

Experiences, Challenges, and Needs of People Living with HIV in Hunan Province, China: A Qualitative Study

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Background: Globally, the human immunodeficiency virus (HIV) epidemic continues to pose significant challenges. In China, the differentiated services delivery (DSD) model has been implemented to improve healthcare for people living with HIV (PLHIV). However, challenges persist in fully implementing and scaling up the DSD model. Given the knowledge gaps and the need for better strategies to support this vulnerable population, our study aimed to explore the experiences, challenges, and needs of PLHIV to inform the development of patient-centered healthcare services.

Methods: We employed a qualitative design to interview 20 PLHIV from July 27 to October 13, 2024, in the Infectious Disease Ward at the Second People's Hospital in Chenzhou, Hunan Province. Individual face-to-face in-depth interviews were conducted to collect data. Colaizzi's seven-step analysis method and NVivo 14 was used to analyze the transcripts.

Results: The participants, aged 23 to 83 years, had been living with HIV for durations ranging from one month to 19 years. The interview data revealed four themes: (1) the *physiological* dimension: multi-organ physical symptoms, increased physical vulnerability, and a desire for healthcare guidance; (2) the *psychological* dimension: emotional distress, inadequate HIV-related knowledge, considerable stigma and discrimination, and a desire for respect and dignity; (3) the *societal* dimension: huge economic burden, fragile social networks, and a desire for social support; and (4) the *spiritual* dimension: mixed feelings about death, negative expectations of the future, seeking solace in faith, and a desire for a "good" death.

Conclusion: PLHIV in this study have undergone complex journeys across physical, psychological, societal, and spiritual dimensions, expressing urgent needs for support from various stakeholders. Our findings highlight the urgency of implementing patient-centered care, enhancing psychological support, reducing discrimination, and providing robust social and spiritual care through stakeholder collaboration to optimize the DSD model and resource allocation.

Keywords: HIV, AIDS, qualitative research, delivery of healthcare

Introduction

Human immunodeficiency virus (HIV) continues to pose a significant challenge worldwide, impacting millions of lives. By the end of 2023, 39.9 million people worldwide were infected with HIV, and the number of HIV-related deaths was 630,000; however, nearly 13 million of those infected still have not received anti-retroviral therapy (ART).¹ China has adopted numerous globally recognized strategies for HIV prevention, care, and treatment within its national framework.² Nonetheless, the burden of HIV/AIDS remains high,³ particularly in the rural and underserved regions, with significant disparities in access to care and treatment. By the end of June 2024, China had reported 1,329,127 people living with HIV (PLHIV), along with a cumulative total of

474,006 HIV-related deaths.⁴ From 1990 to 2019, China witnessed an increase in HIV/acquired immunodeficiency syndrome (AIDS) incidence from 0.82 to 2.24 per 100,000, mortality from 0.23 to 2.23 per 100,000, disability-adjusted life years (DALYs) from 13.18 to 98.15 per 100,000.⁵ This situation highlights the urgent need for continued efforts and resources to combat HIV epidemic. Although the global HIV/AIDS burden has declined and international disparities have narrowed over the past two decades,⁶ ongoing challenges remain due to a lack of political commitment, conflict and political instability,⁷ and inadequate healthcare resources,⁸ including stigma, discrimination, drug use, inadequate provision of ART, and a lack of psychosocial support.⁹

HIV affects not only the physical health of individuals but also their psychological, social, and spiritual well-being¹⁰ as well as that of their caregivers.^{11,12} PLHIV often face a range of distressing emotions such as shock, fear, guilt, and depression following a positive diagnosis, along with substantial psychological disorders, necessitating support from healthcare facilities and their families.¹³ Concerns over self-stigma, isolation, fear of HIV disclosure, substance abuse, and adjustment-related challenges significantly affect people's capacity to adhere to ART and manage their health.^{14,15} A range of ongoing policies and strategies is recommended to address these multifaceted issues. To date, China's HIV/AIDS policies have evolved through four key phases: (1) enhanced surveillance, (2) public education, (3) comprehensive government strategies, and (4) the implementation of evidence-based prevention methods.¹⁶ Healthcare facility counseling projects,¹⁷ mass media,¹⁸ and health education and empowerment programs¹⁹ play a crucial role in enhancing medication adherence, alleviating depression and anxiety, reducing stigma and discrimination, and optimizing quality of life (QoL). Moreover, it is essential for formal healthcare systems and informal support networks to collaborate in order to manage HIV/AIDS and provide hospice care as well as support the bereavement process.^{20,21}

PLHIV encounter a variety of unique challenges that impact their physiological, psychological, societal, and spiritual well-being. It is crucial to identify these issues early on and to intervene in them in order to improve QoL and health outcomes. PLHIV experiences vary across settings, populations, cultures, and the broader socio-economic and political contexts. In China, due to the influence of traditional Confucian philosophy and moral judgment, PLHIV often suffer from additional social pressure and discrimination.² Previous studies have focused on epidemiology,^{22,23} ART,¹⁵ sentinel surveillance,²⁴ and legal frameworks.²⁵ However, the psychosocial experiences, challenges, and needs of PLHIV have not received adequate attention. Hunan Province, a populous region in central China, faces a substantial HIV burden,²⁶ with over 56,850 reported PLHIV as of 2023.²⁷ The epidemic is predominantly driven by sexual transmission and disproportionately affects individuals aged 50 and older.²⁸ Stigma and healthcare access disparities remain persistent challenges in HIV management across the province. We aimed to capture the experiences, and needs of PLHIV in Hunan, China, which can provide information to develop tailored DSD model, healthcare and psychosocial support programs. Our findings can help inform health strategies to combat HIV and achieve the UNAIDS 95–95–95 targets (95% of PLHIV knowing their status, 95% of diagnosed individuals on ART, and 95% of those on ART achieving viral suppression).²⁹

Materials and Methods

Study Design

We employed a descriptive phenomenological approach to identify the experiences, challenges, and needs of PLHIV via semi-structured in-depth interviews; this helped us gain deep insights into the participants' potential and intangible perceptions and experiences. We have reported our results in accordance with the COREQ checklist.³⁰

Study Setting

This study was conducted in the Infectious Disease Ward at the Second People's Hospital in Chenzhou, Hunan Province. The ward specializes in the treatment and management of infectious diseases, including HIV/AIDS. The hospital serves a diverse infectious patient population, providing comprehensive care and support services for PLHIV.

Participants

We applied a purposive non-probability approach to recruit PLHIV and employed the principle of maximum variation to recruit potential participants based on socio-demographic traits such as age, sex, education level, and marital status. Eligible participants were identified through medical records and consultations with the ward's healthcare team.

Inclusion Criteria

(1) Have been diagnosed with HIV at least one month (meeting the diagnostic criteria of the *Guidelines for the Treatment of HIV/AIDS*, 2024 edition);³¹ (2) being aged 18 or older; and (3) voluntarily participating in the study.

Exclusion Criteria

(1) Individuals who could not fluently express their thoughts, such as those with severe cognitive disorders or communication impairments; (2) participants with mental disorders or exposure to other traumatic events within the last 3 months.

We determined the sample size upon reaching data saturation, with no new themes emerging.³² This study achieved data saturation at 20 participants.

Ethics Approval

This study was approved by the Ethics Committee of the Affiliated Hospital of Xiangnan University (#K2024-015-01), and strictly adheres to the Declaration of Helsinki. All participants signed the informed consent form before the formal interviews and voluntarily participated. The informed consent included publication of anonymized responses or direct quotes. They had the right to withdraw from the study at any time without any reason. All research-related documents and audio files were de-identified and saved on a private computer with a password, accessible only to the researchers. The participants received 100 RMB (approximately 13.8 USD) as compensation for their contribution and time.

Data Collection

Between July 27 and October 13, 2024, after obtaining approval from hospital management, potential participants were recruited in Infectious Disease Ward, which specializes in treating PLHIV. Two interviewers (Chunhong Shi and Yehua Dai) independently conducted one-on-one, face-to-face, semi-structured in-depth interviews and informed potential participants about the study's purpose, process, potential risks, benefits, and the necessity of recording the interviews. Formal interviews began only after participants signed the informed consent form. Both interviewers hold PhDs and are registered nurses who have received training in qualitative methods, research ethics, and carrying out in-depth interviews. The interviews took place in quiet rooms (meeting rooms or lounges) during periods when participants were not undergoing treatment procedures, often between 3 and 5 PM. The initial interview outline was formulated through literature reviews^{13,33} and group discussions. The initial interview outline was used in the pilot interviews with two PLHIV. The formal outline was refined based on reflections from the pilot interviews; it included a series of open-ended questions about the experiences, challenges, and needs of PLHIV (see Table 1). Throughout the interview process, the

Table 1 Open-Ended Questions Used to Guide in-Depth Interviews

Content	Open-ended Questions
Experiences	(1) What symptoms have you been suffered lately?
	(2) How would you describe your psychological state after a positive diagnosis?
	(3) How are your social relationships?
	(4) How would you describe your spiritual well-being?
Challenges and needs	(1) What challenges have you been facing during your hospitalization?
	(2) What needs are you seeking to fulfill to overcome these challenges?

interviewers applied facilitation techniques such as attentively listening, repeating, observing, and recording participants' speech rate, tone, and facial expressions. The participants were encouraged to describe their experiences, challenges, and needs deeply and specifically. We offered immediate psychological support, provided contact information for local mental health services, and conducted follow-up checks for participants experiencing severe distress during the interviews. The interviews lasted 16.52 to 58.06 minutes (mean 34.28 ± 10.89 minutes).

Data Analysis

The recorded data were transcribed verbatim into transcripts within 24 hours of the interviews. The interaction process, significant statements, expressions, and tones with the interviewees were marked within the transcripts. Participants' demographic characteristics were summarized into a table. All interviews, transcripts, and data analysis were conducted in Mandarin. We carefully read and re-read the transcripts to fully understand interviewees' narratives. We employed Colaizzi's seven-step analysis method³⁴ for inductive coding of the transcripts and utilized NVivo 14 to manage the qualitative data and facilitate the analysis. The specific steps were as follows: (1) read the interviewees' transcripts thoroughly; (2) extract important statements and representative content related to the experiences, challenges, and needs of PLHIV; (3) formulate meanings based on repetitive and representative statements; (4) summarize the meanings, identify common codings, and form categories and themes; (5) articulate the themes from the perspectives of PLHIV; (6) report the basic structure of the discussed phenomenon; (7) return the final results to the interviewees for validation. Additionally, we informed them of the established categories and themes by phone to check if the results matched their experiences and needs, and we modified the findings based on their feedbacks.

Rigor

We employed the criteria of credibility, dependability, transferability, and confirmability as proposed by Lincoln and Guba³⁵ to ensure the rigor of the results. (1) *Credibility*: Data management and analysis were conducted using NVivo 14 (QSR International Pty Ltd.) along with Colaizzi's seven-step analysis method. Two researchers independently coded the transcripts, compared their results, and any discrepancies were discussed by the research team to ensure intercoder reliability. (2) *Dependability*: The researchers have received extensive training in qualitative research methods, which they are adept at applying interview skills. Additionally, as the interviewers were registered nurses with professional nursing education and training, the high trust between the interviewers and participants facilitated the credibility of the data obtained. (3) *Transferability*: Open-ended questions allowed the participants to freely express themselves, and the interviewers encouraged the participants to talk about their experiences, challenges, and needs in depth. (4) *Confirmability*: The researchers maintained detailed documentation for traceability, including interview outlines, audio recordings, transcripts, and the coding process.

Results

Socio-Demographic Characteristics of the Participants

We ultimately interviewed 20 PLHIV, comprising 7 females (35%) and 13 males (65%), ranging in age from 23 to 83 years (mean: 52.15 ± 15.10). Approximately half (55%, $n=11$) of the participants lived in urban areas. Regarding education, 50% had either a primary school education ($n=7$) or were illiterate ($n=3$). Only 1 participant (5%) held religious beliefs, and 10 (50%) were married. Seventy percent ($n=14$) were enrolled in the new rural cooperative medical system (NRCMS). Their duration since HIV-positive diagnosis ranged from one month to 19 years. Table 2 presents the socio-demographic details of the participants.

The Experiences, Challenges, and Needs of PLHIV

The transcripts of 20 participants were analyzed and categorized into four themes: the physiological, psychological, societal, and spiritual dimensions of experiences, challenges, and needs, as shown in Table 3.

Table 2 Socio-Demographic Characteristics of the Participants

Characteristic	Frequency (n=20)	Percentage (%)
Age group (years old)		
20–30	2	10.00
31–40	3	15.00
41–50	2	10.00
51–60	8	40.00
61–70	4	20.00
≥71	1	5.00
Sex		
Female	7	35.00
Male	13	65.00
Residency site		
Urban	11	55.00
Rural	7	35.00
Suburb	2	10.00
Education level		
Illiterate	3	15.00
Primary school	7	35.00
Junior high school	5	25.00
Senior high school	2	10.00
Technical secondary school	1	5.00
Undergraduate	2	10.00
Religious belief		
Yes	1	5.00
No	19	95.00
Marital status		
Unmarried	4	20.00
Married	10	50.00
Divorced	3	15.00
Widowed	3	15.00
Healthcare insurance		
NRCMS	14	70.00
UEBMI	3	15.00
URBMI	2	10.00
No	1	5.00

(Continued)

Table 2 (Continued).

Characteristic	Frequency (n=20)	Percentage (%)
Duration since HIV-positive diagnosis(months)		
1–23	10	50.00
24–36	7	35.00
>36	3	15.00

Abbreviations: NRCMS, new rural cooperative medical system; UEBMI, urban employee basic medical insurance; URBMI, urban resident basic medical insurance.

Table 3 Themes and Categories in the Interviews

Themes	Categories	Examples of Codings
Physiological dimension	Multi-organ physical symptoms	Oral symptoms, respiratory and pulmonary symptoms, extremity symptoms, gastrointestinal symptoms, cardiovascular symptoms, urinary symptoms, dermatological symptoms
	Increased physical vulnerability	Fatigue, fever, dizziness, weight loss, reduced mobility, frequent illnesses
	Desiring healthcare guidance	Symptom management, rehabilitation guidance, preventive care, patient education, nutritional guidance, medication advice, follow-up visit
Psychological dimension	Complex emotional distress	Shock, devastation, depression, horror, despair, exasperation, angry
	Inadequate HIV-related knowledge	Misconceptions about HIV symptoms and transmission, unawareness of HIV testing options, lack of knowledge about ART, limited knowledge of available support services
	Considerable stigma and discrimination	Self-stigma, family-based discrimination, stigma from HCPs, public stigma
	Desiring respect and dignity	Social acceptance, healthcare equity, personal identity
Societal dimension	Huge economic burden	Increased expenditures: healthcare costs, household expenses (eg, special diets) Decreased income: loss of productivity, reduced opportunities for decent employment, informal care costs
	Fragile social networks	Retreating social roles, decreased social interactions
	Desiring social support	Financial support, employment support, family support, public campaigns
Spiritual dimension	Mixed feelings about death	Fear: fear of losing dignity or autonomy, fear of a painful death, irreleasable family ties Acceptance: acceptance of life's natural cycle, resigned acceptance due to the illness
	Negative expectations of the future	Lack of future orientation, loss of interest in life, suicidal thoughts
	Seeking solace in faith	Participation in religious activities, prayer and meditation, belief in divine protection
	Desiring a “good” death	Palliative care: quick death without suffering, dying with dignity Death education: fearlessness about death Funeral preparation: coffin, grave, last will and testament

Abbreviation: HCPs, Healthcare Professionals.

Participants' Physiological Experiences and Needs

All participants stated that they suffered significant physical deterioration and expressed need for healthcare guidance; the categories included multi-organ physical symptoms, increased physical vulnerability, and desiring healthcare guidance.

Multi-Organ Physical Symptoms

The majority of respondents reported suffering from systemic syndrome reactions due to the negative impact of the virus, such as respiratory and pulmonary symptoms, gastrointestinal symptoms, cardiovascular symptoms, and urinary symptoms. One participant who has been on ART for one years stated:

I experienced heart failure, felt heart discomfort, had wheezing [the inability to breathe easily], chest tightness, shortness of breath, and suffered from renal failure with hematochezia [various symptoms]. (P1)

Another participant, who has received ART for nineteen years, experienced similar symptoms:

I previously suffered from hydronephrosis in both kidneys, which resulted in not only physical pain but also significant mental stress as I feared the progression to uremia and potential renal failure. (P11)

Increased Physical Vulnerability

Most respondents reported experiencing chronic fatigue, frequent illnesses, and reduced mobility after being infected with the virus.

I don't have enough strength to sustain longtime work; I always feel short of breath, and my health has deteriorated significantly compared to before. (P16)

The following statement emerged from the transcript of P20:

Before being hospitalized, I felt listless all over, had no appetite for a long time, and always wanted to sleep...

Desiring Healthcare Guidance

Respondents mentioned that they frequently suffer from physical symptoms and require sustainable professional guidance from healthcare providers regarding symptom management, rehabilitation guidance, preventive care, and follow-up visit.

I just hope to receive follow-up medical guidance from doctors; sometimes I might feel unwell, and then I need to consult a doctor... (P19)

A patient who had stopped taking anti-retroviral medication for several years stated:

At that time, I wanted to contact a doctor to ask about the medication... But after realizing I didn't have the doctor's contact information; I didn't pay much attention to it. Then, after not taking the medication, I started to waste away, felt aches and swelling in my body, and experienced dizziness. (P10)

Participants' Psychological Experiences and Needs

The participants struggled through a dark psychological journey and desired to be treated fairly to gain more respect and dignity. This theme consisted of four categories: complex emotional distress, inadequate HIV-related knowledge, considerable stigma and discrimination, and desiring respect and dignity.

Complex Emotional Distress

The majority of the participants reported a negative emotional response to their HIV-positive diagnosis, including shock, devastation, depression, horror, despair, and exasperation.

One participant stated,

I feel very depressed and on the verge of a breakdown. I never thought something like this [referring to HIV infection] could happen to me. I felt like my world had collapsed. (P10)

Another interviewee expressed fears and despair:

I was very surprised when the doctor told me I was infected with HIV. I immediately burst into tears and felt a deep despair about the disease; it was very scary. (P11)

Inadequate HIV-Related Knowledge

Respondents mentioned that both they and their surroundings had inadequate HIV-related knowledge, which led to their limited understanding of therapy and rehabilitation options, as well as the negative stereotypes associated with PLHIV.

A participant stated,

I initially had little knowledge of this disease; people seemed to say that it would cause the body to rot all over, and then I also felt that this disease was very terrifying. (P11)

Another patient expressed that a family member had insufficient knowledge of HIV:

My family [member] does not understand HIV [and misunderstood] this disease, because the rural people feel that this disease is actually very terrible. (P8)

Considerable Stigma and Discrimination

The majority of participants described that they had encountered great stigma and discrimination from family members, healthcare professionals, and the general public. Additionally, some participants exhibited self-stigma.

One participant noted,

Even my own sister treats me with disdain, avoiding my home as if it were a contaminated zone—never sharing a meal, never even deigning to sit on my sofa... (P11)

Another client shared similar feelings:

I feel great pressure. I've heard that this disease [referring to HIV] is very scary, and I'm afraid others will mock me, saying that I suffer from this unclean disease. (P14)

Desiring Respect and Dignity

Many respondents mentioned that they expected social acceptance, healthcare equity, and personal identity. They also hoped that potential strategies could reduce negative attitudes and behaviors toward them and eliminate discrimination.

As stated by Participant 11:

I believe the most important need is to eliminate discrimination, because many people have misconceptions about this disease. If even healthcare providers discriminate against our group [referring to PLHIV], it feels as if we're being pushed to the edge, left without a foothold.

Another participant added:

One of my friends has set up a chat group in which people from all over the country talking about their physical discomfort and what they feel. In that group, we can talk normally and happily, helping and loving each other. (P10)

Participants' Societal Experiences and Needs

Participants shared their experiences and needs in the societal dimension, which included three categories: huge economic burden, fragile social networks, and desiring social support.

Huge Economic Burden

Financial issues have become one of the most pressing concerns for PLHIV; most clients expressed that they faced immense economic pressure. They needed to cover the costs of regular antiretroviral therapy (ART) and potential complications, as well as cope with loss of productivity and reduced opportunities for decent employment—all of which contribute to a significant economic burden.

One respondent stated,

I can't earn money when I'm sick, and being in the hospital requires spending money. My biggest difficulty is financial hardship. (P15)

Economic burden was also expressed by another participant:

My son is here caring for me, with no source of income. It means that there is no money... No money means no treatment. (P2)

One participant added,

Later, I found out that some people who have this disease are working. I should also be able to... but some factories exclude [PLHIV]. Even if they can't check it out, the manager will slowly look at your whole state and feel that if you have some disease, then you won't [be able to] continue to work anymore. (P10)

Fragile Social Networks

Respondents described that they had retreated from social roles and reduced their social interactions, relying mainly on virtual social media to pass the time—such as TikTok and Watermelon Video—and living in a relatively closed, self-contained world.

Another interviewee who had been helping care for grandchildren noted,

At first, I was taking care of my grandchildren, but after I got sick, my daughter-in-law wouldn't even let me touch my grandchildren. (P3)

A respondent expressed:

I no longer have any interpersonal interactions; my wife divorced me, and my children have distanced themselves from me... Even relatives and friends no longer visit me. (P1)

Likewise, another participant stated,

My neighbors, knowing that I have this disease, have all cut off contact; people are a bit afraid when they see you... (P11)

Desiring Social Support

Some participants described that they hoped the government and society will commit to increasing the reimbursement coverage of healthcare insurance, providing employment opportunities, and initiating public campaigns to eliminate discrimination against HIV/AIDS.

As described by one participant:

I hope that organizations like the Red Ribbon Association can help everyone care for each other. This way, PLHIV can interact and communicate just like the general population. (P10)

Participant 15 mentioned,

I was hospitalized in a county town, and the total cost was over 20,000 yuan. The medical insurance bureau covered 4,000 yuan. I really hope the government can provide more financial support to help with the costs.

Participants' Spiritual Experiences and Needs

Participants summarized important spiritual experiences and needs, which included four categories: mixed feelings about death, negative expectations of the future, seeking religious solace, and desiring a “good” death.

Mixed Feelings About Death

Death is a sensitive topic in Chinese culture. The majority of participants conveyed their mixed feelings about death, including fear and acceptance.

One participant expressed,

I do not like using ICU medical measures to prolong life, such as intubation; it looks very cruel... (P11)

Another participant added,

I feel that death is not scary. Death always comes one day. The Earth is so big, and the universe is even bigger. A person is so small. I think birth, aging, sickness, and death are all very normal things. (P19)

Negative Expectations of the Future

Many respondents indicated that they had lost hope in life and viewed the future as overshadowed by gloom.

One participant mentioned,

I have no expectations whatsoever now; I don't even want to travel anymore, I just want to prepare for my grave... (P5)

Another participant expressed suicidal intentions:

Thinking about suicide, I definitely feel a desire to end my life because of this damn virus [HIV]. (P18)

Seeking Solace in Faith

A few of respondents mentioned that seeking psychological comfort in faith helped them to relax and increase their confidence in life.

One participant pointed out,

Some of our peers here [practice] Buddhism. When I am sick, I listen to Buddhist scriptures to seek comfort. (P8)

Another participant reported,

I feel that listening to the melody of the Buddhist scriptures changes my entire mood. Living a peaceful life, having a peaceful heart... I feel a great sense of inner tranquility. (P10)

Desiring a “Good” Death

Many respondents mentioned that they would prefer to have a “good” death over medical survival and the ability to arrange a decent passing for themselves.

One participant stated,

If the hospital has euthanasia, please offer me euthanasia. I'll give anyone 10,000 RMB (equally to 13,796.3 USD) to help me die quickly. (P1)

Another interviewee expressed,

My time left is limited... If I had the money, I would buy a coffin to ensure that I could pass away in a dignified and peaceful manner. (P3)

Discussion

We explored the experiences, challenges, and needs of PLHIV within the Chinese context, revealing the complex challenges they face in the physiological, psychological, societal, and spiritual dimensions. The findings highlight the need for policies and interventions that emphasize patient-centered care, psychological services, social support, and spiritual care. These strategies are essential to better assist PLHIV, improve their overall well-being, and contribute to achieving the UNAIDS 95–95–95 targets.

Our findings indicate that PLHIV experience a spectrum of physical symptoms and health-related vulnerabilities, which is consistent with previous research.^{36,37} Sabranski et al³⁸ also found that symptom-related distress is very common among HIV-infected clients who have been on ART, with the most frequently reported symptoms being fatigue, insomnia, and sexual dysfunction. More than 50% of PLHIV experience chronic physical pain, which leads to emotional disorders and threatens their QoL.³⁹ HIV infection often progresses to AIDS, characterized by a spectrum of opportunistic infections, malignancies, and ultimately, mortality.⁴⁰ In China, the prevalence of late presentation to HIV/AIDS care is notably high, reaching 43.26%.⁴¹ With the initiation of ART, non-AIDS-defining diseases such as advanced renal disease, non-AIDS-defining cancers, cardiovascular disease, and end-stage liver disease also negatively impact QoL for PLHIV.^{42,43} Additionally, physical vulnerability is common among PLHIV, consistent with studies from China and other countries.^{44,45} The prevalence of frailty was 10.9%, and prefrailty was 47.2% among adults living with HIV aged 50 and older,⁴⁶ with an increase observed in those over 70 years of age.⁴⁷ HIV-related frailty may be associated with mitochondrial dysfunction, chronic inflammation, and oxidative stress⁴⁸ and is primarily manifested as weak grip strength, slow gait, fatigue, and low levels of physical activity.^{45,49} Frailty in PLHIV is associated with a higher risk of falls, disability, and polypharmacy, as well as increased comorbidity and mortality,⁵⁰ which urgently requires comprehensive pharmacological and non-pharmacological interventions (eg, lifestyle adjustments, emotional regulation, and self-care education).⁵¹ As expected, most participants expressed a significant need for healthcare guidance, which aligns with the current consensus.^{52,53} Addressing the needs of PLHIV in terms of preventive measures, counseling, diagnostic methods, treatment, and rehabilitative care is essential for improving their QoL and well-being.⁵⁴ Approximately half of the HIV-positive population in China has experienced one or more unmet symptom management needs,⁵⁵ which negatively affect progress in halting the spread of HIV. The findings highlight the urgent need for efforts to address multiple healthcare needs, such as managing physical symptoms, preventing physical vulnerability, and providing collaborative and integrated healthcare services and guidance, in order to achieve optimal public health outcomes.

Respondents in this study reported a complex psychological experience, including emotional distress, inadequate HIV-related knowledge, and considerable stigma and discrimination, and expressed a strong desire for respect and dignity. The majority experienced emotional distress, reporting feelings of disappointment, despair, shock, devastation, and horror in response to their situation. Our results align with those of Ncitakalo et al,⁵⁶ who reported that 34.3% of HIV-positive individuals have psychological distress, and of Zhu et al,⁵⁷ who found that sadness, self-abasement, and self-loathing are the most central psychological symptoms during different periods of HIV infection. Compared to the general population, the prevalence of psychological issues among PLHIV is higher, with a global prevalence of depression at 31%⁵⁸ and anxiety disorders at 15.5%.⁵⁹ Moreover, psychological issues among PLHIV persist over the long term.^{38,60} Stigma and discrimination remain significant barriers in the global fight against HIV. Most participants in this study have faced various forms of stigma, such as discriminatory attitudes and behaviors in healthcare, communities, and family settings, which is consistent with prior research.^{56,61,62} Worldwide, about 44% of HIV-positive individuals have experienced high levels of HIV-related stigmatizing attitudes.⁶³ In the collectivistic Chinese culture, contemporary societal groups tend to metaphorically label PLHIV as a “high-risk group”, describe them as having an “incurable disease”, portray them as living a “dissolute lifestyle”, and view them as “fated”.⁶⁴ Moreover, HIV-related stigma is highly prevalent in China, with 66.6% of the general population endorsing moderate to high levels of HIV-related stigma,⁶⁵ this hinders effective prevention, testing, and treatment initiatives. Unfortunately, healthcare providers also exhibit embedded stereotypes and prejudice against HIV-infected clients.^{33,66} HIV-related stigma is associated with

several factors, including socio-demographic characteristics (eg, older age, living in rural areas, and being female), clinical factors (eg, poor medication adherence and depression), and service use factors (eg, nondisclosure of HIV status and poor access to care).^{63,67} Stigma and discrimination have complex and negative impacts on both mental and physical health.^{68,69} Most interviewees expressed that both themselves and the general population, especially their rural relatives, had inadequate knowledge or a distorted view of HIV. This finding is similar to prior studies, which indicate that 62% of PLHIV have a general understanding of ART⁷⁰ and that the general population has a low level of HIV/AIDS awareness.⁷¹ Inadequate knowledge regarding HIV/AIDS is particularly pronounced among marginalized groups (eg, low-income people, rural residents, individuals with low education levels, and women).^{72,73} Lack of awareness about HIV/AIDS is a key driver of the epidemic's spread and the root cause of stigma, psychological distress, and economic hardship. Misconceptions about HIV fuel fear and discrimination, limiting employment opportunities for PLHIV, as well as leading to social isolation, marginalization, and a lack of support from family, friends, and the community.⁷⁴ The cycle of ignorance, stigma, and exclusion exacerbates the psychological and economic burdens faced by those living with HIV, thereby deepening both the social consequences and the health impacts of the epidemic.⁷⁵ Finally, the interviewees have conveyed a great need for respect and dignity. Psychosocial support (such as individual counselling, peer support, and group therapy) plays a significant role in promoting adherence and retention in ART⁷⁶ and in maintaining mental health. However, there is a scarcity of mental health resources, inadequate infrastructure, and a shortage of well-trained personnel to deliver necessary psychological support worldwide.⁷⁷ Collaborative efforts and national health priorities—such as education, community engagement, and media campaigns—are urgently needed^{68,78} to create a stigma-free environment and improve the well-being of affected populations.

PLHIV face significant social challenges, including a heavy economic burden, fragile social networks, and a strong desire for social support. Participants reported that they faced substantial economic burdens for necessities like food, housing, education, and ongoing healthcare costs, similar to the findings of Nguyen et al⁷⁹ and Godongwana et al.⁸⁰ PLHIV not only face an average annual hospitalization cost of \$96 ± 139,⁸¹ but also 63% of them report difficulties in finding decent employment.⁸² HIV-infected individuals with sufficient economic empowerment achieved significant improvements in viral suppression and mental health,⁸³ and those with health insurance experienced fewer unmet health needs.⁸⁴ Further, some individuals with HIV withdrew from their previous social roles, encountering challenges like unemployment, marital issues, family conflict, and even homelessness, similar to the findings of a study conducted in Iran.⁸⁵ Participants also experienced a reduction in social interactions following their HIV diagnosis. Moreover, individuals with HIV may self-isolate as a coping strategy or experience isolation from family and their community due to stigma, fear of contagion, and misconceptions about transmission.^{86,87} Notably, 63.7% of PLHIV were classified as socially isolated,⁸⁸ with the loneliness rate among older adults with HIV reported at 33.9%.⁸⁹ PLHIV highly value social support and call for actions to end discrimination against those with HIV/AIDS, enhance insurance coverage for medical expenses, and expand educational and supportive services. Unfortunately, social support is often insufficient for PLHIV, particularly among the elderly, the divorced, and those with a low economic status.⁹⁰ These findings highlight the necessity of providing social support for PLHIV at the family, community, and government levels, including financial support, family engagement, and public campaigns.

The present study revealed that PLHIV frequently navigate a spiritual journey marked by mixed feelings about death, negative expectations of the future, a search for religious solace, and a desire for a “good” death. Respondents expressed mixed feelings about death, characterized by a fear of losing dignity or autonomy, fear of a painful death, acceptance of life's natural cycle, and resigned acceptance due to illness. The fear of losing dignity or autonomy and the fear of a painful death are particularly prominent, reflecting concerns about the QoL during the dying process.⁹¹ This is similar to findings in other countries where individuals express significant death anxiety about the physical and psychological aspects.⁹² Furthermore, family members often play a crucial role in end-of-life decisions in China.⁹³ The acceptance of life's natural cycle and resigned acceptance due to illness reflect a cultural resignation to fate, which is also observed in other cultures.⁹⁴ The variations in death attitudes can be attributed to cultural, social, and individual factors. In China, the collectivist culture and strong family ties influence how individuals approach death.⁹⁵ Additionally, the availability and quality of palliative care services can impact individual's attitudes towards death and healthcare utilization outcomes.⁹⁶ Most participants felt pessimistic about the future, and even experienced suicidal thoughts, which is consistent with

qualitative research on newly diagnosed HIV-positive individuals in Ghana.⁹⁷ Another survey showed that 52.8% of PLHIV perceive their lives as failures and feel worthless, while 37% lack a belief in their ability to make short- or long-term plans.⁸² Fear of the future and hopelessness greatly affects their well-being.⁹⁸ Healthcare professionals and clergy could strive to assist these individuals in finding meaning in life, as well as to promote the development of autonomy and a positive future orientation. Some participants tried to seek solace in religious beliefs, which can calm the mind and build resilience against the challenges of HIV/AIDS. Studies overwhelmingly indicate a positive link between religious or spiritual practices and reduced HIV-related stigma⁹⁹ as well as higher social support.¹⁰⁰ PLHIV in this study also expressed a desire for a “good” death (the “spirit” is accepted by God), which aligns with prior findings.⁹¹ A painless and dignified death protects individuals, their families, and healthcare providers from unnecessary suffering, which is consistent with clinical, cultural, and ethical norms.¹⁰¹ However, in China, achieving a “good death” may be challenged by uneven resource distribution, a shortage of professionals skilled in end-of-life care, and limited access to hospice facilities.^{102,103} Future research efforts should focus on evidence-based interventions that address both the spiritual needs of PLHIV and their desire for a “good” death, in order to provide better holistic end-of-life care.

As HIV progresses, it is essential to develop tailored DSD models that address the unique needs of PLHIV, ensuring their equitable access to healthcare services. Public health campaigns and community-based interventions should be implemented to reduce stigma and promote social inclusion. Financial assistance and employment support are also crucial to alleviate the economic burdens faced by PLHIV. Additionally, recognizing the importance of spiritual and end-of-life care in healthcare services is vital to provide holistic support. Future policies should prioritize strengthening support systems, optimizing healthcare delivery, and promoting community initiatives to foster resilience and enhance the well-being of those affected by HIV/AIDS.

Limitations

This study has some limitations. First, we collected the data from a single geographic area in China (the city of Chenzhou) and relied on a small sample size (20 HIV/AIDS clients), both of which may limit the generalizability of the findings. Second, the interview data did not allow us to explore differences in experiences and needs regarding the participants’ demographic characteristics, such as sex and education level. Third, qualitative research inherently carries limitations, including potential subjectivity in data analysis and social desirability bias influencing participant responses. Future research should collect data from larger samples or employ a multicentered approach to gain broader insights.

Conclusions

This study highlights the complex, multidimensional needs of PLHIV, encompassing physiological, psychological, societal, and spiritual challenges that significantly affect their well-being. PLHIV experience complex challenges and multidimensional needs, including multi-organ physical symptoms, considerable stigma and discrimination, substantial economic burdens, mixed feelings about death, and a strong desire for support from their families, healthcare institutions, and communities. Our findings call for the development of holistic, patient-centered policies and interventions that address the multifaceted needs of PLHIV, to better support individuals with HIV in navigating the stressful journey of illness. Furthermore, this study could inform the DSD model, offering potential guidance for future research and policy-making aimed at delivering more responsive and equitable care, reducing the burden of HIV, and enhancing the well-being of affected individuals.

Abbreviations

HIV, human immunodeficiency virus; AIDS, acquired immunodeficiency syndrome; ART, anti-retroviral therapy; DALYs, disability-adjusted life years; QoL, quality of life; NRCMS, new rural cooperative medical system; UEBMI, urban employee basic medical insurance; URBMI, urban resident basic medical insurance.

Data Sharing Statement

The datasets used and/or analyzed during the current study are available from the corresponding author upon reasonable request.

Ethics Approval and Consent to Participate

The protocol of this qualitative study was reviewed and approved by the Ethics Committee of the Affiliated Hospital of Xiangnan University (#K2024-015-01). Informed consent was obtained from each participant before they took part in the study. The informed consent included publication of anonymized responses or direct quotes. All procedures adhered to the ethical standards set forth in the Declaration of Helsinki as well as to applicable local guidelines and regulations.

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Author Contributions

All authors made a significant contribution to the work reported, whether that is in the conception, study design, execution, acquisition of data, analysis and interpretation, or in all these areas; took part in drafting, revising or critically reviewing the article; gave final approval of the version to be published; have agreed on the journal to which the article has been submitted; and agree to be accountable for all aspects of the work.

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Disclosure

The authors report no conflicts of interest in this work.

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