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Exploring palliative care needs of advanced AIDS patients in China: insights from a descriptive phenomenological study

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Abstract

Background HIV is still an incurable disease, causing many problems in the daily lives of patients and affecting their overall quality of life. Previous studies have shown that advanced AIDS patients have more serious physical, psychological, social, and economic problems than HIV patients and that advanced AIDS patients have more unmet needs at this time. The main objective of this study is to better understand the needs of late-stage AIDS patients and to develop targeted palliative care services for them.

Method Descriptive phenomenological methods were used. Advanced AIDS patients were selected using purposive sampling in a tertiary infectious disease hospital. Participants ($n = 15$) were interviewed in one-to-one semi-structured interviews between March and May 2024. Data saturation was reached after the 15th interview, as no new themes emerged. A phenomenological thematic analysis method was used to analyze the interviews.

Results The following four themes emerged and are reported in this study: (1) Physiological needs: Participants often reported that chronic pain and fatigue were the main concerns and needed help from daily activities. (2) Information needs: Patients emphasized the gap in understanding treatment plans and drugs, hoping to get clear guidance from medical service providers. (3) Psycho-spiritual needs: Participants expressed their desire for respect, friendship, and dignity, as well as their fear of future uncertainty and humiliating experiences. (4) Social support needs: economic burden, limited nursing continuity, and social discrimination are the outstanding challenges faced by participants.

Conclusion This is the first study to comprehensively examine the palliative care needs of advanced AIDS patients in China. The findings underscore the urgent need for culturally sensitive, policy-driven interventions to address these multifaceted needs. Tailored strategies can significantly enhance the quality of life for this vulnerable population and provide actionable insights for healthcare policymakers to bridge existing care gaps.

Keywords Palliative care, HIV, China, Unmet needs, Qualitative study

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Background

Human Immunodeficiency Virus (HIV) and Acquired Immunodeficiency Syndrome (AIDS) remain a threatening epidemic that affects many lives, and according to the Lancet Commission on Palliative Care and Pain Relief, HIV is ranked as the disease most in need of palliative care in China, apart from cancer [1]. The World Health Organization (WHO) and The Joint United Nations Programme on HIV/AIDS (UNAIDS) have also emphasized the importance of palliative care for people living with HIV/AIDS (PLWHA), particularly during the advanced stages of HIV [2–3]. Advanced AIDS patients are defined by the WHO as having a CD4 cell count of less than 200 cells/mm3 and/or stage III or IV disease for children older than 5 years old and adults, characterized by severe immunosuppression, recurrent opportunistic infections, and a high dependency on medical and supportive care [4–5]. This stage often results in significant physical suffering, psychological distress, and complex social challenges, necessitating a comprehensive, patient-centered approach to care [6–7]. Evidence suggests that palliative care can improve the quality of life for PLWHA by addressing pain, psychological issues, and social needs, thereby alleviating the burden on the healthcare system [8]. However, globally, the accessibility of palliative care services remains limited, with only 12% of the demand being met. Significant disparities exist in access to palliative care services, with 64% of countries having limited or no palliative care services, and approximately 75% of unmet adult palliative care needs occurring in low- and middle-income countries [9–10].

In China, AIDS remains a significant public health challenge [11]. By the end of 2023, an estimated 1,289,700 people were living with HIV/AIDS (PLWHA) in China, and 457,609 people had died of AIDS, of which 570,236 were AIDS patients [12]. In recent years, despite the implementation of various government policies to combat the epidemic and improve healthcare services, including the “Four Free and One Care” policy - free antiretroviral treatment, free AIDS screening, free treatment for HIV-infected pregnant women, and care for orphaned and disabled children [13], as well as China’s Plan for Containing and Preventing AIDS (2024–2030) [14]; it is evident that China has made more significant progress in antiretroviral treatment. In addition, China has made progress in palliative care policy, education, drug supply, and service delivery in recent years [15]. For example, since the introduction of the PLWHA palliative care approach in China in 2013 [16], the National Health Commission has issued a number of guidelines, such as the 2017 Code of Practice for the Management of Palliative Care Centers and the 2018 Guidelines on Promoting the Reform and Development of Nursing Care Services, which have laid the foundation for the integration of palliative care into the national healthcare system [17–18]. These relevant policies reflect the growing recognition of palliative care as an important component of the Healthy China 2030 strategy, as well as the emphasis on whole-life health services, including end-of-life care [19]. However, despite these advances, there is still a need for further in-depth explorations in the area of hospice care for people living with HIV.

In the context of Chinese culture, AIDS patients face multiple barriers to accessing hospice care [20]. First, traditional filial piety and death taboos in China make family members prefer active treatment and neglect the patient’s hospice needs to avoid being perceived as “unfilial” [21–22]; second, the stigmatization of HIV and intra-family decision-making disagreements may further impede the patient’s access to timely and appropriate care [23]; stigma not only affects the patient’s psychological condition but may also reduce the acceptance of AIDS patients in some healthcare institutions [24–25]. In addition, there is still room for improvement in the level of policy support and social support systems in the hospice system, and the distribution of healthcare resources between urban and rural areas in China still varies greatly [26]. For example, in rural areas, the lack of infrastructure and shortage of professionally trained healthcare providers may affect the accessibility of comprehensive healthcare services for patients in certain areas, limiting the opportunities for patients to receive palliative care [27]. Finally, high financial burdens may also further limit patients’ difficulties in accessing hospice care [28]. Together, these issues contribute to the unmet needs for palliative care and psycho-social support among advanced AIDS patients.

To the best of our knowledge, there have been no published qualitative studies on the palliative care needs of advanced AIDS patients in China, particularly considering the influence of sociocultural factors. Existing research primarily focuses on quantitative data or general palliative care strategies, often neglecting in-depth exploration of the specific needs and experiences of patients, especially those in the advanced stages of AIDS [29–30]. Unlike quantitative research, qualitative research methods offer a unique perspective, allowing for a deeper understanding of individual life experiences and the sociocultural factors that influence care needs [31]. This approach is crucial for understanding patients’ specific viewpoints, addressing complex issues such as cultural barriers, and developing effective, individualized palliative care strategies. Therefore, this study aims to fill this gap by using qualitative research to explore the palliative care needs of adult patients with advanced AIDS in China, with a particular focus on their physical, psychological, and social support needs, to provide valuable insights for improving the accessibility and quality of palliative care for this vulnerable population.

Methods

Study design

This study involved a descriptive phenomenological approach using in-depth, semi-structured, face-to-face interviews conducted from March to May 2024. The Standards for Reporting Qualitative Research guided this study [32].

Setting

The study was conducted at the Public Health Clinical Center of Chengdu, Chengdu, Sichuan, China, which is the only national Grade 3 A infectious disease specialist hospital in Chengdu, and is a non-profit medical institution integrating medicine, teaching, research, and training. It can receive thousands of HIV/AIDS patients each year, and the hospital's care center follows up and manages nearly 6,000 HIV/AIDS patients, which ensures an adequate sample size.

Participant recruitment

In this study, purposive sampling was used to identify participants and to obtain maximum variation in the designed sample. This sampling strategy helped to select participants who were knowledgeable about the study topic and could provide detailed information on key information in a specific setting. The participants were recruited by health professionals at a tertiary care infectious disease hospital in China. The participants were briefed on the content and objectives of the study by health professionals who had direct contact with them. Subsequently, after signing a written informed consent form, the research team contacted participants directly by email or telephone to confirm the interview. A total of 22 potential participants were contacted during the study, of whom three declined to participate because they did not wish to discuss their situation and two opted out halfway through the interview because they felt it was too long. A total of 17 participants were eventually interviewed, However, theoretical saturation was reached after the 15th interview, as no new codes or themes emerged in the subsequent two interviews [33], and therefore 15 participants were eventually included. Variables selected for the participants included: stage of disease (advanced), place of residence (rural, urban), age (<50 or >50 years), gender, time of HIV diagnosis, marital status, and education level. Figure 1 shows the flowchart of the study's recruitment of advanced AIDS patients.

The final sample consisted of 15 participants: 7 with advanced AIDS diagnosed ≤ 1 year ago and 8 with advanced AIDS diagnosed >1 year ago. A total of 15 semi-structured in-depth interviews were conducted by the researchers. By including patients of different ages, places of residence, occupations, marital statuses, and sexual orientations, different narratives could be explored through the different perspectives, needs, and connections gathered. Table 2 shows the socio-demographic characteristics of these participants.

Inclusion criteria

The study population consisted of patients with a diagnosis of advanced AIDS who were well-informed about their condition and had no cognitive impairment. Mentally incompetent patients who have not been informed of their condition, minors under 18 years of age, and seriously ill patients are excluded from the study.

Data collection

Semi-structured face-to-face interviews were conducted in a private room at the hospital by two professionals with experience in qualitative research in healthcare and palliative care, ZY and ZX, who had no prior contact with the interviewees to avoid bias in the data collection process. In addition, two interviewers received specialized training to ensure consistency and reduce potential bias. The training included qualitative research methods, effective communication skills, and ethical considerations when interacting with people living with HIV. The interviews were conducted at a time of the participants' choosing lasted an average of 45 min, and were audio-recorded with the consent of the interviewees, subsequently transcribed verbatim and anonymized in full, in addition to the verbal consent of the researcher conducting the interviews, which was obtained from the participants before the interviews. They were also allowed to ask questions and address concerns before the interview began. The researcher did not offer any payment in exchange for participation in the study. Before the commencement of the formal interview, ZY and ZX introduced themselves briefly to the interviewer to establish rapport with the participant and to clarify the purpose, significance, and methodology of the study. The participants were informed of their right to withdraw from the study at any stage.

The interview scripts were based on relevant literature [34–36], as well as being designed by HIV specialists and a nursing team with extensive experience in palliative care. A pilot version was first developed and subsequently pretested with three participants, with adjustments made to assess the appropriateness and comprehension of the questions based on respondents' circumstances and characteristics. Feedback from the pilot test led to minor refinements in wording and sequence of questions, ensuring the guide was clear and effective for data collection. (These changes included simplifying technical terms and reordering questions to create a more logical

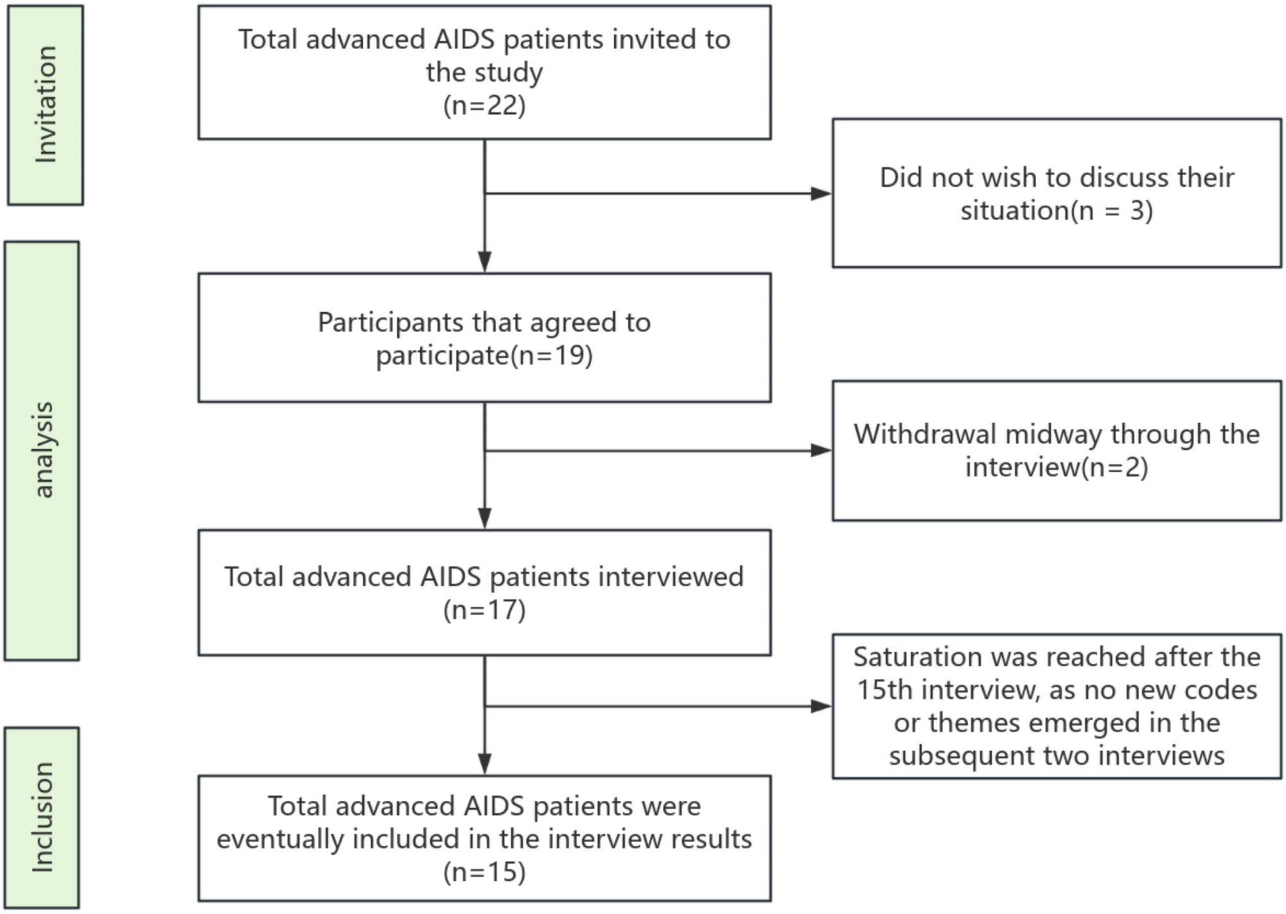

Fig. 1 Flowchart of advanced AIDS patients recruitment to the study

Table 1 Semi-structured interview questions

No	Interview questions
1	How have your sleeping and eating habits changed since you became ill? How have these changes affected you?
2	How do you feel after the recent treatment (observe the patient's demeanor and tone of voice)? Do you still feel unwell?
3	How do you think the disease has affected you (physically, psychologically, spiritually, in terms of family, social interaction, and economically)? How do you feel about this change?
4	What kind of help or support have you received since the illness? (physical, mental, spiritual, family, social interaction, economic, etc.)
5	Who have you told about your illness in your social interactions? How do you think they feel about your illness?
6	At this stage, what support do you need to improve your quality of life or to fulfill your aspirations so that you can better achieve these goals?
7	What other problems or needs do you currently face? What support would you expect to receive if you were in the later stages of your illness?

flow.) The main topics discussed were (1) the experience of being ill in the late stages of the disease; (2) difficulties encountered and needs identified in the late stages of the disease, including both met and unmet needs; and (3) requirements and recommendations for addressing these needs at the professional and institutional levels. Table 1 lists the final scripted questions. Data collection continued until information saturation occurred and no new themes or information emerged from the interviews.

Data analysis

Data collection and analysis took place simultaneously. All interviews were audio-recorded, and transcribed, and the responses to each question were subsequently compiled into a Word document. The data from the compiled word document was analyzed based on Colaizz's methodology [37]. The research team imported the transcribed text into NVivo12 (QSR International) and then read the text data in detail and discussed some of the transcripts, extracting and coding statements relevant to the research questions. The coding was done independently by two members of the research team (ZY and ZX), who then compared the codes for consistency until a consensus was reached on whether to merge some codes, delete others, or propose new codes. The research team interpreted the findings according to the thematic areas and subsequently, significant utterances were given meaning and categorized into themes. For example, quotes such as “I feel isolated and judged” were categorized under “psycho-spiritual needs.” The findings were then consolidated into a detailed description of palliative care needs, supported by illustrative extracts from the interviews. The extracts were attributed to the participants using numbering and age. The exhaustive descriptions were also validated by seeking feedback from participants, the participants reviewed summarized findings to ensure both accuracy and credibility. To ensure credibility, the rigor of the analysis of results was assured through a rigorous peer review process as the team met regularly to discuss and refine the analysis to confirm the consistency of findings and to identify and reduce potential bias. All researchers agreed on the results of the coding process and the main categories generated. The study followed the Consolidated Standards for Reporting Qualitative Research (COREQ) [38].

Ethical considerations

The study was approved by the Ethics Committee of the Public Health Clinical Center of Chengdu (Ethics Approval No. YJ-K2024-03-01). The study was conducted in accordance with the principles of the Declaration of Helsinki and followed relevant guidelines and regulations. Informed consent was obtained from all participants before they participated in this study. To protect the rights of this vulnerable population, participants were fully briefed on the purpose of the study and were assured that they were able to refuse to answer any questions and withdraw from the study at any time before the time of data analysis. The principles of anonymity and confidentiality were strictly adhered to throughout the study.

Table 2 Sociodemographic characteristics of advanced AIDS patients (*N* = 15)

Characteristics	Categories	Number of participants (*N* = 15)
Age	≤ 50	5
	>50	10
Gender	Female	5
	Male	10
Race	Han ethnic group	13
	Other nationalities	2
Marital status	Married	6
	Widowed	3
	Divorced	5
Education	Junior high school and below	9
	High school and above	6
sexual orientation	Gay	1
	Heterosexual	14
Residence/location	Urban	6
	Rural	9
Duration of HIV diagnosis	<10 years	9
	≥ 10 years	6

Results

Patients’ demographic characteristics

Between March and May 2024, A total of 22 potential participants were contacted between March and May 2024, and a total of 17 participants were eventually interviewed, reaching saturation after the 15th interview, 15 advanced AIDS patients were finally included in this study as no new codes or themes emerged in the two subsequent interviews. To protect patient privacy, patients were assigned numerical codes in the order of their participation in the study, with the letter N preceding the numerical code, and the patients numbered N1, N2, N3……N12, and N15. The study participants’ place of residence was from rural and urban areas, 10 (66.67%) patients The study participants were from rural and urban areas, 10 (66.67%) patients were aged > 50 years, 10 (66.67%) were males, 2 patients were religiously affiliated, 6 (40%) patients were married, only one patient was homosexual, 6 (40%) were highly educated and 6 (40%) were aware of their HIV serostatus for at least 10 years. Table 2 shows the demographic information of the study participants.

In this section, four themes emerged from the interviews and were discussed with the support of direct quotes from patients. This study found that the palliative care needs of advanced AIDS patients were not adequately met, as evidenced by (1) Physiological needs (Relief of multiple physical symptoms, need for self-care); (2) Informational needs (Knowledge and guidance on HIV treatment, Drug-related information, Participation in communication and medical decision-making, Choosing a palliative care place); (3) Psycho-spiritual needs (Desire for respect and companionship, Preservation of dignity and reduction of discrimination, guilt and ambivalence towards family, worries and fears for the future); (4) Social support needs (Social interaction, financial support, continuity of care needs) Table 3 describes the themes and sub-themes that emerged from the study.

Theme 1 Physiological necessity

Subtheme: Relief of multiple physical symptoms The majority of advanced AIDS patients repeatedly mentioned in interviews the persistence of symptomatic distress, including AIDS-related symptoms and adverse reactions caused by medication, especially insomnia, pain, and fatigue, which affected their daily lives; symptoms such as coughing and recurring fevers further aggravated physical discomfort. Although some of the symptoms were partially relieved by treatment during hospitalization, the overall situation has not completely improved and con-

Table 3 Themes and subthemes for palliative care of advanced AIDS patients

Themes	Subthemes
Physiological needs	Relief of multiple physical symptoms
	Need for self-care;
Informational needs	Knowledge and guidance on HIV treatment,
	Drug-related information
	Participation in communication and medical decision-making
	Choosing a palliative care place
Psycho-spiritual needs	The desire for respect and companionship
	Preservation of dignity and reduction of discrimination
	Guilt and ambivalence towards family
	Worries and fears for the future
Social support needs	Social interaction
	Financial support
	Continuity of care needs

tinues to have a serious impact on the quality of life of the patients.

"The kidneys on both sides of my lower back hurt excruciatingly (rubbing the area). The pain is constant and recurring, making it impossible to sleep, even with painkillers. It's so irritating and offers no relief." (N6, male, age 75, urban).

"I have no strength in my body, no strength, no strength at all, no strength at all, what should I do? (crying quietly)" (N11, male, age 55, urban).

Subtheme: Need for self-care Many patients gradually lost their ability to care for themselves due to the deterioration of their illness and expressed a strong need for assistance with daily activities during the interviews, mainly in terms of control over their movements and independence in life. However, due to the impact of the disease, many patients often had limited mobility were often dependent on the help of others, and were unable to take full control of their lives. However, age-related differences were also evident, with participants over the age of 50 expressing greater concern about mobility and loss of independence.

"Being here for a long time in the future for dialysis is cumbersome for one person to be admitted to the hospital because of problems with vision due to age and not being good at operating the process of treatment or payment." (N2, male, age 57, urban).

"I got this disease at a young age and I have parents and children to support, every day I just lie in the hospital, I'm weak, I can't do anything, I can't go to work, I don't know what to do, I want to earn money to support my family." (N13, female, age 29, urban).

Theme 2: Information needs

Subtheme: Knowledge and guidance on HIV treatment Advanced AIDS patients generally lacked sufficient knowledge related to disease treatment in the face of a complex condition. They wanted more timely and detailed information on the progress and effectiveness of disease treatment, treatment options, next steps, and prognosis. For more guidance, especially in coping with and managing common symptoms. Some patients mentioned that they could only obtain information on their own through the Internet or other sources, but the accuracy and applicability of this information could not be guaranteed.

"My idea is the first one is to add a little bit of family promotion on family HIV prevention and control so that no one thinks that if a family lives together they will be infected, and the second question is what is the bridging program for the medication taking process for retired, off-site patients like us." (N2, male, age 57, urban).

"I noticed red bumps a year ago and thought it was a skin disease, but it worsened. After searching online, I suspected AIDS. A home test kit confirmed my fears, and the hospital diagnosis felt like my world collapsed." (N14, female, age 44, rural).

Subtheme: Drug-related information Patients generally report difficulties in obtaining disease-related information, and they want to know more about how medications are used, potential side effects, and their relationship to symptom management. However, serious problems such as information asymmetry arise due to insufficient communication between doctors and patients and the often overly specialized information provided, resulting in patients' difficulty in understanding and often feeling confused and anxious.

"When I asked the doctor about the medicine, he explained, but I couldn't understand. I just trusted the prescription and took it without knowing what it was for (shaking hands)?" (N3, male, age 39, rural).

"Yes, I still want to know about my disease, some of its treatment options and medication and so some (knowledge), and my treatment of other diseases need to eat the medicine there is no influence and conflict, what are the side effects? What's it all like?" (N4, male, age 84, rural).

Subtheme: Participation in communication and medical decision-making In addition to treatment progress, patients also wanted to know the future direction of their condition, aspired to have more autonomy in disease management and treatment, and hoped that doctors and nurses could communicate with them about their condition, rather than just passively accepting treatment options, and they hoped that doctors would listen to them and respect their choices.

"The doctors seem to be pretending like they don't know. I've had lab tests so many times, and I've told the doctor that my skin was itchy, but nobody cared. I kept saying it, and it seemed to annoy them, so now I don't dare to mention it anymore." (N2, male, age 57, urban).

"When the doctor checks on me every morning, they talk among themselves and don't explain anything to me. After they leave, I still don't know my current condition. I wish they would communicate properly, ask questions, and help me understand what's happening. It would give me peace of mind." (N13, female, age 29, urban).

Subtheme: Choosing a palliative care place Patients demonstrated a strong need when it came to choosing a suitable place of care, however, many patients reported a lack of comprehensive information about the different places of care, including information on the treatment options available, the type of services provided, the healthcare-related costs and the quality of care, as well as various limitations and barriers to accessing them, which resulted in patients often struggling to make an appropriate choice.

"I didn't know which hospital to go to receive appropriate treatment care; no one gave me clear guidance. I had to rely on internet searches, which only added to my anxiety." (N3, male, age 39, rural).

"The community hospital transferred me but they did not explain why, only that they did not want me to stay in the hospital anymore; I felt abandoned and lost." (N10, female, age 58, rural).

In addition, geographic and socio-economic factors played an important role in decision-making. For example, the challenge is more acute for patients in rural areas. Limited healthcare facilities and the cost of traveling add to their burden. Patients from rural areas tend to spend more time and money and have limited options, while those living in cities cite concerns about overcrowding in hospitals and difficulty in staying there.

"It's not just about finding the right place, it's about how far I have to travel and whether I can afford to go there." (N12, female, age 56, rural).

"The city hospital is better equipped but it is always full, I have to queue for a long time every time to be admitted and I don't know if they will be able to admit me in time." (N2, male, age 57, urban).

Theme 3: Psycho-spiritual needs

Subtheme: Desire for respect and companionship AIDS patients, especially those in the terminal stage of the disease, face great psychological pressure and loneliness. They longed for more love and companionship from family, friends, and healthcare professionals. Many patients mentioned that they felt socially isolated and lacked emotional support due to the specificity of the disease. However, it is worth noting that female participants emphasize social stigma and discrimination more frequently than male participants, and hope to be understood and accompanied by their families.

"Because of my condition, my parents don't understand me and feel ashamed of this disease, I am afraid to get close to my children and some hospitals treat me differently…" (N14, female, age 44, rural).

Compared to the female participants, the male participants were more inclined to discuss their concerns about their jobs as well as financial instability.

"I am under a lot of stress because of this disease, I am afraid of losing my job if my colleagues and bosses in the company find out, and my wife has divorced me." (N15, male, age 47, rural).

Subtheme: Preservation of dignity and reduction of discrimination Patients not only had to endure physical pain but also faced prejudice and discrimination from society. Many patients mentioned in the interviews that they felt different levels of discrimination during the medical process, and even in some public places, they encountered unfair treatment because of their condition.

"Going to another department for a checkup is still inconvenient; people know you have this disease and look at you strangely, almost like you're contagious. I hope the community understands us better, as we don't have any bad intentions!" (N8, male, age 52, rural).

Subtheme: Guilt and ambivalence toward family For advanced AIDS patients, family relationships are often an important pillar in their journey through the disease. However, due to the long duration of the disease, many patients feel a deep sense of guilt towards their family members. They believe that they are not only a financial burden to their families, but also put their families under tremendous emotional stress. Patients' attitudes towards treatment are often full of contradictions. On the one hand, they want to continue to adhere to the treatment, on the other hand, they worry about becoming a burden to their family.

"If there was a special help center, it would relieve my family's burden so that I could also receive treatment with peace of mind. My mother is old and has to worry about me. I am so sorry for them (cover up the face and cry)." (N14, female, age 44, rural).

Subtheme: Worries and fears about the future In the face of the irreversibility of the disease and the limited nature of treatment, the interviewed patients were filled with uncertainty and a sense of helplessness about the future effects of treatment and the outcome. This sentiment was strongly echoed in the interviews. Many patients expressed anxiety about their future survival, and patients were often skeptical about future treatments, especially if multiple treatments failed to bring about significant improvement, and they may develop a loss of confidence in treatment.

"I still have a child to support, and my parents depend on me. I feel helpless about the future. I hope to be cured, but after researching online, I know that there is no cure. This illness will follow me until I die (crying)." (N14, female, age 44, rural).

Theme 4: Social support needs

Subtheme: Social interaction Patients generally expressed the need for normal social interactions, especially in the face of illness and loneliness, and the desire to establish normal interactions and connections with family and friends, other patients, and the community. However, due to the special nature of AIDS, patients often suffered from social discrimination and rejection, coupled with the fact that many of them often suffered from deteriorating conditions, which led to great restrictions on social activities, and they hoped to receive understanding and support from society.

"Sometimes talking with other patients helps ease the heart, but we dare not share too much due to privacy concerns. Everyone is afraid of others spreading rumors, and I do not want to discuss my illness with others." (N1, female, age 56, rural).

"It's just me, you know it's a bit inconvenient for us to talk and communicate all this in the first place, and there's no one to communicate with..." (N15, male, age 47, rural).

Subtheme: Financial support Financial stress is a significant issue for advanced AIDS patients. Many patients often reported that the high cost of treatment and daily living expenses were overwhelming that expectations for treatment and recovery from the disease were often limited by their financial situation, and that lack of financial support prevented effective treatment, so many patients mentioned the need for more financial support.

"Can the medical fees be further reduced a little bit for special people like us, you see we would have had this humiliating disease, and it's not good to borrow money, not good to tell our relatives. Seriously, it would be better if there could be some financial help to ease the burden on the family." (N6, male, age 75, urban).

"If we can provide help, we hope that the medical fees can be reduced a little bit, you see we are all rural people, we don't have any money, and we still want the hospitalization fees to be lower." (N10, male, age 58, rural).

Subtheme: Continuity of care needs Patients want continuity of care after the disease has reached its terminal stage. However, existing continuity of care resources are insufficient, such as bed constraints and inter-regional transfers, leaving patients with a severe care gap after discharge. This care disconnect leads to significant uncertainty and safety risks for patients after discharge, and they would like more support to ensure timely care in the event of a change in their condition.

"My family and friends abroad told me that in foreign countries when a patient is hospitalized, family members are not allowed to enter for care. The hospital provides comprehensive care for the patient until discharge and even offers psychological counseling to the family after the patient passes away. But it's not like that here. We need holistic care like they have abroad." (N2, male, age 57, urban).

"To be honest, after discharge, it's inconvenient to return. Hospitals often require advance bed reservations, and transferring to other hospitals is complicated. Smaller hospitals often say they don't have the necessary medicine or can't provide treatment, making it very inconvenient." (N10, male, age 58, rural).

Discussion

Given the unique nature of the disease in the AIDS population and the complexity of assisting them during this difficult period of advanced disease, research on this particular period has been limited [39]. The purpose of this study was to explore the palliative care needs of advanced AIDS patients, and its novelty is that this is the first qualitative study of palliative care needs for advanced AIDS patients in China, which provides qualitative information about the unmet palliative care needs of these individuals in the later stages of the disease, helping to guide the further development of AIDS palliative care, selecting individualized palliative care services that are appropriate for advanced AIDS patients, and enhancing the quality of clinical care.

Based on the needs expressed by advanced AIDS patients, our findings suggest that patients may have a large number of unmet needs in the advanced stages of the disease. The complexity and severity of the challenges they face during this period of AIDS result in a large number of needs, including physical needs, psychological and spiritual support needs, social support needs, and other needs. While the needs of advanced AIDS patients are diverse, they are also, on the whole, significant in number. While our purely qualitative study does not allow for precise comparisons with other countries, these findings are generally consistent with quantitative studies of people living with HIV/AIDS in China and selected other countries [34, 35]. For example, the persistence of symptoms such as pain, fatigue, and insomnia is consistent with findings from Kenya and Uganda, where physical discomfort was a major symptomatic problem noted by patients [40]. However, the present study emphasized some unique patterns compared to studies in other countries. For example, compared to studies conducted in Rwanda and Vietnam [41–42], Chinese patients in the present study reported higher unmet information needs, particularly needs such as information about treatment options, medication side effects, and future care plans, whereas the first two studies emphasized issues such as financial barriers. These differences emphasize the importance of tailoring palliative care strategies to the unique cultural, institutional, and socioeconomic contexts of each country.

This study outlines one of the major physical needs of advanced AIDS patients. These include the need for relief of multiple physical symptoms and assistance with self-care. Respondents in this study also indicated that ‘relief of multiple somatic symptoms’ was the most important palliative care need in their opinion, and was also a basic need to ensure the safety of the patient’s life. Lofgren, Jameson, et al. [43–44]. showed that control of somatic symptoms was the most important palliative care need for patients entering the advanced stages of AIDS. Patients often face a variety of somatic symptoms when they enter the advanced AIDS stage, with pain, fatigue, and insomnia being the most predominant distressing problems for patients, previous research quantitative studies have shown that approximately 54–83% of patients have pain, 20–60% experience chronic fatigue, and 46–73% have insomnia [8, 45] and that insufficient control of these types of symptoms may lead to a significant reduction in patients’ quality of life and increased need for palliative care. In addition, similar to the findings of Ibrahim et al. [46], patients’ desire for self-care capacity is particularly prominent, especially in the advanced stages of the disease, accompanied by a gradual loss of self-care capacity, which may further exacerbate patients’ mental stress and affect their quality of life.

Consistent with research conducted in other countries [35], the subjects in this study described a desire for information about their illness, with patients expressing a need for more knowledge and guidance about their illness treatment, information about the medications they were taking, a desire for good communication with healthcare workers, and assistance in choosing an appropriate place of care. Many patients felt unclear about information related to their illness and wanted to know more about their diagnosis, prognosis, and treatment, and previous studies have also shown that providing patients with timely and accurate knowledge and guidance about medical information can help to alleviate their anxiety, especially during repeated hospitalizations and treatment of their illness [34]. In addition, patients have a strong desire for knowledge about the medications they are taking during treatment, and Pham et al. [41] have argued that this knowledge includes not only how the medications are used, possible side effects, and their management strategies, but also how to effectively alleviate disease-related symptoms such as pain, fatigue, and mental disorders. Secondly, participation in medical decision-making is also crucial for the psychological comfort of patients. WHO recommends standard palliative care training for all doctors, one of which includes information sharing [47]. Good medical communication can help patients better understand their diagnosis and prognosis information, express their needs and expectations, and improve the relevance and effectiveness of treatment [41]. At the same time, patients’ sense of participation in the healthcare decision-making process can enhance their sense of trust, thereby alleviating anxiety due to the unknown [48]. Finally, many patients report a lack of knowledge about the choice of healthcare services and places of care, which directly affects their ability to carry out follow-up treatment, especially in the advanced stage of AIDS, where patients face multiple and complex healthcare needs, such as specialized pain management, psycho-social support, and comprehensive care services [49]; however, a lack of awareness of available healthcare resources leaves patients confused and helpless in choosing the right services.

Similar to the findings of other studies, our study also found that HIV patients often face Psycho-spiritual problems, which not only lead to complex and diverse psychological needs but may also have a profound impact on treatment adherence and quality of life [42, 50]. The stigma and discrimination associated with the disease often cause patients to experience emotions such as loneliness, and they crave respect from the outside world and the companionship of others to reduce their sense of isolation [51]. Despite serious health challenges, patients in the late stages of the disease still desire to be seen as dignified individuals rather than carriers of the disease, and they hope to reduce discrimination from society, maintain their dignity, and have normal life interactions [52]. Second, advanced AIDS patients often fear that the stigma associated with the disease affects their family members, and they feel guilty and ambivalent about their families, a complex emotion that exacerbates their psychological suffering [53–54]. Finally, many patients feel great anxiety about the unknown effects of treatment, fearing further deterioration of the disease or threats to their survival, making them psychologically stressed [55]. The deterioration of this psychological state affects patients’ quality of life and reduces their desire for treatment. Therefore, the psychological support and companionship of nursing staff are particularly important, especially through psychological counseling and humanistic care, which can help patients alleviate their fear and loneliness and enhance their psychological comfort [56].

In addition, this study found that the need for social support is also one of the palliative care needs of advanced AIDS patients. Study participants described a desire to have normal social interactions, reflecting that they often experienced discrimination in their daily lives from people around them in hospitals, workplaces, and housing. Data show that the overall prevalence of stigmatization is as high as 43.5–88.0%, and discrimination and stigmatization can have a serious negative impact on both the treatment and the psychology of patients [57–58]. In the context of Chinese culture, traditional concepts and social stigmatization have a profound impact on the acceptance of hospice care by AIDS patients [20]. Traditional filial piety concepts emphasize all-out efforts to save the lives of elders, which may result in family members being more inclined to opt for aggressive treatment and ignore the need for hospice care [21]; in addition, death is considered a taboo topic in traditional culture, and patients and family members tend to avoid discussing end-of-life needs, which makes it more difficult for patients with AIDS to accept hospice care when confronted with it [22]. Second, the stigma and shame associated with the disease put patients under psychological pressure when facing hospice care. They are afraid of being labeled as having "AIDS" by outsiders and do not dare to actively seek medical help, choosing to hide their illnesses or avoiding routine medical checkups instead [59]. For example, a previous study on the generalized impact of stigma on healthcare participation in low- and middle-income countries showed that they avoided routine healthcare visits for fear of social judgment [19]. At the social level, stigmatization may affect the service attitudes of some healthcare providers and healthcare workers, and some healthcare workers may hold negative attitudes towards patients or even refuse to provide them with quality healthcare due to fear of AIDS or moral bias [60]. Studies have shown that AIDS patients have experienced unequal treatment in healthcare facilities, such as cold treatment, unfair allocation of healthcare resources, or denial of admission to hospitals [61]. These behaviors not only make patients feel ostracized but also cause them to lose trust in the healthcare system, further reducing the likelihood that they will participate in hospice care. Therefore, addressing these cultural barriers requires multilevel strategies, including community involvement and implementation of relevant policies. For example, relevant education and mobilization should be carried out to cultivate a correct public perception of HIV and reduce misconceptions and discrimination against HIV-positive people; in addition, the dissemination of anti-discrimination and anti-stigma laws should be strengthened and their implementation in healthcare facilities should be ensured to improve the attitudes of healthcare workers and create a favorable environment for HIV-positive people [62].

Finally, the interviewees in this study indicated that illnesses often cause serious financial burdens, and previous studies have also pointed out that patients in poor health have to face more financial problems, and these patients are often forced to give up treatment due to financial difficulties [63]. Despite improvements in health insurance systems, the financial burden of illness still exists [64]. Diseases make patients lose their jobs, they cannot get enough money to pay for their treatment, and even individual patients living in rural areas or low-income families cannot even solve the problem of normal nutrition and are eager to get financial support [65]. Continuity of care plays an integral role in the treatment and care of advanced AIDS patients. Continuity of care involves the coordination of healthcare services both inside and outside the hospital, ensuring consistency and continuity of care across different locations and stages of treatment [66]. For patients with advanced disease, good continuity of care not only helps them maintain effective disease management but also enhances their confidence in their future lives [67]. However, in rural and resource-poor areas of China, the relatively weak healthcare conditions and uneven distribution of healthcare resources in rural areas often limit patients' access to continuity of care [68]. Studies have shown that patients who lack continuity of care often face increased medical risks and psychological distress [69]. WHO states that social support should be provided as needed, including food parcels, cash payments for rent or children's school fees, transport to health services, in-kind support, and funeral expenses [70–71]. Therefore, policymakers should prioritize funding for rural areas by allocating targeted resources to improve healthcare infrastructure such as rural hospices, mobile health units, and telemedicine services to reduce urban-rural disparities in palliative care [72]. Second, community-based networks should be strengthened to support the development of rural palliative care networks through community engagement, collaboration, and innovation [73]. For example, facilitating collaboration between local clinics and large medical centers to further enhance the delivery of palliative care services. A single per diem model for rural hospices, as well as subsidies or tax incentives for healthcare workers in rural areas, would ensure financial sustainability and high-quality care [21]. Finally, improve training and retention. Consider providing advanced practice healthcare providers to rural hospices and utilize simulation training as well as incentives such as financial support and career development opportunities to maintain a stable healthcare workforce [26].

Conclusion

This study fills a gap in the limited research on palliative care for advanced AIDS patients in China. As the first qualitative study in this context, it highlights the multifaceted needs of these patients, including physical, psychological, and social support. The findings underscore the importance of culturally sensitive, policy-driven interventions to address barriers like stigma, resource disparities, and limited awareness of palliative care. Additionally, integrating palliative care into China's healthcare system through improved policy support and financial coverage is crucial. Addressing gaps in insurance and reimbursement frameworks is essential to enhancing accessibility and affordability, particularly for vulnerable populations in resource-limited rural areas.

Despite its contributions, this study has limitations that warrant consideration. First, the sample size was relatively small and recruited from a single hospital, which may limit the generalizability of the findings to other regions or populations. Second, purposive sampling might have introduced selection bias, as participants willing to share their experiences might not fully represent the diversity of perspectives among advanced AIDS patients. Lastly, the reliance on self-reported data could lead to recall bias, particularly when discussing sensitive topics such as stigma or social interactions. Future research should consider multi-center studies with larger and more diverse samples to validate these findings and provide a broader perspective on the palliative care needs of this population. Nonetheless, as palliative care continues to evolve, policymakers and healthcare providers should consider these insights to develop more effective and culturally appropriate palliative care service programs to better support advanced AIDS patients in mainland China.

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Author contributions

Z.Y., L.C.R., W.B. designed the study, which was conceived by W.C.T., Z.X.;Z.Y., L.C.R., S.D., Y.X. carried out the data collection. Z.Y., L.C.R., Z.L., L.C.M. led the data analysis, with the contribution of W.B., and the writing of the manuscript. Z.Y., L.C.R., W.B. contributed to the creation of the interview guide, gave feedback on initial themes and reviewed the manuscript. Z.Y., L.C.R., W.B., W.C.T., Z.X., Y.T.T. contributed to the interview guide and reviewed the manuscript. All authors have read and approved the final version of this manuscript.

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Data availability

No datasets were generated or analysed during the current study.

Declarations

Ethics approval and consent to participate

The study was approved by the Ethics Committee of the Public Health Clinical Center of Chengdu, Chengdu, Sichuan, China (Ethics approval number: YJ-K2024-03-01). Our study was conducted according to the principles of the Declaration of Helsinki and followed relevant guidelines and regulations. Each participant was adequately informed of the aims and methods of the study and informed consent was obtained from all individuals to participate in this study. No personal information has been used and the individual's identity has been protected by removing any personal identifiers from the data. Codes were designated to the respondents to guarantee their anonymity.

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

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