the stigma of treatment-naïve patients with acquired immune deficiency syndrome[J]. Journal of Clinical Nursing in Practice,2022,8(08):38-41.

[29]Zhang Ruiling, Wang Yuying, Guo Jianlin, et al. Construction and application of remote continuous nursing mode for HIV patients based on mobile medical APP[J]. Chinese Nursing Research,2022,36(3): 517-521.

[30]Liu Di, Wang Zhaochen, Zhai Xiaomei. Ethical Considerations on HIV Cure Research: Values and Challenges[J]. Medicine & Philosophy, 2024,45(23):10-15.

[31]Qin Ziqi, Cao Guiying, Xie Jianping, et al. Disease acceptance in HIV/AIDS patients and related factors[J]. Chinese Journal of Infection Control,2024,23(08):1016-1022.

[32]Wan Shenmin, Lu Hongzhou, Bao Meijuan, et al. Effect of stigma and rumination on posttraumatic growth of patients with HIV[J]. Chinese Journal of AIDS & STD, 2019, 25 (8) : 828-832. The DOI: 10.13419 / j.carol carroll nki AIDS. 2019.08.18.

[33]Hou Siwei, Zhang Bin, Zhang Bo, et al. Effect of Traditional Chinese Medicine Emotional Therapy on Anxiety, Depression and Rumination in HIV/AIDS Patients[J]. Acta Chinese Medicine, 2023, 38 (12) : 2684-2689. The DOI: 10.16368 / j.i SSN. 1674-8999.2023.12.427.

[34]Zhang Min, Guo Huijun, Xu Qianlei, et al. Correlation of Social Adaptability with Self-acceptance and Self-concealment in HIV/AIDS Patients[J]. The Chinese Journal of Dermatovenereology, 2021, 35 (11) : 1262-1267. DOI: 10.13735 / j.carol carroll JDV. 1001-7089.202103113.

[35]Huang Mingrong, Zhang Wanqun, Dong Chaoqun. Relationships among social avoidance and distress, emotional and social loneliness, anxiety and depression in AIDS patients[J]. Journal of Nursing Science,2019,34(14):69-72.

[36]Xiang Xuelin, Zhao Hongrui, Wang Zhongjie, et al. Social Support Status and Influencing Factors of HIV-infected Patients on Antiviral Therapy[J]. Journal of Kunming Medical University,2024,45(9): 156-162.

[37]Liu Rui. An Experimental Study on the Implicit Attitudes of Nurses to Physicians Based on Social Comparison[D]. Xinxiang medical college, 2020. DOI: 10.27434 /, dc nki. Gxxyc. 2020.000302.

[38]Han Juan, Ma Jiajia, Chen Dongli, et al. The mediating and moderating role of relative deprivation in the relationship between perceived overqualification and occupational well-being among ICU nurses[J]. Journal of Nursing Science,2021,36(20):68-72.

[39]Zhang Duo, Zhou Yanrong, Wang Xiaoxiao, et al. Latent profile analysis of academic achievement among nursing master degree students[J]. Journal of Nursing Science, 2024,39(13):84-88+105.

559 [40] Yang Xiaoxia, Lyu Liming, Chen Meixu, et al. Cancer survivors social comparison and
560 the related research progress[J]. Journal of Nursing Science, 2022, 29 (23) : 28-32. DOI:
561 10.16460 / j.i ssn1008-9969.2022.23.028.
562 [41] Han Shuyu, Wu Yangfeng, Li Ke, et al. Construction of a training system for HIV peer
563 support volunteers[J]. Journal of Nursing Science, 2023, 38(16):38-42.
564 [42] Feng Bo, Xia You, Shi Aoli, et al. A study on the effect of patient-centered therapy on
565 negative emotion and coping style in HIV/AIDS patients undergoing surgical treatment[J].
566 Psychological Monthly, 2024, 12 (21) : 184-186. The DOI: 10.19738 / j.carol carroll nki psy.
567 2024.21.052.