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ORIGINAL RESEARCH

# Navigating Adversity: Psychosocial Transformation, Service Advocacy, and End-of-Life Perceptions Among Family Caregivers of PLWHA During Inpatient Treatment in Hunan, China

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**Background:** The HIV epidemic remains a global challenge. In China, family caregivers bear most caregiving responsibilities for people living with HIV/AIDS (PLWHA). However, the lived experiences of these caregivers regarding psychosocial transformation, service advocacy, and end-of-life perceptions during hospitalization remain underexplored within the Chinese sociocultural context.

**Methods:** From August 2024 to January 2025, a descriptive qualitative design was utilized to interview 17 family caregivers of inpatients with HIV/AIDS at the Infectious Disease Ward of the Second People's Hospital in Chenzhou, Hunan Province. Data were collected through face-to-face in-depth interviews and analyzed using the thematic analysis method with NVivo 14. The criteria of credibility, dependability, transferability, and confirmability were applied to ensure rigor.

**Results:** Seventeen participants (nine females, 52.9%; eight males, 47.1%) aged 22 to 74 years were interviewed. Three major themes emerged: (1) positive transformation and growth (psychological resilience, caregiving responsibility, caregiving capital, and family bonds); (2) advocacy for enhanced services (psychological support, HIV education and medication management, healthcare accessibility, respectful non-discriminatory care, and financial relief); (3) complex death perceptions (diverse attitudes towards death, anticipatory grief, and dignified dying).

**Conclusion:** The findings reveal that family caregivers of PLWHA experience positive personal growth, hold complex end-of-life perceptions, and advocate for service improvements. Healthcare policies and clinical practices are recommended to develop structured, family-centered support interventions, including professional psychological support, financial assistance, as well as integrated end-of-life care and death education for both PLWHA and their families.

**Keywords:** HIV, AIDS, family caregivers, qualitative research, delivery of healthcare

## Introduction

The human immunodeficiency virus (HIV) and acquired immunodeficiency syndrome (AIDS) remain a formidable global public health challenge,[1] particularly in the lower socio-demographic index (SDI) regions.[2] Global data indicate approximately 40.8 million people living with HIV/AIDS (PLWHA) worldwide; 31.6 million were on antiretroviral therapy (ART), with 1.3 million new infections and 630,000 AIDS-related deaths in 2024.[3] China had reported approximately 1.41 million PLWHA and 0.52 million AIDS-related deaths by the end of December 2025.[4] Although substantial global efforts have been made to combat HIV, lifelong ART for a global population exceeding 40 million

https://doi.org/10.2147/PPA.S604420
Received: 20 February 2026
Accepted: 14 May 2026
Published: 26 May 2026

remains a significant long-term challenge for healthcare systems.[5] As a manageable chronic condition, HIV infection requires lifelong care for PLWHA from both healthcare professionals and informal caregivers.

As primary informal caregivers for PLWHA, family members provide essential medical assistance, psychological support, and daily living care, including accompanying patients to medical appointments, assisting with medication adherence, and facilitating routine daily activities.[6] Nevertheless, HIV-related symptoms, complications, and a lack of professional care knowledge impose physiological, psychological, and economic burdens on caregivers,[7] which intensify particularly during patient hospitalization. The hospitalization period represents a high-acuity phase in which PLWHA often experience acute illness progression, medication adjustments, or opportunistic infections,[8] thereby generating unique and intensified caregiving demands. Simultaneously, family members need to navigate internalized stigma, fear and guilt, and financial strain while caring for PLWHA.[9,10] Most literature reports that such high-intensity caregiving burden negatively impacts family caregivers' well-beings, leading to a lower quality of life[11] and exacerbating physiological and psychological distress.[12] However, the caregiving trajectory can also foster positive transformation, including positive emotional experiences, perceived social support, and health promotion behaviors.[6] Furthermore, several studies have reported promising caregiver-directed interventions, including home-based care (HBC) programs[13] and family support models,[14] as well as information dissemination model,[15] to help PLWHA and their families optimize their quality of life.

Although China has made substantial progress in access to and optimization of ART,[16] the country continues to report persistently high rates of HIV mortality, incidence, and infection.[17] Informal family caregivers of PLWHA are required to transcend adversity to provide emotional, material and financial support to sustain PLWHA's treatment outcomes and well-being.[18] Additionally, the hospitalization of PLWHA represents a high-acuity period that may generate distinct caregiving experiences compared to community-based care—an underexplored context that deserves greater attention. During hospitalization, caregivers exhibit unique caregiving experiences, including more frequent involvement in bedside clinical decision-making, exposure to sudden changes in the patient's condition, coordination with multiple healthcare professionals, and heightened emotional distress due to the potential deterioration of the patient.[19] Thus, understanding the lived experiences of family caregivers of PLWHA during this high-risk hospitalization phase is critical, as these experiences can influence patients' treatment adherence, care satisfaction, and post-discharge planning.[20] Although a growing body of qualitative research has explored the experiences of family caregivers of PLWHA, most of these studies have been conducted in sub-Saharan African contexts.[10,21–24] In Asia, a few available studies have primarily focused on caregiver burden, stigma, and barriers to ART adherence.[25,26] Specifically within the Chinese context, existing qualitative researches have largely concentrated on the psychological distress and coping strategies of PLWHA themselves[27,28] and the caregiving burden of PLWHA family members.[7,29] However, scant attention has been paid to the psychosocial transformation, service advocacy, and end-of-life perceptions of family caregivers during the hospitalization period. Descriptive qualitative research is well-suited for exploring participants' subjective experiences, perspectives, and feelings, and for providing accurate and rich descriptions of phenomena.[30] This study shifted the analytical focus from caregiver burden (eg, stigma, distress) toward a more adaptive perspective that includes positive transformation and advocacy behaviors, incorporated end-of-life perceptions into the Chinese cultural and policy context, and specifically targeted the hospitalization phase. Adopting a descriptive qualitative design, we explored these lived experiences of HIV/AIDS family caregivers during inpatient treatment in Hunan, China, aiming to inform culturally sensitive family-based care programs.

# Materials and Methods

## Study Design

This study utilized a descriptive qualitative design to explore the psychosocial transformation, service advocacy, and end-of-life perceptions of PLWHA family members. The methodology was chosen for its suitability in providing a nuanced understanding of caregivers' lived experiences and perceptions. The reporting of this study adhered to the Consolidated Criteria for Reporting Qualitative Research (COREQ).[31]

## Study Setting

This study was conducted in the Infectious Disease Ward of the Second People's Hospital in Chenzhou, Hunan Province (25.77° N, 113.03° E). This hospital is a non-profit, tertiary specialty institution dedicated to infectious disease care and serves as the national benchmark for standardized HIV medical services. The Infectious Disease Ward specializes in managing both HIV-related and non-HIV/AIDS defining illnesses.

## Participants

We used purposive sampling to recruit family members of PLWHA during inpatient treatment from the Infectious Disease Ward. Potential participants were identified through inpatient records and recommendations from nursing staff. The inclusion criteria were as follows: (1) being a family member of an inpatient with an HIV diagnosis ≥1 month; (2) aged ≥18 years; (3) serving as the primary caregiver for the PLWHA; and (4) the ability to communicate in Mandarin and willingness to participate in this study. Participants were excluded based on the following criteria: (1) having any serious physical or mental illness; (2) receiving a salary for caregiving. Maximum-variation sampling was adopted to recruit the potential participants in terms of age, sex, education, and relationship to the patient. The sample size was determined based on the principles of data saturation commonly applied in qualitative descriptive studies.[32] Recruitment continued until no new themes or subthemes emerged from three consecutive interviews.[33] The final sample of 17 participants was achieved thematic saturation in this study. In addition to saturation, the sample size was further justified using the information power framework:[34] a narrowly focused study aim (to explore the caregiving experiences of family caregivers), a specific and homogeneous sample (family caregivers of PLWHA during inpatient treatment in a single tertiary hospital), rich dialogue during in-depth interviews, and an explicit thematic analysis strategy to maintain information power. Moreover, previous studies have revealed that saturation typically occurs within the first twelve interviews[35] and is typically achieved within a range of 9 to 17 interviews in health research.[32]

## Ethics Approval

The study was approved by the Ethics Committee of the Affiliated Hospital of Xiangnan University (Reg. No. K2024-015-01) and conducted in accordance with the Declaration of Helsinki (2024 revision). Written informed consent was obtained from each participant before the interview. Participation could withdraw at any time without giving a reason, and their withdrawal did not impact on ongoing treatment of PLWHA. All audio recordings and transcripts were anonymized using codes (eg, P1, P2) and stored on a password-protected computer accessible only to the research team. Each participant received 100 CNY (≈13.8 USD) as compensation for their time and contribution.

## Data Collection

Data were collected from August 3, 2024, to January 26, 2025. Following approval from the hospital administrators, the research team collaborated with the head nurse of the Infectious Disease Ward to identify and approach potential participants. The research team comprised two PhDs (CS and YD, both registered nurses with 10 and 15 years of nursing education), three undergraduate nursing students (XL, MC, and XL) who had completed nursing courses in infectious diseases, and two clinical nurses (YL with 20 years of care experience in HIV inpatient care, and WY with 16 years of clinical experience). Before the interviews, interviewers explicitly stated their role as researchers to the participants and wore civilian attire to reduce potential role confusion. The head nurse (YL) initially introduced the study to potential candidates, explaining its purpose, interview procedures, estimated duration, and potential benefits. For those who expressed interest in participating, two members of the research team (CS and YD) initiated a formal screening and consent procedure and then conducted a face-to-face semi-structured interview. Interviews were conducted in a quiet, private meeting room or lounge after obtaining written informed consent from each participant. The semi-structured interview guide was developed based on a literature review of HIV caregiving[6,10] and clinical experience from the research team. It was refined through pilot interviews with two family members of PLWHA and team debriefings. The formal guideline comprised open-ended questions about family members' lived experience of caregiving, specifically covering their psychosocial transformation, service advocacy, and end-of-life perceptions (see Box 1). Participants were

**Box 1** Open-Ended Questions Used to Guide in-Depth Interviews

| **Open-ended Questions** |
|---|
| 1. Could you describe your typical experience and the context of providing care for your family member living with HIV/AIDS? |
| 2. What have been the most significant challenges or sources of stress for you as a primary caregiver of PLWHA? |
| 3. How have you managed to cope with these challenges? |
| 4. What personal strengths, family support, or community resources have you drawn upon to deal with these stresses? |
| 5. What were your primary concerns during your family member's hospitalizations? |
| 6. What support do you hope to receive from healthcare staff, community organisations, or government agencies? |
| 7. How do you perceive the possibility that your family member's health may be declining toward the end of life? |
| 8. Is there anything else you would like to add, or any other suggestions you have? |

encouraged to express themselves freely, and non-verbal cues were documented to enrich data interpretation. After each interview, the interviewers wrote reflexive field notes, documenting their personal reflections and emotional responses to the interview process. The interviews lasted 18 to 54 minutes (mean, 34.05 ± 9.30).

## Data Analysis

All interviews were transcribed verbatim into Chinese within 24 hours, with non-verbal cues annotated in the transcripts. To ensure accuracy, the transcripts underwent peer debriefing through cross-checking among the research team. The data were then imported into NVivo 14 for thematic analysis,[36] which followed an iterative process comprising the following steps: (1) immersion in the data; (2) extraction of significant statements; (3) generation of initial meanings; (4) iterative categorization of codes into potential themes; (5) development of a comprehensive thematic structure; (6) refinement and definition of final themes; and (7) member checking, conducted via telephone, to validate that the identified themes reflected participants' lived experiences.

## Rigor

Rigor was safeguarded through Lincoln and Guba's four criteria.[37] (1) Credibility: the interviewers were registered nurses with professional expertise in HIV/AIDS care, which facilitated the establishment of rapport and trust with participants. Credibility was enhanced through triangulation.[38] Data triangulation was achieved by recruiting participants with diverse relationships to the care recipients (sons, daughters, spouses, and a sister). Investigator triangulation was used by including both clinical nurses and full-time nursing academics in the coding and interpretation process; disagreements were resolved through team consensus. In addition, reflexive notes were reviewed during team discussions to identify potential biases and suspend any premature assumptions. The research team members examined emerging categories, codes, and supporting materials. (2) Dependability: two clinical nurses audited the data collection method, data analysis, and contents. (3) Transferability: maximum-variation sampling was adopted to capture a broad range of caregiver's experiences and perceptions. The study also provided a thick description of the context, participants, and findings to facilitate transferability. (4) Confirmability: all raw data (audio recordings, verbatim transcripts, and field notes) were stored on individual computers, and the formulation of codings and categories could be tracked using NVivo 14.

# Results

## Socio-Demographic Characteristics of the Participants

We ultimately interviewed 17 family caregivers of in-patients living with HIV/AIDS. The sample consisted of nine females (52.94%) and eight males (47.06%), with ages ranging from 22 to 74 years. Most participants were married (n=10, 58.82%), rural residents (n=10, 58.82%) and had an educational level of primary school (n=5, 29.41%) or junior secondary school (n=5, 29.41%). The majority of care recipient were covered by the urban resident basic medical insurance (n=12,70.59%). Table 1 summarizes the sociodemographic characteristics of the participants.

## Lived Experiences among Family Caregivers of PLWHA during Inpatient Treatment

The data collection yielded approximately 597 minutes of recordings, which were transcribed into 107,204 words, and 17 pages of field notes. Thematic analysis of the 17 in-depth interviews revealed three themes: (1) experiencing positive transformation and growth, (2) advocating for enhanced service delivery, and (3) navigating complex perceptions of death (Table 2). Figure 1 shows the thematic framework.

### Experiencing Positive Transformation and Growth

The caregiving journey facilitated participants' positive transformation and growth in terms of resilience, capacity, and connection.

#### Built Psychological Resilience

Participants builted psychological resilience through acceptance of the illness and maintaining daily optimism.

> We can only take each day as it comes. As the saying goes, "When the enemy approaches, the general blocks it; when the water rises, the earth holds it back". What will come will come, and I have come to terms with this reality [referring to the fact of patient infected with HIV]. (P12)

> Because people are bound to get sick, there's nothing you can do… If this happens, you just have to look forward. There's no choice; you must slowly move forward… When facing it, you just face it gradually… (P15)

#### Shoulder Caregiving Responsibility

Participants shouldered caregiving responsibilities under a familial obligation and moral imperative to sustain family functioning and support PLWHA.

> As the eldest son, I understand this duty best. Since they're unwilling to come (take care of their Dad), I'll just do it myself. Look, from a father's perspective, he naturally hopes his children will be by his side, right? That's just human nature. (p1)

**Table 1** Demographic Characteristics of Family Members of PLWHA (n=17)

| Participants ID | Age (Years Old) | Sex | Residence | Educational Level | Marital Status | Medical Insurance | HIV Diagnosis Duration of PLWHA (Months) | Occupation | Relationship with PLWHA |
|---|---|---|---|---|---|---|---|---|---|
| P1 | 42 | Male | Rural | Associate degree | Married | URBMI | 6 | Sculptor | Son |
| P2 | 30 | Female | Urban | Bachelor degree | Unmarried | URBMI | 72 | Programmer | Son |
| P3 | 35 | Male | Urban | Bachelor degree | Married | URBMI | 7 | Self-employed (Business) | Son |
| P4 | 74 | Female | Rural | Primary school | Married | UEBMI | 120 | Farmer | Wife |
| P5 | 43 | Male | Rural | Primary school | Widowed | URBMI | 48 | Decoration Worker | Son |
| P6 | 32 | Female | Urban | Secondary vocational school | Divorced | URBMI | 3 | E-commerce | Daughter |
| P7 | 64 | Male | Rural | High school | Married | UEBMI | 60 | Farming | Son |
| P8 | 54 | Female | Rural | Primary school | Married | Out-of-pocket | 1 | Farming | Wife |
| P9 | 50 | Female | Urban | High school | Divorced | UEBMI | 60 | Freelancer | Daughter |
| P10 | 40 | Female | Rural | Junior high school | Married | URBMI | 20 | Unemployed | Wife |
| P11 | 60 | Female | Rural | Primary school | Married | Out-of-pocket | 36 | Retired | Wife |
| P12 | 31 | Male | Urban | Junior high school | Unmarried | URBMI | 62 | Freelancer | Son |
| P13 | 29 | Male | Rural | Junior high school | Married | URBMI | 6 | Migrant Worker | Son |
| P14 | 29 | Male | Rural | Junior high school | Unmarried | URBMI | 12 | Migrant Worker | Son |
| P15 | 22 | Male | Urban | Associate degree | Unmarried | URBMI | 6 | Migrant Worker | Son |
| P16 | 35 | Female | Urban | Junior high school | Married | URBMI | 1 | Housewife | Sister |
| P17 | 38 | Female | Rural | Primary school | Married | URBMI | 1 | Housewife | Daughter |

**Abbreviations**: UEBMI, Urban employee basic medical insurance; URBMI, Urban resident basic medical insurance.


https://doi.org/10.2147/PPA.S604420

**Table 2** The Themes, Categories, and Codings of the Interviews

| Themes | Categories | Codings |
|---|---|---|
| Experiencing positive transformation and growth | Built psychological resilience | Sustaining emotional stability, maintaining optimism amidst adversity, acceptance of the reality of illness |
| | Shoulder caregiving responsibility | Providing daily care and companionship, facilitating medical visits and treatment adherence, covering medical and living expenses, offering psychological support |
| | Appreciate institutionalized support | Providing free antiviral medications, medical insurance coverage, regular home visits, professional health guidance |
| | Improve HIV/AIDS awareness | Understanding transmission modes, recognizing disease nature, perceiving the importance of treatment and medication, practicing prevention measures |
| | Strengthen family bonds | Deepening sibling understanding, improving intergenerational relationships, reinforcing spousal support |
| | Develop caregiving capital | Sustaining physical well-being, acquiring practical care skills, mastering adaptive communication, cultivating altruistic engagement |
| Advocating for enhanced service delivery | Enhance psychological support | Providing psychological counseling, facilitating therapeutic communication, fostering psychological resilience |
| | Optimize the healthcare environment | Improving physical space and comfort, ensuring dietary support and quality, maintaining a restful and quiet atmosphere |
| | Provide HIV-related education | Popularizing transmission routes and safety precautions, promoting understanding of manageable prognosis, providing information on medical status and treatment progress, offering guidance on end-of-life care |
| | Improve medication management | Streamline drug distribution channels, ensure medication adherence and continuity, optimize drug efficacy and reduce side effects |
| | Facilitate healthcare accessibility | Narrowing regional disparities in medical resources, enhancing the admission capacity of primary-level hospitals for infectious diseases, upgrading necessary medical equipment |
| | Deliver respectful and non-discriminatory care | Preserving patients' privacy, reducing institutional stigma, demonstrating empathy and compassion |
| | Alleviate treatment-related financial burden | Expanding insurance coverage, stabilizing drug subsidy programs, reducing regional disparities in reimbursement |
| Navigating complex perceptions of death | Exhibit diverse attitudes towards death | Accepting death as a natural inevitability, intense fear and resistance towards death, a sense of numbness |
| | Express anticipatory bereavement and concerns | Loneliness and loss of meaning, fearing social judgment |
| | Negotiate a dignified end | Desiring a painless and dignified death, ritualistic considerations |

> …to make sure he [referring to patient] receives good care, and to provide him with food whenever he wants it. I'm willing to care for him a bit more to help him recover, but the primary goal is to treat him. Then, the question is, how do we raise the money? (p10)

### Appreciate Institutionalized Support

Participants expressed appreciation for both the financial support from national policies and the material and emotional assistance from local disease control department.

> The antiviral drugs are all provided free of charge by the state. Also, the specific department in our county responsible for HIV/AIDS prevention and treatment visits us at home every year. They even bring gifts. They really care about the patient—they added me on WeChat and frequently checked on my mom's condition. (P12)

> Now the national policies are so good, there are high reimbursement rates for HIV treatment, so it's okay—it's not like before when we had to pay for everything out of pocket. After reimbursement, we can afford it… As for precautions regarding HIV prevention and control, they [referring to healthcare staff] will tell us everything and let us know in advance. (P16)

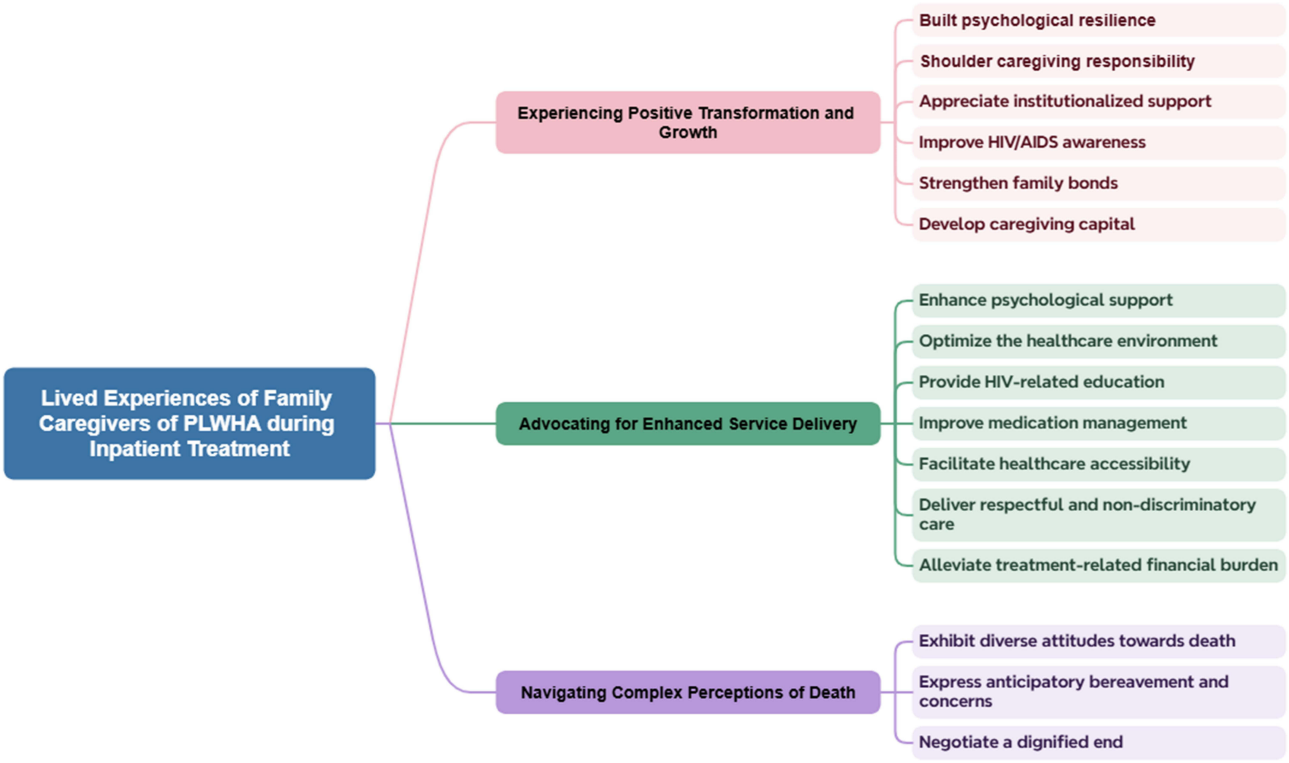


**Figure 1** Thematic framework of psychosocial transformation, service advocacy, and end-of-life perceptions among family caregivers of PLWHA during inpatient treatment.

### Improve HIV/AIDS Awareness

Participants improved their HIV/AIDS awareness through proactive information-seeking, which corrected misconceptions about transmission and the manageability of the disease.

> I found out that it's [HIV] transmitted through blood, and then through sex… the routes of transmission for this disease are very few. Having been to the hospital so many times, I saw that it isn't that easy to catch, and I haven't been infected either. (P12)

> [This disease] is controllable… I mean, if he takes his medication and stays home, he'll be fine—just like a normal person, it's the same as diabetes… Anyway, there are only three transmission routes, so it's fine, don't be afraid. (P13)

### Strengthen Family Bonds

Participants described that they strengthened their family bonds during the caregiving journey.

> When we were in Guangzhou, the reimbursement was low, and the expenses were so high. He felt like he was a burden on us, and that made his temper turn bad. He would pick fights and take it out on us, hoping we'd give up. Sigh. My father just felt—(voice starts to tremble, looking at the ceiling to hold back tears)—that since he was such a burden, he didn't want to continue treatment. (P15)

> Now it feels like my mom and dad worry about him a lot… They care about his health even more than before. They used to scold him over little things, but now they don't do that anymore; they just speak to him nicely, just like teaching a child. (P16)

### Develop Caregiving Capital

Caregivers acquired caregiving skills and psychological strategies to deliver better care.


https://doi.org/10.2147/PPA.S604420

> At that time, when I was first exposed to it, I didn't expect the disease to be this serious. Later, after getting to the hospital, I slowly learned how to take care of him—like how to use a urinal. I searched for some information online myself and then slowly learned… (P6)

> Since the disease has been diagnosed, whether it is the patient or the family, I think it is necessary to have a good understanding of the dangers of the disease and its transmission routes, so that it is more helpful for the family to take good care of the patient… Learn more on your own, study this area of knowledge more deeply. (P9)

## Advocating for Enhanced Service Delivery

Caregivers advocated for the optimization of healthcare services for PLWHA across psychosocial, clinical, and financial domains to enhance patients' treatment outcomes.

### Enhance Psychological Support

Participants called for professional psychological support to help patients boost treatment confidence, and promote treatment adherence.

> Because a person is often defeated by their own psychology—that is, regarding psychological counseling, I hope this can be increased. For example, let the doctor tell them face-to-face that this disease is treatable and it's fine. Give them more confidence… Don't be afraid of this thing [referring to HIV]. Often, it is not others who defeat him; he defeats himself. (P1)

> His [referring to the patient] attitude towards treatment is quite pessimistic… Actually, I hope you can say more encouraging things to him or help him cooperate with the treatment. Occasionally, he is not very cooperative, and sometimes when we speak, it's not as effective as when medical staff speak—he seems to trust the medical staff's authority more… If you have time, please encourage him more. (P2)

### Optimize the Healthcare Environment

Some family caregivers expressed a need for an optimal healthcare environment to enhance comfort and the hospitalization experience.

> I hope the hospital ward could be a bit larger, with fewer patients in one room… When you're trying to sleep, you suddenly realize how small the space is with so many people inside. It feels almost suffocatingly cramped… The hospital should provide good food and make sure the patient's dietary needs are taken care of as much as possible. (P1)

> With so many people in one ward, even in a collective dormitory, it would be noisy enough to keep people from sleeping… I feel the hospital should try to keep as quiet as possible. (P12)

### Provide HIV-Related Education

Participants emphasized the need for HIV-related education to provide accurate information to fill knowledge gaps and alleviate information anxiety among patients and their families.

> It would be better if you provided disease education to the patients… Publicize it more to the patients so that they know their illness situation. We are young people, but some are older; unlike us young people, they can't understand it through various channels. I hope you [referring to medical staff] increase this knowledge for them, [to improve] their understanding of the illness. (P12)

> Popularize the precautions for family members a bit more, especially for the parents. Tell them how to act in a way that is better for him. Let everyone know that this thing [referring to HIV] isn't something you get infected with just by being next to someone, or that it transmits through daily contact. (P16)

### Improve Medication Management

Family members expressed an urgent need to optimize medication management to improve treatment and health outcomes.

> The HIV patients in our ward all interrupted their treatment at some point, leading to drug resistance. Many felt a sense of self-abandonment—thinking that medication wouldn't extend their lives. I believe future efforts should focus on providing support in this area… to help them adhere to their medication and achieve long-term life maintenance. (P3)

> Are there any other treatment methods for HIV besides antiviral therapy? In the future, with the country's development, I hope there will be more efficient treatment methods. (P16)

### Facilitate Healthcare Accessibility

Participants' narratives underscored the urgent need to narrow regional disparities in medical resources to substantively advance healthcare accessibility.

> The biggest inconvenience is that many hospitals refuse to admit my dad. If he even has a minor cold, we have to send to your hospital. County hospitals might perform a CT scan, but they won't allow him to be hospitalized. (P2)

> Because there are no hemodialysis machines in our area—I am from Yongzhou—we have to go to Changsha or come here to Chenzhou. Nowhere else has this dialysis equipment; this place is a bit closer. (P5)

### Deliver Respectful and Non-Discriminatory Care

Participants stated respectful and non-discriminatory care is crucial for making patients feel safe and building trust in healthcare providers.

> It's just that before, at the hospital in our small county town, the service attitude of the doctors and nurses was not very good. Sometimes they would even ignore the patients.I also hope that the medical staff won't discriminate just because someone has this disease and won't look at patients with colored glasses. (P6)

> When hospitalized in Nanshan (a county hospital), he [referring to the patient] felt uneasy and insecure, but felt immediately at ease in Chenzhou (a specialized infectious disease hospital). The staff provided a warm, family-like atmosphere for patients and families, fostering mutual trust. (P9)

### Alleviate Treatment-Related Financial Burden

Participants highlighted the need to alleviate their financial burden, calling for expanding insurance coverage, stabilizing drug subsidy programs, and reducing regional disparities in reimbursement.

> It seems that there have been some changes to the national free medication policy; now some are free, and some are not. I still hope for continued state investment and greater reimbursement coverage. (P3)

> Medical examination and bed fees were not reimbursed, with coverage mainly limited to medication. Although our local reimbursement rate used to be 80%, it dropped to 56% in recent years. Since I am receiving treatment out-of-town (from Yongzhou to Chenzhou), the reimbursement rate is even lower and varies by location. (P5)

## Navigating Complex Perceptions of Death

Participants navigated cultural perceptions of death and expressed a desire for dignified departure of PLWHA.

### Exhibit Diverse Attitudes Towards Death

Some participants expressed a fatalistic acceptance of death, viewing it as a natural inevitability.

> If someone has this disease (referring to HIV infection), then it's better for them to pass away sooner to be reborn sooner. Now that he has this illness, we also feel no regrets if he goes this way. (P17)

> I think (the patient's) time of death is something to be accepted as it comes. As the saying goes, if fate decides your time is today, you can't postpone it until tomorrow. (P10)

### Express Anticipatory Bereavement and Concerns

Several participants expressed profound anticipatory grief, as well as concerns about social ridicule and loss of life's meaning if the patient were to pass away.

> I'm just afraid that he [the patient] will die; if he dies, I'll be all alone. In the countryside, I won't have anyone [to rely on], and I won't have any money… I just feel lonely, with no one to accompany me… and I'm afraid others will laugh at me; everyone else has a partner, but I won't anymore… If he goes [dies], I might as well die too. (P4)

> If (my mother) died of AIDS, I would still find it very hard to accept and would feel very distressed. It might not be accepted by the public, and I would also find it very hard to accept. (P12)

### Negotiate a Dignified End

Some participants described negotiating end-of-life arrangements and expressing a strong desire to ensure a dignified, less painful departure of PLWHA.

> This is unavoidable, right? If he ultimately doesn't pull through, he will have to go. It's better to let him go peacefully. When the time comes, according to our rural customs, if we sense he's about to die, we will take him back to the village. In the end, it's about being laid to rest in the earth—the place that gave your life and raised you. (P3)

> If he [referring to PLWHA] must pass away, I don't want him to suffer like that. For instance, if the doctor says there's truly no cure in further treatment, I will consider euthanasia—just to let him go swiftly, without so much pain and being hooked up to tubes everywhere, so he can leave with dignity. (P6)

## Discussion

This study revealed a complex dialectic between adversity and growth among family members of PLWHA during inpatient treatment in China. Family caregivers demonstrated psychological resilience and underwent positive transformation while providing care to PLWHA. The findings underscore the necessity for policies that integrate family-centered care programs, psychosocial support, and end-of-life care into healthcare delivery, contributing to the UNAIDS 95–95-95 targets.

Family members of PLWHA experienced positive transformation and growth despite the tremendous caregiving burdens and profound physical and psychological distress, consistent with prior research.[6] Some participants reported building psychological resilience to cope with emotional distress (eg, fear, guilt, shame, and suicidal ideation).[10,21] Resilience is defined as the capacity for positive adaptation in the face of adversity, manifesting as the ability to "bounce back" from trauma.[39] Multisystem resilience strategies for PLWHA and their families could include adaptively responding to HIV disclosure, improving access to community support, and enhancing awareness of legal protections.[40,41] Within the Chinese collectivism and familism sociocultural context, families constitute the primary caregivers for PLWHA.[42,43] Similar to the study of Tang et al,[44] participants reported a heightened sense of responsibility and undertook a range of caregiving activities, and these activities strengthened familial bonds—a process of "facing it together". The act of shared caregiving responsibility functions not only as a practical coping mechanism but also as a reaffirmation of family identity and relational continuity. Continuous support from families, neighbors, and collaborative engagement in care activities serves as a critical resource for caregivers managing caregiving burdens,[45] and protects them from role strain.[46] Family caregivers also expressed appreciation for institutionalized support. China's "Four Frees and One Care" policy[47] and HIV/AIDS Prevention and Control Plan (2024–2030)[48] provide institutional support for affected families, alleviate financial and psychological burdens, and achieve high treatment coverage and viral suppression.[49,50] However, the effectiveness of these policies at the grassroots level remains highly uneven, particularly in less-developed regions. At the individual level, participants actively improved their HIV/AIDS awareness and developed their caregiving capacities to

better fulfil their roles, similar to positive adaptations observed among caregivers of people with dementia.[51] Enhancing caregivers' HIV/AIDS knowledge and practical competencies may empower them to assume additional supportive roles (eg, health education and guidance), which could improve PLWHA treatment adherence and well-being. These findings highlight the importance of integrating resilience-focused HIV care[52] and family-based or home-based care (HBC) programs,[13] and establishing family care networks to sustainably support caregivers and optimize care outcomes for PLWHA.

The narratives of this study advocated for service improvements in terms of psychosocial and non-discriminatory care, HIV/AIDS management and education, and accessibility and financial support. Given the pervasive uncertainty, emotional distress[53] and even treatment abandonment or non-compliance in PLWHA,[54] participants noted the necessity of psychological support for patients. Previous research has demonstrated that community-based psychosocial support interventions can reduce disease-related stigma,[55] improve adherence and retention in ART care,[56] and enhance quality of life. Thus, it is essential to implement client-centered psychological interventions to address the specific psychosocial needs of this vulnerable group. Some participants complained about the noisy and crowded ward environment, limited food options, and lack of entertainment and relaxation facilities in hospitals, calling for an optimal healthcare environment. Notably, nutritional interventions significantly improve blood lipid profiles in PLWHA, potentially reducing mortality risk.[57] Previous research has documented similar concerns about interior color schemes, air quality, noise levels, temperature, humidity, seating comfort, and bathroom cleanliness in outpatient settings.[58] Sustainable physical space, sanitation, and appropriate infrastructure serve as fundamental prerequisites for healthcare facilities to deliver safe and high-quality care.[59,60]

Family caregivers also called on healthcare providers to disseminate knowledge regarding transmission routes and safety precautions, treatment progress, and to offer guidance on end-of-life care, consistent with the findings of Pham et al.[61] Given that caregivers' nutritional literacy and dietary support during daily care directly influence patients' nutritional status, blood lipid levels, and immune function, this underscores the critical need for nutritional education targeting both PLWHA and their families. However, current HIV education primarily focuses on HIV/AIDS pathogenesis, sexual health, and psychosocial support,[62] which may not fully address caregivers' diverse educational needs. Additionally, medication management for PLWHA is essential for enhancing their treatment adherence, continuity of care, and drug efficacy. However, PLWHA often hold misconceptions about medication (eg, believing that prayer can cure HIV[63] or relying on alternative herbal treatments),[64] and exhibit low ART adherence. Future initiatives should focus on novel therapies that reduce HIV-related chronic immune activation,[16,65] as well as community-based differentiated service delivery models[66] and digital interventions,[67] to improve adherence and clinical outcomes.

Regarding the equitable distribution of medical resources, family members advocated facilitating healthcare accessibility by narrowing regional disparities in medical resources and enhancing the capacity of primary-level hospitals to manage infectious diseases. Prior research has indicated that PLWHA residing in rural areas experience poorer outcomes across the HIV care continuum,[68] with limited access to HIV clinical care and providers.[69,70] There is an urgent need to allocate more ART medications to underserved regions and to increase the number of physicians specializing in HIV prevention and treatment.[71] Furthermore, telemedicine[72] and the integration of HIV care into primary health services[73] can enhance service utilization, effectively addressing gaps in HIV care among rural and high-risk populations. Given the persistence of HIV-related stigma even among healthcare providers,[74,75] participants expected healthcare institutions to deliver respectful and non-discriminatory care to PLWHA. Educational interventions like patient testimonials and peer education show great promise in reducing stigmatizing attitudes among healthcare providers.[76] Besides, economic hardship poses a significant challenge for caregivers of PLWHA,[77] hindering their ability to afford food and transportation to ART clinics, and leading to poor treatment adherence among care recipients.[61] Consistent with prior research,[78] family caregivers expressed the need to alleviate treatment-related financial burdens. Economic empowerment initiatives —like Zambia's Family Project[79] and Uganda's "Towards an AIDS Free Generation" programme[80]—may represent promising interventions for reducing caregivers' financial burden. Thus, family-centered interventions (eg, psychosocial support, HIV-specific education, accessible services, and financial assistance) are recommended to address caregivers' needs and improve the quality of care and treatment for PLWHA.

This study revealed that informal caregivers of PLWHA exhibit diverse attitudes towards death, ranging from rational acceptance to intense fear, with some developing emotional numbness. Michaels et al,[81] found that caregivers acknowledge imminent death and strive to maintain normal activities to honor final wishes and facilitate home deaths. Conversely, Leung et al,[82] observed that caregivers avoid acknowledgment of death, instead finding meaning through relational obligations and spiritual beliefs while sustaining shared activities. Healthcare providers' compassionate communication could help families feel emotionally prepared for the bereavement.[83] Similar to end-life perceptions of cancer patients' families,[84,85] participants expressed anticipatory grief and distress. The grief is associated with the impending loss of a loved one and contributed to emotional anxiety, and uncertainty about the future.[86] Several caregivers expressed a determination to "continue treatment at all costs", which articulated both a profound moral practice and an expression of love, representing the ultimate fulfillment of filial piety and family duties within Chinese society. However, this "at-all-costs" attitude can also impose overwhelming physical, psychological, and financial burdens on caregivers, which requires robust healthcare and social support (eg, medical costs and insurance coverage). Additionally, family members strived to negotiate a dignified end for PLWHA, hoping to ensure patients' comfortable departure and local burial arrangements, similar to the findings of previous research.[27] Distinct from funeral cultures in other countries, the funeral rites—including preparations for the wake, mourning attire, body preparation, encoffining, vigil-keeping, and burial or cremation—are essential components of traditional Chinese social culture. These traditional practices serve as expressions of filial duty, partly because of the belief in a continuing relationship between the living and the deceased. The wish for a "good death" extends beyond medical criteria (eg, pain control, symptom management) to encompass ritual completeness and the fulfillment of familial obligations to the deceased.[87] Formal advance care planning[88,89] is recommended to support PLWHA's physical symptom management and emotional well-being. However, the implementation of advance care planning in China faces unique cultural barriers, including a cultural atmosphere for avoiding discussions about death and the risk of violating social expectations and damaging social relationships.[90,91] Culturally appropriate adaptations—rather than transplanting Western advance care planning models, such as family-based advance care planning that formally incorporates caregiver perspectives and respects patient autonomy—represent a priority for future intervention development. Thus, healthcare systems should not only focus on clinical treatment but also establish culturally appropriate terminal care models to help PLWHA and their families navigate the end-of-life journey.

## Limitations

This study has several limitations. First, data were collected from a single geographic area (Chenzhou City, China), which may limit the transferability of findings to other socio-cultural or healthcare contexts. Second, the sample included family caregivers aged 22–74 years with diverse relationships to the care recipient and wide variation in HIV diagnosis duration, resulting in substantial heterogeneity in caregiving experiences. Future research should use stratified sampling by age, family role, and caregiving duration, and recruit multi-center samples to enhance the depth and transferability of insights. Third, the interview questions were generated from literature and clinical insights rather than a specific theoretical framework, which may limit the depth of theoretical interpretation. Future research should consider applying theoretical frameworks (eg, family systems theory) to guide data collection and analysis.

## Conclusions

Family caregivers of inpatients with HIV/AIDS experienced positive psychosocial transformation and growth amidst the adversity of providing care, including psychological resilience, caregiving responsibility, caregiving capital, and family bonds. These findings suggest that resilience-oriented interventions—such as peer support groups, coping skills workshops, and HIV education modules—can activate innate potential for growth, transforming adversity into strength. Beyond individual transformation, caregivers advocated for HIV-related service improvements, particularly in psychological support, HIV education and medication management, healthcare accessibility, respectful care, and financial relief. A service advocacy package including counseling services, an HIV education toolkit, community medication distribution, stigma-reduction training, and expanded insurance coverage is recommended to enhance HIV service quality. Caregivers also held complex end-of-life perceptions,

ranging from fatalistic acceptance to anticipatory grief and concern for dignified dying. This calls for integrating advance care planning and culturally appropriate death education into routine HIV care, helping both caregivers and PLWHA manage end-of-life issues. These findings demonstrate that a family caregiver support program requires a multi-level approach of family empowerment, community coordination, and policy support to optimize HIV care outcomes.

## Abbreviations

HIV, human immunodeficiency virus; AIDS, acquired immunodeficiency syndrome; PLWHA, people living with HIV/AIDS; SDI, lower socio-demographic index; ART, anti-retroviral therapy; HBC, home-based care.

## Data Sharing Statement

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

## Ethics Approval and Consent to Participate

This qualitative study was approved by the Ethics Committee of the Affiliated Hospital of Xiangnan University (#K2024-015-01). Prior to participation, written informed consent was obtained from all participants, including permission to publish anonymized responses and direct quotations. The study procedures were conducted in compliance with the Declaration of Helsinki and relevant local policies and regulations.

## Acknowledgments

We thank the Ethics Committee of the Affiliated Hospital of Xiangnan University for granting approval, and extend our sincere appreciation to all participating family members of PLWHA for sharing their lived caregiving experiences.

## Funding

This study was supported by the Hunan Province College Student Innovation Training Program (Grant # Xiangjiaotong [2024] 191-4843).

## Disclosure

The authors report no competing interests in this work.

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