Psychology Research and Behavior Management

Dovepress
Taylor & Francis Group

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REVIEW

Psychosocial Experience and Coping of AIDS Patients About the Disease: A Systematic Review and Qualitative Meta-Synthesis

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Aim: To systematically integrate the psychosocial experiences and coping mechanisms of AIDS patients after the disease, and to understand their true feelings, in order to provide a basis for better implementation of psychological interventions for AIDS patients.

Methods: An automated search of the Cochrane Library, PubMed, JBI, CINAHL, Web of Science, EBSCO, Embase database, CNKI, Wanfang Database, Wipro Database, and SinoMed from the database's creation until March 2025 turned up all the literature on the psychosocial experience of AIDS patients and response strategies. The quality of the gathered literature was assessed using the JBI Center for Evidence-Based Health Care's 2016 Qualitative Research Evaluation Tool, and the results were compiled and interpreted using the pooled synthesis approach.

Results: A total of 15 papers were included, and 36 themes were distilled and grouped into 11 new categories, which were brought together into 3 integrative results: complex psychological responses: identity ruptures and struggles, reconstructing psychological adaptations: and from collapse to reconstruction, adapting coping strategies: from passive acceptance to active resistance.

Conclusion: The psychosocial experience of AIDS patients is multidimensional and dynamic, and clinical staff should pay attention to the psychosocial problems of patients. In the future, through policy optimization, individual empowerment and social support, personalized psychological intervention and effective health education will be provided to build a more inclusive AIDS care ecosystem.

Patient or Public Contribution: This systematic review did not directly involve people living with HIV to design or conduct the review. However, this finding will inform a qualitative study designed to explore the psychosocial feelings and illness coping experiences of people living with AIDS.

Keywords: acquired immune deficiency syndrome, AIDS, psychosocial, meta-synthesis, qualitative research

Introduction

Acquired immune deficiency syndrome (AIDS) is a chronic infectious disease caused by infection with the human immunodeficiency virus (HIV). It damages CD4+ T lymphocytes, which are central to the human immune system, leading to severe impairment of immune function.[1] This makes patients susceptible to various opportunistic infections and malignant tumors, ultimately threatening their lives. Since the first cases of AIDS were reported worldwide in the 1980s, AIDS has become a major global public health issue.[2] According to a report by the Joint United Nations Programme on AIDS (UNAIDS), at the end of 2023, around 39 million people were living with HIV worldwide. Throughout the year, there were approximately 1.3 million new HIV infections and around 630,000 AIDS-related

Received: 10 May 2025
Accepted: 31 August 2025
Published: 8 September 2025

deaths.[3,4] While widespread access to antiretroviral therapy (ART) has significantly increased the life expectancy of infected people and transformed AIDS from a "lethal disease" to a "chronic and manageable disease",[5,6] this transformation has created new challenges - infected people have to deal with the complex psychosocial adjustment to the disease for the rest of their lives.

As a chronic infectious disease, AIDS not only seriously endangers patients' physical health but also has emerged as a significant psychosocial concern in the field of global public health because of the social stigmatization, psychological strain, and interpersonal relationship issues that it causes.[7–9] In regions with limited resources, such as East Africa, patients continue to face multiple pressures despite improvements in ART coverage. These include prejudice, stigmatization, and challenges in obtaining a diagnosis.[10–12] HIV infection is still a difficult illness for many complicated reasons, and individuals living with HIV/AIDS are susceptible to psychological and emotional problems. Tadesse's research shows that, in regions with a high HIV prevalence, such as sub-Saharan Africa, up to 56% of individuals infected with the virus report experiencing perceived stigma.[13] This figure is significantly higher than that for patients with other chronic diseases. Bai's research shows that AIDS patients experience negative psychological perceptions such as loneliness, irritability, anxiety, negativity, and discrimination.[14] At the same time, people living with HIV face crises of self-identity and challenges in managing their emotions. A study of HIV-positive men who have sex with men (MSM) found that patients generally experience a "self-disclosure dilemma" after diagnosis, facing significant psychological conflict when deciding whether to disclose their infection status to others.[15] Patients are often trapped in self-condemnation and even actively hide their condition to avoid being ostracized by society's moralizing judgements about the means of transmission of the disease. This "double pressure" - the need to cope with the threat of the disease itself as well as social discrimination - further increases the psychological load on the patient. The Machisa study found that women with HIV had suffered from emotional neglect and significant stress after receiving their diagnosis, which is even more worrisome.[16] A lack of support networks and depressive symptoms were identified as factors that contributed to their psychological distress. A lack of social support, such as inadequate medical insurance and insufficient family support, can leave patients feeling isolated and helpless. Some patients are forced to interrupt treatment due to financial pressures or an unequal distribution of resources,[17,18] which threatens their health, affects their ability to manage their condition, and impacts their quality of life. The chronic nature of HIV, its potentially lethal characteristics and the current inability to cure it completely make patients extremely susceptible to negative emotions such as fear, anxiety and depression.[19] When combined with the emotional impact of diagnosis, this can lead to severe mental distress and have a cumulative negative effect on patients' mental health.

In recent years, the international community has set a new target based on the "90–90-90" prevention and control goals: "90% of infected individuals should achieve a high quality of life through virological suppression".[20–22] This highlights the central role of psychosocial health in the overall prevention and control of HIV/AIDS. The health outcomes of people living with HIV/AIDS are influenced not only by biomedical factors, but also by the sociocultural environment, psychological adaptation processes and behavioral coping strategies. The link between disease management and psychosocial factors is intricate and dynamic. Patients who are stigmatized tend to hide their illness, which makes it harder for them to engage in social activities as usual. Their mental health and social integration are significantly impacted, which negatively affects illness management and treatment compliance. Therefore, developing a thorough understanding of the psychosocial experiences and coping strategies of people living with HIV/AIDS is crucial for optimizing the overall care model for this condition.

Qualitative research can deeply explore the subjective experience of patients, understand the psychological distress and social challenges they face in the diagnosis of the disease, the treatment process, and their daily lives, and provide rich and detailed information for a comprehensive understanding of the real situation of AIDS patients.[23] Although qualitative research has revealed more about the psychological experience of AIDS patients in recent years, existing results are fragmented and limited in their interpretation of patients' overall state of being.[24–26] As a sophisticated approach to evidence synthesis, meta-integration can transcend the limitations of a single study's explanatory power to construct a more comprehensive and generalized theoretical framework.[27] By conducting a thorough search, applying strict screening criteria, carrying out scientific evaluations and deeply integrating relevant qualitative studies, themes that are common and universal can be identified, and potential links and patterns between different studies can be explored.

This will make it possible to build a more thorough, in-depth, and theoretically sound model of the psychological experiences and reactions of AIDS patients. The aim is to provide clinical medical personnel, psychologists and social workers with more targeted and practical guidance, to promote the optimization and improvement of relevant interventions and support services, and to improve the psychosocial adaptation and quality of life of AIDS patients.

Materials and Methods

Literature Inclusion and Exclusion Criteria

Inclusion criteria: (1) The research subjects are HIV-positive patients, regardless of age and gender; (2) The phenomenon of interest is the exploration of the social and psychological experiences and/or coping strategies or processes of people living with HIV/AIDS. For example, phenomena such as stigma and discrimination, emotional distress, and disclosure decisions and experiences. (3) The context is the actual circumstances of AIDS patients' everyday social lives; (4) the research methodology is qualitative research, which includes ethnographic research, phenomenological research, rootedness theory, and observational research, among other methods.

Exclusion criteria: (1) literature for which full text was not available; (2) literature on mixed research designs; (3) literature not in Chinese or English; (4) reviews, conference papers or incomplete information on literature.

Literature Search Strategies

In accordance with guidance from PRISMA checklist,[28] ENTREQ,[29] and meta-synthesis guidance[30] from the Cochrane group, we used a comprehensive search strategy to identify all relevant studies in English. A computerized search of the Cochrane Library, PubMed, JBI, CINAHL, Web of Science, EBSCO, Embase database, CNKI, Wanfang Database, Wipro Database and SinoMed was carried out from the date of database construction to March 2025. All qualitative studies of psychosocial experiences and coping styles of people with AIDS were included. Search terms include "AIDS, AIDS patients, AIDS positive, AIDS infected, HIV positive, acquired immune deficiency syndrome", "psychological experience, feelings, experiences, needs, coping, mental", "qualitative research, qualitative research, grounded theory, phenomenological research, ethnography", etc. The search strategy is shown in Figure S1.

Data Extraction

One researcher conducted an electronic search and excluded duplicates. All titles were screened for relevance to the meta-synthesis topic. Two researchers trained in evidence-based methods independently screened the abstracts and made a list of exclusion categories, and then independently screened the full-text manuscripts and provided reasons for exclusion. In case of disagreement, the decision was discussed jointly by a third researcher. Data extraction included authors, publication date, study population, country, study methodology, phenomenon of interest and findings.

Literature Quality Evaluation

The quality of the literature was assessed using the 2016 edition of the Quality Evaluation Criteria for Qualitative Research from the Centre for Evidence-Based Health Care at the Joanna Briggs Institute (JBI), Australia.[31] The criteria included 10 entries, each of which was graded "yes", "no" and "unclear". Literature that fully met the criteria was graded A, partially met the criteria was graded B, and did not meet the criteria at all was graded C. The quality of the literature was assessed independently by two researchers. Two researchers independently evaluated the literature's quality. In the event of a disagreement, a third researcher was invited to discuss and determine whether the included literature should receive a grade of A or B.

Methods of Data Analysis

The pooled meta-integration method is a rigorous research methodology that involves analyzing and integrating findings from existing qualitative research to construct deeper meanings by identifying overarching themes. A thematic synthesis approach as outlined by Thomas and Harden was used. Thomas and Harden's approach to theme synthesis consists of three steps: initial line-by-line coding, descriptive themes construction, and analytical themes generation. Researchers

trained in evidence-based care methodology were trained to summarize similar results and form new categories after reading the understanding set repeatedly, analyzing the included literature, and finally summarizing the categories into integrated results to form new interpretations. Firstly, the researchers carefully read each article to gain a comprehensive understanding of its content, before conducting an initial code of the results section of each article. These initial codes were then grouped to form descriptive themes, highlighting the commonalities and differences between the review guidelines. These descriptive themes were refined through group discussions and synthesized into analytical themes that aligned with our research objectives. The identification of analytical themes then emerged through repeated discussions. Based on these themes, the research team conducted further discussions and reviews to determine the final analytical themes.

Results

Literature Search Results

1677 duplicates were removed, leaving 1015 documents. After reading the titles and abstracts, the remaining literature was screened initially, and 880 articles were excluded, leaving 135 articles. After reading the full text, the remaining literature was re-screened, and 120 articles were excluded. The final 15 research articles were included. The process of literature screening and the results are shown in Figure S2.

Basic Characteristics and Quality Evaluation of the Included Literature

A description of the basic characteristics of the 15 included literature is presented on Table S1. Quality evaluation of the included literature, presented on Table S2.

Meta Integration Results

After repeated reading, comparing and analyzing, 15 papers were included and 36 themes were distilled, grouped into 3 new categories and summarized into 11 integrated results.

Complex Psychological Responses: Identity Ruptures and Struggles

Denial and Stigmatization

The patient finds it difficult to accept their HIV diagnosis and tries to avoid reality by disputing the results, thinking the test results are incorrect or belong to someone else.

> When the doctor informed me that it was incorrect, untrue, and couldn't have happened to me—possibly the result of someone else's actions—I was very taken aback.[32]

Doubting why you contracted AIDS, disbelieving and questioning this fact, and how you contracted AIDS through repeated recollection, reflection and introspection.

> I bought one of those tests online and tested 3 times because I didn't think I could have AIDS.[33]

Many patients opt to keep the matter private and do not share it with others out of fear of being judged, questioned, and viewed differently. They claim that the stigma and shame associated with the condition, as well as the fact that being infected is socially stigmatizing, are the main reasons for not sharing.

> I feel like I've lost my reputation, and I find it annoying when people believe I'm a nasty person.[34]

They are reluctant to tell their partner or others that they are HIV positive out of fear of losing them or facing discrimination.

> I have a boyfriend, and we are very close, but he doesn't know about my HIV status. It hurts me to hide it, but I'm afraid of losing him and I don't know what to do.[35]

> Others cannot understand what I'm going through, and I don't want to be perceived differently.[26]

Fear and Desperation

When patients faced with a positive diagnosis of the disease, they can experience severe emotional shock, experiencing varying degrees of fear and trepidation. Participants expressed fear and anxiety about the future, fear of transmitting the disease to their families, causing great suffering to the patients, fear of the threat of death, believing that the disease could not be cured and that they would soon die.

> When I first found out about AIDS, I felt scared, nervous, panicked, overwhelmed and unable to live.[25]

> During my second trimester, I contracted an infection from my husband. Although I am depressed about my circumstances and prospects, my major worry is that my child may inherit the illness.[36]

AIDS patients have death anxiety as a result of this, which leads to them carrying great psychological loads, worrying and despairing about their futures, losing interest in life, giving up on themselves, or choosing to terminate their agonizing lives by suicide.

> I'm also ashamed to have this disease, I've committed suicide twice, alas, what the heck, just die.[37]

Simultaneously, psychological anguish, including melancholy, anxiety, suicidal thoughts, sadness, and despair, causes patients to lose motivation, believe that their ambitions and dreams will come true, and get discouraged about their prospects.

> All of my dreams have come to an end, and I doubt that I will continue to live. The end of my life will come when I am unable to accomplish anything more, including attending school.[35]

Loneliness and Social Isolation

Many people have misconceptions about HIV, and patients who are afraid of prejudice and discrimination due to the disease intentionally limit their interactions with others, avoid social events, and socialize less. This can result in self-isolation, attempts to distance themselves from others, withdrawal from the community, and, in certain situations, even from their families.

> I try to minimize contact with my friends.[38]

> After this incident, I decided to live alone forever, away from all my family. I made an excuse to break our engagement.[32]

Loneliness becomes the emotional norm for people living with HIV, and adolescents living with HIV choose to isolate themselves and avoid socialization for fear of being judged or rejected by their peers.

> I'd prefer to stay alone myself because I'm terrified of discrimination, I find it awkward to socialize with people, and I fear that my classmates will classify me as having HIV.[39]

AIDS's contagiousness has a profound impact on patients' lives and emotions; older patients experience family alienation and disinterest from their kids, and they are more likely to withdraw from society, limit their social interactions, and live in their own safe spaces to prevent discrimination and victimization due to their HIV-related symptoms.

> My son stays away from me since he is aware of my disease. I'm eating alone now, using special utensils to avoid confusion.[37]

Stigmatization and Guilt

Because of the contagious nature of HIV, the lack of awareness about the virus, and society's extremely low tolerance for AIDS patients, AIDS patients often feel stigmatized and unable to accept the reality of the disease. Some of them blame the infection on "moral failings" or "punishment by fate". A sense of remorse, guilt, and conscience are experienced by certain patients who blame their illness on "moral failings" or "fate's punishment" and give in to the social belief that their own impurity is the primary cause of their circumstance.

> I must have sinned in my past life to get this disease. I can't believe I'm getting it.[33]

Due to cultural and regional differences, patients' perceptions of illness also differ, with Asian patients more likely to associate illness with "karma" and to feel more self-blame and guilt. African patients attribute more to "community transmission" and less to stigmatization.

> When I found out about this disease, I felt very guilty and remorseful about my past because I really didn't have a healthy life. I made a series of mistakes and in that moment, I regretted why I had such a disaster.[38]

> We must communicate with many people who are unaware of the circumstances around others. We all do not want to have HIV, and that's okay.[25]

Reconstructing Psychological Adaptations: And from Collapse to Reconstruction

Reconstructing Self-Identity

Patients' identities and self-images drastically shift after receiving an AIDS diagnosis. At first, they struggle to accept that they are now AIDS patients instead of healthy individuals, and they doubt their own worth and experience poor self-esteem and self-blame.

> After getting sick, I realized that I was most likely at fault, that I had created this circumstance by a string of inappropriate actions, and that I now needed to pay the price.[32]

However, as awareness of the disease grows and patients' self-acceptance and willingness to survive increases, they begin to accept their HIV status, reject shame and seek support from other people living with HIV to build self-esteem and identity.

> It's not appropriate to knock yourself down; instead, talk to individuals who inspire you and look for an HIV support group for encouragement and emotional support.[40]

Patients exhibited remarkable psychological resilience despite the difficulties of reconfiguration; they actively resisted the negative emotions that dominated their lives, tried to return to "normality" as HIV-positive individuals, and gradually changed their focus from lamenting the past to valuing the present.

> This has occurred; continue taking the medication; don't expect a full recovery, but it will help manage some of the symptoms so I can live a regular life without worrying.[41]

Self-Resilience and Acceptance

Resilience is a multidimensional construct that describes the process by which an individual or group adapts after being exposed to or experiencing a negative life event, allowing them to gain the desire and motivation to survive, to better cope with the disease and the power of control over their own lives and destinies, to better accept themselves, to see themselves as whole people, To reduce the psychological space occupied by HIV, so that one can live a more joyful and open life, face one's feelings directly, free oneself from complex psychological experiences, and face the disease with a rational and positive attitude.

> Learning to love myself through life is part of me, but not all of me. I am infected with more than HIV.[42]

> I'm in a good frame of mind now that I have it, I have to face it properly and take my medication on time, so I think I'll live another 20 years.[43]

Although the process of self-acceptance takes place against a background of ambivalence and endless questioning, it becomes an important motivator that drives the patient to continue.

> As an elderly AIDS patient, I have recently asked myself why I have the disease and have yet to discover the answer. I tell myself that I must accept that there is no other way to get the truth.[25]

Post-Traumatic Growth

AIDS is not only a "trauma" but also a "growth" for the patient. A After enduring a traumatic experience, the patient learns from it, keeps going and developing with hope, regains hope and thinks about the future, recognizes the worth of life, and anticipates healing from the traumatic event. In the process of coming to terms with the traumatic experience, feels the value of life and looks forward to recovery from illness.

> I think eventually it [a cure] will be discovered and I have to be positive about it, I have a long life ahead of me.[42]

Over time, the patient's ability to cope with and adapt to the illness grows by itself; they are able to embrace or adjust to new circumstances, integrate internal and external forces, think and plan their lives in a positive way, regain courage and enthusiasm for life, reevaluate their relationships, and take the initiative to look for support, assistance, and strength both internally and externally.

> I've had HIV for about ten years, but I've learned to embrace it, I'm happy today, it doesn't interfere with my life in any way, and I think I'll eventually get better.[36]

> Instead of feeling sorry for myself, I began going to therapy and socializing, and I no longer felt shy about interacting with people.[44]

Adapting Coping Strategies: From Passive Acceptance to Active Resistance

Information Management and Disclosure

HIV education and information is important because patients who are already aware of the disease are more likely to accept and deal with a positive diagnosis. Whether this information comes from friends or HIV organizations, patients are more likely to make important decisions about their medication and to take it as prescribed.

> I learned about HIV from friends and an organization about HIV and that life must go on. I believe in the medication and counselling we get. If I take my medication properly, I will survive.[26]

Additionally, the Internet is a significant tool for sharing or learning about the disease, sharing personal experiences while getting support from peers, participating in community events anonymously, revealing one's HIV status, selectively disclosing one's condition to manage its effects, and getting support and encouragement from external sources.

> Telling others that it's only them. Telling the truth, it's like a breath of fresh air, it's like lifting a weight, it makes me feel uninhibited.[40]

Positive Behavior Adjustment

After receiving a positive HIV diagnosis, patients show a greater desire to live, actively encourage behavioral changes in an effort to improve their quality of life, trust ART medication, and have faith in the advancements in ART treatment that will allow them to lead healthy lives.

> I insisted on taking my medication every day. I stopped drinking because drinking made the medication ineffective.[44]

> According to the nurses, you will live a long life if you take your prescription as directed. I decided that day to trust the treatment and take my medication as prescribed since I wanted to live, and I didn't want this illness to depress me.[25]

Most patients reported that altering their lifestyles helped them deal with the difficulties posed by HIV. These included focusing on their interests, minimizing the mental space that HIV takes up, adjusting their habits in a positive way, eating a healthy diet and getting enough sleep to help them adjust to the disease, and adjusting their pace of life to maintain a comfortable daily routine.

> Enjoy life and alter your perspective; you never know when it will end![34]

Appreciating Social Support

Family and friend support is crucial to the patient's transition to a new life and is what keeps them alive, allows them to talk about their feelings and experiences with "important" people, gives them courage and encouragement, and helps them deal with the diagnosis.

> It was merely a belief, and at the time, I believed that my family would suffer if I survived without emerging. My friend who was a medical student talked to me more about it, which helped me feel less afraid.[33]

Acceptance by family and friends can improve patients' adherence to treatment and mental health. Additionally, it helps boost patients' confidence in their ability to recover and lessen unpleasant feelings.

> My friends and family often ask me if I've taken my medication and offer me strength. For example, my mother asked me when I was going to the clinic today because I was staying with her.[25]

On the other hand, peer support is a mutually beneficial relationship in which individuals who have gone through similar things react favorably to the illness by organizing an AIDS support group to listen, support, and exchange stories in order to restore a feeling of closeness and community, as well as to offer additional emotional support and useful advice.

> I constantly advise new HIV-positive individuals to begin taking medicine when I speak with them in my online HIV chat group. I tell them that I have been on medication for 6 or 7 years and that they will be more receptive to medication.[44]

Government policies to ensure access to treatment and resources for patients, as well as non-profit organizations' supply of pharmacological support and psychological counseling.

> The government provides us with free medications and subsidies, and it is incredibly kind and supportive of us.[26]

The Comfort of Faith

For some AIDS patients, faith has become their spiritual support and a strong spiritual pillar. The concepts of love, tolerance and salvation in the teachings have enabled them to find inner peace and tranquility in their faith, to accept the reality of their illness more openly and to face the sufferings of life in a transcendent state of mind.

> Return to God and forgiveness of all suffering is God's command and help to me.[36]

The groups' creation of a friendly and welcoming community environment also provided them with a sense of acceptance and belonging, making up for any emotional support that they might have missed from their families and society as a result of their illnesses. They were able to reevaluate their lives and discover meaning and purpose under the direction of their religious convictions, which gave them the courage and confidence to recover from their illnesses.

> When I visit, people recognize me and say, "There she is. Every time I go, I get this warmth that I might not have got from my parents.[40]

Discussion

AIDS patients' psychosocial environment is a complicated area where social structural influences, personal agency, and the disease's biology interact. The psychosocial dilemma of the patient is essentially a double victimization of the stigma of the disease: a vicious circle of institutional discrimination in external society, such as exclusion from employment and differential treatment in health care, and self-stigmatization at the individual level, such as moral attribution and denial of self-worth.[45–47] This result is consistent with Goffman's "stigma theory" since patients who have a "devalued social identity" not only experience rejection from social labels but also internalize the stigma as a component of their self-perception. Stigma is internalized as part of self-perception.[48] It is important to note that the current study confirms earlier findings regarding the intergenerational transmission effect of stigmatization: teenage patients are subjected to social discipline pressure in the family field beforehand because of self-denial and overprotective or accusatory parents. Because "sexuality" is banned in traditional notions, elderly patients face moral judgment from their children,

underscoring the cultural heterogeneity of stigmatization in various age groups. This highlights the cultural specificity of stigmatization in different age groups. This "internalization of stigma" not only exacerbates the self-identity crisis, but also leads to the patient actively choosing social isolation, creating a "self-fulfilling stigma prophecy": self-isolation due to the fear of discrimination, which counter-enforces others' stereotypes of them as "dangerous or unclean" stereotypes. For high-stigma risk groups, such as sexually transmitted infections and adolescent patients, cognitive reconstruction workshops were conducted to break the false association that "illness equals moral defect". By "de-labeling communication", medical personnel restore patients' dignity during treatment and enhance their quality of life.

According to studies, people who receive an AIDS diagnosis go through a significant psychological shock and feel depressed, anxious, and afraid. Some patients experience long-term self-denial and hopelessness about the future because they struggle to acknowledge that they have the illness. At the same time, the stereotypical image of AIDS patients in society places them in a dilemma of self-perception. They do not know how to find a balance between their identities as "AIDS patients" and "normal members of society" and are in a constant state of self-contradiction.[49] Many patients' self-stigmatization is exacerbated by the various forms of social discrimination they encounter. Some patients are made to feel inferior by the negligent behavior of medical personnel when they seek medical attention; in their daily lives, their coworkers and neighbors purposefully avoid them after learning about their conditions, and even some of their friends and family members find it hard to accept them.[50–52] This widespread discrimination is rooted in the public's lack of knowledge about AIDS and the fear of spreading the disease, which leads to prejudice against patients. The stigma of the disease keeps patients in a state of self-isolation for a long time and they are reluctant to talk about it, which seriously affects their social interactions and prevents them from integrating into normal social life. Therefore, health care providers, support groups and mental health professionals need to help people with HIV integrate into their daily lives by providing comprehensive care, counselling and psychosocial support, with health care professionals using their professional knowledge to dispel patients' doubts and denials, guide them in managing their disease, and help them adapt to and accept their disease. Psychological counsellors listen to patients' inner concerns and help them alleviate their psychological pain and cope with stigmatizing pressures through cognitive behavioral therapy (CBT) and positive thinking stress reduction therapy. Social groups use various channels such as community outreach, school education and media publicity to disseminate knowledge about AIDS prevention and treatment, correct public misconceptions about AIDS, reduce discrimination against patients and create a social atmosphere of understanding and tolerance.

Social support can take many different forms, such as family, group, state, or treatment. Support systems are designed to give patients emotional and affective support and enhance their mental health. Families provide significant material and moral support, comprehend the circumstances and challenges faced by HIV patients, remind patients to take their medication, encourage them to adhere to the treatment plan, assist them during difficult times, and actively participate in their care.[53] Peer support groups are essential for fostering safe spaces, lowering feelings of loneliness, and fostering relationships of healing that allow individuals living with HIV to freely and safely express their anxieties;[54] and the state facilitates HIV maintenance and treatment by offering pertinent preferential policies, as well as continuous medical and psychosocial assistance. However, community support is still relatively weak and there is a lack of professional psychological counselling services and peer support organizations, making it difficult for patients to receive ongoing psychological care and support. Additionally, some patients face enormous financial pressures during treatment due to economic difficulties, and the social assistance system fails to provide timely and effective support.[55] Therefore, in the future, it is necessary to establish professional psychological counselling services to provide patients with regular psychological counselling and psychological guidance; to develop peer support organizations so that patients can gain emotional resonance and practical experience through mutual exchange; and to optimize the social assistance system to provide more financial support to patients in financial difficulties and alleviate their treatment burden.

Limitations

The study also has some limitations. Firstly, the literature included is heavily dominated by English and Chinese, with French, Portuguese and other regions under-represented in the research. Most of the articles reviewed emphasized the predominance of adults living with HIV, and few focused specifically on children or pregnant women, making it difficult to generalize the findings to other specific populations. Secondly, the study was published over a long period of time,

making it difficult to ensure that the integrated results reflect the most recent psychosocial status and coping patterns of people living with HIV today in real time. Finally, while some research has indicated that patients' involvement in mutual aid organizations can offer some psychological support, the meta-integration was unable to accurately quantify the causal relationship between mutual aid organization participation and the extent of psychological status improvement. This somewhat restricts the data' exact guiding function for the development of clinical therapies and policy.

Conclusion

This meta-synthesis describes the profound psychosocial challenges experienced by people with HIV/AIDS under the shadow of stigma. It also demonstrates the variety of coping mechanisms and inner fortitude they exhibit in order to adjust, endure, and develop. According to the study's findings, patients typically endure severe, multifaceted stigmatization and discrimination, which has a significant negative impact on their mental health, social support, and mental health. It highlights the important role of "stigmatization" as a core driving force and its close connection to mental health and social relationships. Emphasized the core buffering and facilitating roles of "social support" and "resilience" in the coping process. The study revealed that the social and psychological experiences of HIV/AIDS patients exhibit a complex chain of events involving "stigmatization, adaptation difficulties, and coping differentiation". To overcome this dilemma, it is necessary to empower individuals by providing comprehensive disease self-management education and psychological adjustment skills, supporting patients in developing positive coping strategies, and enhancing their autonomy and sense of control. Healthcare professionals receive sensitivity training and learn communication skills to provide non-discriminatory medical services that are respectful of privacy, informative and emotionally supportive. Families are encouraged to participate and are provided with support, while professional, confidential peer support programmes are developed and promoted to establish a strong social support system. The government should improve anti-discrimination laws and regulations and ensure their enforcement to protect patients' rights to employment, medical care, education, etc. Increase investment in HIV-related mental health services and social support projects. By focusing on three key areas — empowering individuals, restructuring social support systems and ensuring policy safeguards — we can build a more inclusive and sustainable care ecosystem, improve the quality of life for people living with HIV/AIDS, and ultimately achieve the global vision of a "zero discrimination society".

Disclosure

The authors report no conflicts of interest in this work.

References

1. Lloyd A. HIV infection and AIDS. *P N G Med J*. 1996;39(3):174–180.
2. Murphy RL, Phair JP. AIDS. *Compr Ther*. 1988;14(1):3–12.
3. Weinberg JL, Kovarik CL. The WHO Clinical Staging System for HIV/AIDS. *Virtual Mentor*. 2010;12(3):202–206. doi:10.1001/virtualmentor.2010.12.3.cprl1-1003
4. UNAIDS.New report from UNAIDS shows that AIDS can be ended by 2030 and outlines the path to get there[EB/OL].(2023-07-13)[2025-08-03]. New report from UNAIDS shows that AIDS can be ended by 2030 and outlines the path to get there.
5. Hendrickson CJ, Pascoe SJS, Huber AN, et al. "My future is bright…I won't die with the cause of AIDS": ten-year patient ART outcomes and experiences in South Africa. *J Int AIDS Soc*. 2018;21(10):e25184. doi:10.1002/jia2.25184
6. Cao W, Hsieh E, Li T. Optimizing treatment for adults with HIV/AIDS in China: successes over two decades and remaining challenges. *Curr HIV/AIDS Rep*. 2020;17(1):26–34. doi:10.1007/s11904-019-00478-x
7. Ma H, Zhu F, Zhai H, et al. Prevalence of psychological distress among people living with HIV/AIDS: a systematic review and meta-analysis. *AIDS Care*. 2023;35(2):153–164. doi:10.1080/09540121.2022.2080802
8. Wang W, Xiao C, Yao X, et al. Psychosocial health and suicidal ideation among people living with HIV/AIDS: a cross-sectional study in Nanjing, China. *PLoS One*. 2018;13(2):e0192940. doi:10.1371/journal.pone.0192940
9. Ayres JR, Paiva V, França I Jr, et al. Vulnerability, human rights, and comprehensive health care needs of young people living with HIV/AIDS. *Am J Public Health*. 2006;96(6):1001–1006. doi:10.2105/AJPH.2004.060905
10. Melku M, Abebe G, Teketel A, et al. Immunological status and virological suppression among HIV-infected adults on highly active antiretroviral therapy. *Environ Health Prev Med*. 2020;25(1):43. doi:10.1186/s12199-020-00881-6
11. Armstrong-Mensah EA, Tetteh AK, Ofori E, et al. Voluntary counseling and testing, antiretroviral therapy access, and HIV-related stigma: global progress and challenges. *Int J Environ Res Public Health*. 2022;19(11):6597. doi:10.3390/ijerph19116597
12. Chimoyi L, Hoffmann CJ, Hausler H, et al. HIV-related stigma and uptake of antiretroviral treatment among incarcerated individuals living with HIV/AIDS in South African correctional settings: a mixed methods analysis. *PLoS One*. 2021;16(7):e0254975. doi:10.1371/journal.pone.0254975

13. Tadesse G, Rtbey G, Andualem F, et al. HIV-related perceived stigma and internalized stigma among people living with HIV/AIDS in Africa: a systematic review and meta-analysis. *PLoS One*. 2024;19(10):e0309231. doi:10.1371/journal.pone.0309231
14. Chunqin BAI, Xuemei, Huzyang, et al. Qualitative study of the experiences and perceptions of social discrimination among people living with HIV/AIDS. *Chin Gen Pract Nurs*. 2023;21(21):2980–2984.
15. Xinyi YOU, Jiayi GU, Wen Q, et al. Self-disclosure experience of HIV-positive MSM based on social-ecological theory: a qualitative study. *Chin J AIDS STD*. 2024;30(03):289–294.
16. Machisa M, Shamu S. Associations between depressive symptoms, socio-economic factors, traumatic exposure and recent intimate partner violence experiences among women in Zimbabwe: a cross-sectional study. *BMC Womens Health*. 2022;22(1):248. doi:10.1186/s12905-022-01796-w
17. Poudel AN, Newlands D, Simkhada P. The economic burden of HIV/AIDS on individuals and households in Nepal: a quantitative study. *BMC Health Serv Res*. 2017;17(1):76. doi:10.1186/s12913-017-1976-y
18. Yakob B, Ncama BP. A socio-ecological perspective of access to and acceptability of HIV/AIDS treatment and care services: a qualitative case study research. *BMC Public Health*. 2016;16:155. doi:10.1186/s12889-016-2830-6
19. Zhang H, Li Z, Li P, et al. Life expectancy and mental related burden of disease among people living with HIV/AIDS. *AIDS Care*. 2024;36 (sup1):15–23. doi:10.1080/09540121.2024.2332444
20. Sabapathy K, Balzer L, Larmarange J, et al. Achieving the UNAIDS 90-90-90 targets: a comparative analysis of four large community randomised trials delivering universal testing and treatment to reduce HIV transmission in sub-Saharan Africa. *BMC Public Health*. 2022;22(1):2333. doi:10.1186/s12889-022-14713-5
21. Fogarty C, Peter T, Karatzas N, et al. Global health facility-based interventions to achieve UNAIDS 90-90-90: a systematic review and narrative analysis. *AIDS Behav*. 2022;26(5):1489–1503. doi:10.1007/s10461-021-03503-6
22. Lancet HIV T, The Lancet H. UNAIDS strategy aligns HIV priorities with development goals. *Lancet HIV*. 2021;8(5):e245. doi:10.1016/S2352-3018(21)00075-8
23. Cypress BS. Rigor or reliability and validity in qualitative research: perspectives, strategies, reconceptualization, and recommendations. *Dimens Crit Care Nurs*. 2017;36(4):253–263. doi:10.1097/DCC.0000000000000253
24. Yang Z, Yang H, Gong B, et al. Exploring stigma experience and coping strategies among women living with HIV/AIDS in China: a phenomenological study. *Psychol Res Behav Manag*. 2024;17:1487–1498. doi:10.2147/PRBM.S456850
25. Hlongwane N, Madiba S. Navigating life with HIV as an older adult in South African communities: a phenomenological study. *Int J Environ Res Public Health*. 2020;17(16):5797. doi:10.3390/ijerph17165797
26. Petersen I, Bhana A, Myeza N, et al. Psychosocial challenges and protective influences for socio-emotional coping of HIV+ adolescents in South Africa: a qualitative investigation. *AIDS Care*. 2010;22(8):970–978. doi:10.1080/09540121003623693
27. Hernandez AV, Marti KM, Roman YM. Meta-analysis. *Chest*. 2020;158(1s):S97–s102. doi:10.1016/j.chest.2020.03.003
28. Moher D, Liberati A, Tetzlaff J, et al. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA Statement. *Open Med*. 2009;3(3):e123–30. doi:10.1136/bmj.327.7423.1083
29. Tong A, Flemming K, McInnes E, et al. Enhancing transparency in reporting the synthesis of qualitative research: ENTREQ. *BMC Med Res Methodol*. 2012;12(1):181. doi:10.1186/1471-2288-12-181
30. Booth A. Searching for qualitative research for inclusion in systematic reviews: a structured methodological review. *Syst Rev*. 2016;5:74. doi:10.1186/s13643-016-0249-x
31. Majid U, Vanstone M. Appraising qualitative research for evidence syntheses: a compendium of quality appraisal tools. *Qual Health Res*. 2018;28 (13):2115–2131. doi:10.1177/1049732318785358
32. Imani B, Zandi S, Khazaei S, et al. The lived experience of HIV-infected patients in the face of a positive diagnosis of the disease: a phenomenological study. *AIDS Res Ther*. 2021;18(1):95. doi:10.1186/s12981-021-00421-4
33. Xueling XIAO, Yixuan LI, Xinyi SU, et al. Exploration of adaptation process and experience among the HIV/AIDS patients based on the comprehensive task-based adaptation model. *J Cent South Univ*. 2023;48(06):887–894.
34. Furlotte C, Schwartz K. Mental health experiences of older adults living with hiv: uncertainty, stigma, and approaches to resilience. *Can J Aging*. 2017;36(2):125–140. doi:10.1017/S0714980817000022
35. Doat AR, Navab E, Sadat Hoseini AS. Lived experiences of adolescent Living with human immunodeficiency virus in Ghana: a phenomenology study. *Nurs Open*. 2021;8(1):299–307. doi:10.1002/nop2.630
36. Alzahrani NS, Almarwani AM. The effect of HIV on patients' lives: a phenomenological qualitative study. *Int J Qual Stud Health Well-Being*. 2024;19(1):2315634. doi:10.1080/17482631.2024.2315634
37. Caiyun FENG, Hang TAN, Lele FU, et al. 5Qualitative study on psychological experience of elderly people living with HIV over 50 years old. *Chin J AIDS STD*. 2019;25(01):40–2+7.
38. Geng L, Chun-mei YA. The qualitative research of psychological experience in AIDS patients. *Tianjin Journal of Nursing*. 2016;24(03):189–192.
39. Wanjala SW, Nyongesa MK, Luchters S, et al. Psychosocial and mental health challenges facing perinatally HIV-infected adolescents along the Kenyan coast: a qualitative inquiry using the socioecological model. *Front Public Health*. 2024;12:1379262. doi:10.3389/fpubh.2024.1379262
40. Koch A, Ritchwood TD, Bailey DE Jr, et al. Exploring resilience among black women living with HIV in the Southern United States: findings from a qualitative study. *J Assoc Nurses AIDS Care*. 2022;33(2):224–234. doi:10.1097/JNC.0000000000000311
41. Donnelly LR, Bailey L, Jessani A, et al. Stigma experiences in marginalized people living with HIV seeking health services and resources in Canada. *J Assoc Nurses AIDS Care*. 2016;27(6):768–783. doi:10.1016/j.jana.2016.07.003
42. Stroumpouki T, Perrett S, Kasdovasilis P, et al. "A journey towards acceptance": the process of adapting to life with HIV in Greece. A Qualitative study. *Appl Nurs Res*. 2020;53:151249. doi:10.1016/j.apnr.2020.151249
43. Jing ZHENG. Psychological experience of AIDS patients: a qualitative study. *Modern Clin Nurs*. 2017;16(01):23–26.
44. Jiang L, Chen T, Cao B, et al. Trajectories of posttraumatic growth among people living with HIV: a grounded theory-based qualitative analysis. *BMC Public Health*. 2025;25(1):574. doi:10.1186/s12889-025-21822-4
45. Anderle RV, de Oliveira RB, Rubio FA, et al. Modelling HIV/AIDS epidemiological complexity: a scoping review of agent-based models and their application. *PLoS One*. 2024;19(2):e0297247. doi:10.1371/journal.pone.0297247
46. Goldin CS. Stigmatization and AIDS: critical issues in public health. *Soc Sci Med*. 1994;39(9):1359–1366. doi:10.1016/0277-9536(94)90366-2

47. Mill JE, Edwards N, Jackson RC, et al. Stigmatization as a social control mechanism for persons living with HIV and AIDS. *Qual Health Res*. 2010;20(11):1469–1483. doi:10.1177/1049732310375436
48. Bates L, Stickley T. Confronting Goffman: how can mental health nurses effectively challenge stigma? A critical review of the literature. *J Psychiatr Ment Health Nurs*. 2013;20(7):569–575. doi:10.1111/j.1365-2850.2012.01957.x
49. Aschieri F. Shame as a cultural artifact: a call for self-awareness and reflexivity in personality assessment. *J Pers Assess*. 2016;98(6):567–575. doi:10.1080/00223891.2016.1146289
50. Sweileh WM. Bibliometric analysis of literature in AIDS-related stigma and discrimination. *Transl Behav Med*. 2019;9(4):617–628. doi:10.1093/tbm/iby072
51. Jan S, Manzoor S, Rashid J. Experiences of stigma and discrimination of women living with HIV/AIDS in health-care settings of Kashmir. *Indian J Public Health*. 2023;67(1):155–158. doi:10.4103/ijph.ijph_485_22
52. Emlet CA. "You're awfully old to have this disease": experiences of stigma and ageism in adults 50 years and older living with HIV/AIDS. *Gerontologist*. 2006;46(6):781–790. doi:10.1093/geront/46.6.781
53. Mohanan P, Kamath A. Family support for reducing morbidity and mortality in people with HIV/AIDS. *Cochrane Database Syst Rev*. 2009;2009(3):Cd006046. doi:10.1002/14651858.CD006046.pub2
54. Chang K, Wu Y, Shan S, et al. Exploring the experiences of peer support participation for HIV peer volunteers: a meta-synthesis of qualitative research. *Int J Nurs Stud*. 2024;153:104715. doi:10.1016/j.ijnurstu.2024.104715
55. Haakenstad A, Moses MW, Tao T, et al. Potential for additional government spending on HIV/AIDS in 137 low-income and middle-income countries: an economic modelling study. *Lancet HIV*. 2019;6(6):e382–e95. doi:10.1016/S2352-3018(19)30038-4