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Beyond Knowledge Deficits: Social Risk, Family Dynamics,and Delayed ART Initiation in a Border Setting—A Qualitative Study

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Abstract

Background

Despite the global Treat-All recommendation and the well-established benefits of early antiretroviral therapy (ART), delayed ART initiation remains common in some settings. Existing studies have often explained delay in terms of insufficient knowledge, stigma, or access barriers, but have paid less attention to how delay unfolds as a socially embedded decision-making process. This study explored how people living with HIV experienced delayed ART initiation and how social risk, family dynamics, and contextual uncertainty shaped this process.

Methods

A descriptive phenomenological design was used. Semi-structured in-depth interviews were conducted with 23 people living with HIV recruited from two designated HIV care institutions in a border setting in southwestern China. Interviews were audio-recorded, transcribed verbatim, and analyzed using Colaizzi's seven-step method.

Results

Delayed ART initiation was not experienced simply as a consequence of insufficient knowledge. Instead, it unfolded through a socially embedded pathway in which treatment was first interpreted as a risk of social exposure rather than an immediate biomedical necessity. Four themes were identified: (1) treatment entry was initially filtered through concerns about social visibility and disclosure risk; (2) family negotiation and uncertainty about treatment urgency jointly prolonged waiting; (3) support, symptom progression, and reappraisal of risk created turning points toward treatment initiation; and (4) delayed ART initiation was better understood as a socially embedded pathway from concealment to waiting and eventual treatment entry, rather than a one-time refusal. Participants'decisions were shaped not only by treatment knowledge, but also by anticipated stigma, relational pressures,and the social consequences of becoming visible as a person living with HIV.

Conclusions

Delayed ART initiation should not be understood solely as a problem of insufficient knowledge or poor treatment awareness. In this study, delay emerged as a socially embedded pathway shaped by social risk, family dynamics, and contextual uncertainty. Public health efforts to promote earlier ART initiation may have limited impact if they focus only on improving knowledge without addressing confidentiality concerns, stigma-sensitive support, and the relational contexts in which treatment decisions are made.

Trial registration

Clinical trial number: not applicable.

Introduction

Since the World Health Organization (WHO) introduced the “treat all” recommendation in 2015, antiretroviral therapy (ART) has been recommended for all people living with HIV regardless of CD4 cell count [1]. Subsequent WHO guidance has continued to emphasize early and rapid ART initiation as part of public health service delivery, including initiation within seven days of diagnosis and, when appropriate, same-day ART start [2]. Early treatment initiation is associated with improved clinical outcomes and remains a cornerstone of contemporary HIV treatment and prevention strategies [3]. Yet, despite the long-standing global consensus on early treatment and expanding access to HIV services, delayed ART initiation continues to be reported across settings [4]. A recent systematic review and meta-analysis confirmed that delayed ART initiation remains a substantial problem globally, suggesting that policy endorsement of rapid initiation does not automatically translate into timely treatment uptake [5].

Existing studies have often explained delayed ART initiation in terms of insufficient knowledge, concerns about side effects and lifelong treatment, financial and logistical barriers, HIV-related stigma, and fears surrounding disclosure of HIV status [6–9]. However, a barrier-list approach alone is insufficient. While it identifies what obstacles patients may face, it less often explains why treatment is still deferred even when its benefits are widely recognized.

In the context of HIV, treatment decisions are rarely purely biomedical; they are often embedded in social relationships, moral judgment, identity management, and the anticipated consequences of being seen as HIV-positive [10–11].

Recent evidence supports this view. In a qualitative study conducted in Rwanda under the Treat All policy, participants described how HIV care engagement could increase their social visibility as people living with HIV, while anticipated, enacted, and internalized stigma shaped care engagement in complex ways [12–13].

Similarly, recent studies and reviews have shown that HIV-related stigma, disclosure concerns, and relational contexts continue to influence access to care, retention, and treatment engagement [14–16]. Delayed ART initiation, therefore, may be better understood not simply as a knowledge deficit, but as a socially situated process of risk appraisal and decision-making [17–18].

These issues may be especially salient in border settings, where multi-ethnic coexistence, close-knit social networks, population mobility, and cross-regional information flows may complicate treatment decision-making [19–21].

Recent work has further highlighted mobility as an important determinant of HIV care engagement and has called for more context-sensitive research on how movement across places and social environments shapes treatment trajectories [22–23].

In such settings, family dynamics may also be particularly influential, as treatment decisions are often negotiated within close relational networks in which family members can function both as sources of psychosocial support and as sources of pressure, stigma management, and disclosure-related concern [24–26].

From this perspective, delayed ART initiation in a border setting may be influenced not only by individual attitudes or knowledge, but also by social visibility, family relationships, and uncertainty arising from mobility-related information and care continuity. Against this background, the present study examines the subjective experiences and decision-making processes of people living with HIV who delayed ART initiation in a border setting, with the aim of developing an explanation that goes beyond knowledge deficits alone.

Methods

Study design

This study adopted a descriptive phenomenological design to explore the lived experiences of delayed antiretroviral therapy (ART) initiation among people living with HIV in a border setting [27]. Descriptive phenomenology was selected because the aim of the study was to describe how treatment delay was experienced, sustained, and eventually altered in everyday life, rather than to generate a deeply interpretive account of personal meaning. The study focused on the experiential process of delayed ART initiation, including how delay occurred, how the border context shaped treatment decisions, and what factors contributed to eventual treatment initiation.

Study setting and participants

The study was conducted from January 2025 to Octorber 2025 in two HIV-designated hospitals in Yunnan Province, China. Participants were recruited using purposive sampling guided by the principle of maximum variation. In line with qualitative sampling logic, the study emphasized information richness and experiential variation rather than statistical representativeness. Eligible participants were those who: (1) had laboratory-confirmed HIV infection [28]; (2) had delayed ART initiation for at least 1 month after diagnosis [29]; (3) had initiated treatment within 1 year after diagnosis; (4) were able to communicate without major barriers; and (5) voluntarily agreed to participate. Individuals were excluded if they had a history of psychiatric illness, severe physical impairment, or were unwilling to participate. Fourteen participants were ultimately included in the study. The sample covered variation in age, sex, ethnicity, marital status, education, occupation, route of infection, and duration of treatment delay.

Development of the interview guide

A semi-structured interview guide was developed through literature review and research team discussion. During guide development, the team drew on core dimensions identified in HIV-related stigma research [30], particularly perceived risk of identity exposure, pressure arising from social evaluation, and the influence of stigma-related experiences on delayed treatment initiation. These concepts were used to define the domains of questioning rather than to impose a deductive coding framework. The guide was organized around the experiential process of "diagnosis–delay–turning point–treatment initiation" and remained open-ended to facilitate in-depth narration, consistent with recommendations for phenomenological interviewing. Three pilot interviews were conducted to refine the guide before formal data collection. Core questions addressed why participants did not initiate treatment immediately after diagnosis, what later prompted treatment initiation, how they understood HIV, what emotional and social changes followed diagnosis, whether they received support from others, how disclosure and concealment were negotiated, and how their thoughts changed during the period between diagnosis and treatment initiation. Example questions from the interview guide are provided in Additional file 2.

Data collection

Data were collected through semi-structured, in-depth interviews conducted in a quiet and private clinic room. All interviewers received training in qualitative interviewing prior to data collection. Interviews were conducted in Mandarin Chinese and, where needed, in local dialects or ethnic minority languages familiar to participants. Before each interview, participants were informed of the purpose of the study and provided written informed consent. With participants' permission, all interviews were audio-recorded. During the interviews, the researchers also documented non-verbal expressions, including tone of voice, facial expressions, emotional reactions, and body movements. Follow-up questions were used flexibly according to each participant's narrative and responses.

Each interview lasted approximately 20–30 minutes. Audio recordings were transcribed into text within 24 hours after the interview. Two members of the research team checked the transcripts for accuracy. To protect confidentiality, participants' names were replaced with study codes. A total of 26 individuals were approached, and 23 completed the interviews. Data collection and analysis were conducted concurrently. Following each interview, the team carried out rolling coding and comparative analysis to identify newly emerging meaning units and thematic patterns. Recruitment was stopped when subsequent interviews no longer generated substantively new meaning units and the existing thematic structure remained stable in accounting for new material, indicating information saturation. This approach is consistent with the principle that adequate qualitative sample size is determined by information power rather than numerical targets alone.

Data analysis

Data were analyzed using Colaizzi's seven-step method [31]. First, all transcripts were read repeatedly to gain an overall understanding of participants' experiences of delayed treatment. Second, statements relevant to the study aim were extracted. Third, these significant statements were subjected to initial open coding and organized into meaning units. Fourth, themes and subthemes were developed. Fifth, the themes were integrated to describe the essential characteristics and internal logic of the delayed treatment experience. Sixth, the preliminary findings were returned to participants for verification and refinement. Seventh, a detailed phenomenological description was produced.

NVivo 15.0 was used to assist data organization and coding [32]. Coding was conducted independently by two researchers, followed by comparison and discussion until consensus was reached. The thematic structure was generated inductively from the interview material. The HIV-related stigma framework informed the construction of the interview domains, but it was not used as a rigid deductive coding template during analysis. Instead, the emergent findings were later interpreted in relation to relevant theories and prior studies in the discussion section.

Trustworthiness

Several strategies were used to enhance the trustworthiness of the study. First, audio files were transcribed promptly, and transcripts were checked by two members of the research team. Second, member checking was performed by returning transcripts and analytic results to participants for verification. Third, concurrent data collection and analysis supported iterative comparison and assessment of information saturation. Fourth, independent coding by two researchers followed by consensus discussion strengthened analytic consistency. In addition, the descriptive phenomenological approach was used to prioritize faithful representation of participants' accounts before moving to theoretical comparison and interpretation. The study was reported with reference to the Consolidated Criteria for Reporting Qualitative Research (COREQ) [33].

Results

Participant characteristics

A total of 23 people living with HIV who had delayed antiretroviral therapy (ART) initiation were included in this study. Participants ranged in age from 18 to 75 years and included 16 men and 5 women. They represented diverse ethnic backgrounds, including Han, Bai, Tibetan, Yi, Hui, Miao, Naxi, Dai, Zhuang and Suli. Marital status varied across unmarried, married, divorced, and widowed participants. Educational attainment ranged from primary school to undergraduate level, and occupations included unemployed individuals, farmers, employees, temporary workers, retirees, and students. Routes of HIV infection included predominantly heterosexual transmission, as well as homosexual transmission, injection drug use, and blood transmission. The duration of delayed treatment ranged from 2 months to 9 years.

The sample showed considerable variation in sociodemographic background, route of infection, and duration of treatment delay. This variation was intended to capture a broad range of experiences of

delayed ART initiation in a border setting rather than to support subgroup comparison. In particular, the sample included both short-term and long-term delays, as well as participants with different family situations, social positions, and illness experiences, providing an empirical basis for examining how delayed ART initiation was formed and sustained across diverse life contexts.

Qualitative findings

Four major themes were identified from the interview data. Together, these themes showed that delayed ART initiation was not experienced simply as a consequence of insufficient knowledge, but unfolded as a socially embedded process shaped by social visibility concerns, family negotiation, uncertain treatment urgency, and later turning points that reshaped the perceived balance of risk. The themes and subthemes identified from the interview data are summarized in Table 1.

Table 1
Summary of themes and subthemes related to delayed ART initiation

Level	Code	Theme / Subtheme	Analytic focus
Theme	Theme 1	Entering concealment: diagnosis as a problem of social visibility	Delayed ART initiation began when diagnosis was experienced not simply as a medical condition, but as a threat of social visibility. Participants initially responded by managing exposure risk, anticipated stigma, and the social consequences of being recognized as living with HIV.
Subtheme	1.1	From "being found out" to "hiding first": treatment was initially experienced as a risk of exposure	Treatment entry was first filtered through concerns about disclosure, recognition, and being known by others. Early non-initiation reflected efforts to reduce social exposure rather than straightforward rejection of care.
Subtheme	1.2	From external stigma to internalized shame	External and anticipated stigma were gradually intemalized as shame, self-blame, and identity threat, making treatment initiation emotionally and socialy harder to approach.
Subtheme	1.3	Concealment, denial, and avoidance as early pathways to delay	Concealment, denial, and avoidance functioned as early self-protective responses. These responses did not simply reflect passivity; they formed the initial pathway through which delay was established.
Theme	Theme 2	Living with delay: family negotiation and uncertain urgency sustained prolonged non-initiation	After concealment was established, delay became prolonged through everyday negotiation within family life, mixed and informal information, uncertain treatment urgency, and the ongoing sense that waiting was still possible.
Subtheme	2.1	Family was not a one-way source of support, but a relational field of ongoing negotiation	Family relationships simultaneously generated shame, obligation, dependence, care, and protection. Family therefore sustained delay in some cases while also creating conditions for later treatment initiation.
Subtheme	2.2	Treatment urgency was not self- evident, but was shaped by informal information and everyday interpretation	Participants did not always interpret treatment timing through formal medical logic alone. Informal information, peer experiences, social media, and cross-border comparisons shaped how urgently treatment was perceived.
Subtheme	2.3	Symptom-free periods, concerns about side effects, and the sense that "I was still okay" reinforced waiting	As long as illness did not feel immediately threatening, waiting remained justifiable. The absence of severe symptoms, together with fears of side effects, reduced the perceived necessity of immediate treatment.
Subtheme	2.4	From concealment to waiting: delay became	Delay evolved from an early defensive response into an ongoing state of prolonged waiting. Non-

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Level	Code	Theme / Subtheme	Analytic focus
		a sustained condition of everyday life	initiation became normalized in everyday life rather than experienced as a single, definitive refusal.
Theme	Theme 3	Reaching a turning point: when support, symptoms, or reappraised risk moved patients toward ART	Treatment initiation occurred when the balance of risk changed. Supportive relationships, persistent provider contact, symptom progression, and risk reappraisal disrupted prolonged waiting and made treatment entry more possible and necessary.
Subtheme	3.1	Support from family members and significant others helped break the state of waiting	Relational acceptance, encouragement, and family responsibility reduced the social and emotional cost of entering treatment and helped weaken the logic of continued delay.
Subtheme	3.2	Continued contact from healthcare providers helped reconnect participants to treatment	Provider follow-up did more than deliver information: it reduced isolation, conveyed care without judgment, and helped reconnect participants to formal treatment after prolonged avoidance.
Subtheme	3.3	Symptoms and complications turned abstract risk into an immediate reality	Symptoms transformed delayed treatment from a manageable option into a bodily and urgent problem. Physical deterioration made the cost of continued waiting tangible.
Subtheme	3.4	Treatment initiation followed a reordering of risk rather than a sudden change of attitude	ART was initiated when the perceived risks of delay came to outweigh the risks of exposure, judgment, or medication. Treatment entry followed a reordering of priorities rather than a simple change in knowledge.
Theme	Theme 4	A socially embedded pathway from delay to ART initiation in a border setting	Taken together, the findings support a process-based explanation in which delayed ART initiation unfolded as a socially embedded pathway from concealment to waiting, re-evaluation, and eventual treatment entry. This pathway was shaped by linked social, relational, and contextual forces and cannot be fully explained by knowledge deficits alone.
Subtheme	4.1	From concealment to waiting: delay developed as a staged process	Delay developed in stages rather than through a single decision. Early concealment created the conditions for prolonged waiting and later re-evaluation.
Subtheme	4.2	Social risk, family dynamics, and reappraised urgency operated as linked forces	Social risk, family dynamics, and changing perceptions of treatment urgency were closely interconnected in shaping both non-initiation and eventual treatment entry.
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Level	Code	Theme / Subtheme	Analytic focus
Subtheme	4.3	The border setting functioned as a contextual condition rather than a standalone mechanism	The border context shaped social visibility, information environments, and urgency appraisal, but it is best understood as a contextual condition rather than a single independent mechanism.
Subtheme	4.4	A process-based explanation beyond knowledge deficits	Overall, delayed ART initiation was better understood as a socially embedded and temporally unfolding pathway in which social exposure, family relationships, and changing risk assessments jointly shaped treatment timing.
initiation Based on the final manuscript: Beyond Knowledge Deficits: Social Risk, Family Dynamics, and Delayed ART Initiation in a Border Setting-A Qualitative Study			

Theme 1. Entering concealment: diagnosis as a problem of social visibility

Participants did not initially experience ART initiation as a purely biomedical issue. Instead, following diagnosis, treatment was often interpreted through the lens of social visibility. In the close-knit social environment of the border setting, an HIV diagnosis was understood not only as a health condition but also as something that could expose one's identity, trigger gossip, invite moral judgment, and disrupt social relationships. As a result, delayed ART initiation often began not with explicit rejection of treatment, but with efforts to reduce exposure and manage the social consequences of becoming visible as a person living with HIV.

Subtheme 1.1. From "being found out" to "hiding first": treatment was initially experienced as a risk of exposure

A central reason for delaying ART initiation was fear of being known by others. Participants did not necessarily reject treatment itself; rather, they feared that entering care might make their HIV status visible in a close-knit social environment. Early non-initiation therefore reflected exposure management more than a simple unwillingness to be treated. As one participant explained, "I had thought about going to the hospital earlier, but I was afraid that others would know. In a small place like ours, once people know something like this, it spreads very quickly" (P11). Another participant described the same problem in more intimate terms: "I could never tell other people about this. I did not even dare tell my parents. I had to carry it by myself. What I feared most was that others would find out" (P1).

Subtheme 1.2. From external stigma to internalized shame

Participants' fear of treatment was reinforced not only by anticipated gossip but also by experienced and perceived stigma. Avoidance by others was gradually internalized as shame, self-blame, and a more negative sense of self, making treatment initiation harder to approach. One participant recalled, "When I was hospitalized, the patient in the next bed was friendly on the first day, but after they learned that I had HIV, they started avoiding me. I could feel it" (P17). Another participant described how this entered

everyday family life: “My parents never said it directly, but I could tell they still minded it. Even at meals, we ate separately” (P5). Together, these accounts suggest that stigma was not only encountered from others, but also absorbed into participants’ own emotional and relational experience of diagnosis.

Subtheme 1.3. Concealment, denial, and avoidance as early pathways to delay

Under the combined effects of exposure concerns and internalized shame, participants often responded through concealment, denial, and avoidance. These responses did not simply reflect passivity; they functioned as short-term forms of self-protection in a socially risky environment. As one participant put it, “ I could never tell other people about this. I did not even dare tell my parents. I had to carry it by myself. What I feared most was that others would find out” (P18). A related account showed how this logic also extended into minimizing the need for treatment: “ When I was first diagnosed, I did not feel physically uncomfortable. I usually do not even take medicine for a cold, so I did not take it very seriously” (P21). Taken together, these narratives indicate that delayed ART initiation often began with a process of concealment and avoidance, through which participants tried to preserve social safety before treatment could be considered as a medical necessity.

Theme 2. Living with delay: family negotiation and uncertain urgency sustained prolonged non-initiation

Once concealment had been established, delayed ART initiation did not simply resolve over time. Instead, it was sustained through ongoing family negotiation and persistent uncertainty about treatment urgency. Participants did not describe delay as a single refusal of ART, but as a prolonged and livable condition shaped by relational pressures, informal information, and the continuing sense that treatment could still wait.

Subtheme 2.1. Family was not a one-way source of support, but a relational field of ongoing negotiation

Family relationships shaped delayed ART initiation in complex and sometimes contradictory ways. For some participants, treatment was postponed because disclosure was feared to bring distress, shame, or emotional burden to parents or spouses. For others, responsibility toward family members later became a reason to seek treatment. As one participant explained, “ Sometimes I worried that if the hospital called my family because I was taking the medicine here, my parents would find out, and they definitely would not be able to handle it” (P12). In another account, family responsibility gradually made treatment feel necessary rather than avoidable: “ My mother often said that my child was still so young, and that I had to keep living and continue treatment for the child’s sake” (P6).

Subtheme 2.2. Treatment urgency was not self-evident, but was shaped by informal information and everyday interpretation

Participants did not always interpret treatment timing through formal medical advice alone. Instead, their sense of urgency was shaped by peer experiences, social media, acquaintances, and everyday comparisons with others who had delayed treatment. One participant said, “ When I was using drugs abroad before, I had already come across this kind of medicine. Some people around me also waited several years before starting it, and nothing seemed to happen, so I felt I could delay for a while too” (P2). A different but related account showed how informal information could also gradually reduce resistance: “ At first I could not accept it at all. Later, I saw on social media that many people had started taking the medicine and were still living normal lives, and only then did I gradually feel more at ease” (P12).

Subtheme 2.3. Symptom-free periods, concerns about side effects, and the sense that ‘ I was still okay’ reinforced waiting

Delayed ART initiation was further sustained when participants did not initially feel seriously ill. In the absence of obvious symptoms, many concluded that treatment was not yet necessary, while concerns about side effects reinforced the logic of postponement. One participant put it plainly: “ At the time, my test results were still okay, almost like a normal person’s, so I felt it was not a big problem and decided to leave it for later” (P22). Another participant emphasized how anticipated treatment reactions deepened this hesitation: “ I had heard from others that the medicine could cause strong reactions like nausea and diarrhea, so I was always afraid to take it” (P14).

Subtheme 2.4. From concealment to waiting: delay became a sustained condition of everyday life

Taken together, these accounts show that delay gradually shifted from an early strategy of concealment into a more durable state of waiting. Participants were not simply making a final decision against treatment; rather, they entered a condition in which postponement remained livable and repeatedly justifiable within everyday life. As one participant recalled, “ When I was first diagnosed, I did not feel physically uncomfortable. I usually do not even take medicine for a cold, so I did not take it very seriously” (P4). Another participant described a similar normalization of delay through comparison with others: “ Some people around me also waited several years before starting it, and nothing seemed to happen, so I felt I could delay for a while too” (P23).

Theme 3. Reaching a turning point: when support, symptoms, or reappraised risk moved patients toward ART

Although many participants described prolonged periods of concealment and waiting, delayed ART initiation was not permanent. Across interviews, ART initiation was rarely described as the result of a single cause. Rather, it emerged when support became available, symptoms made health risks more tangible, or the costs of continued delay were reappraised.

Subtheme 3.1. Support from family members and significant others helped break the state of waiting

Family relationships could sustain delay, but they could also become an important turning point toward ART initiation. For some participants, encouragement, acceptance, or a renewed sense of responsibility toward family members reduced the emotional cost of entering care and made treatment more possible. One participant said, " I had planned to just die, but in my family there was only my mother and me left. My mother was already over eighty. If I did not stay alive, what would happen to her?" (P3). A related account showed how family encouragement could reframe treatment as necessary: " My mother often said that my child was still so young, and that I had to keep living and continue treatment for the child's sake" (P16).

Subtheme 3.2. Continued contact from healthcare providers helped reconnect participants to treatment

Healthcare providers also played an important role in interrupting prolonged non-initiation. In some cases, ART initiation required continued and nonjudgmental contact from professionals, which reduced isolation and helped reconnect participants to care after extended avoidance. As one participant recalled, " At first I had decided not to get treated at all. It was Doctor Zhang who kept calling to check on me and persuade me to come for medication. That was when I made up my mind to start treatment" (P20).

Subtheme 3.3. Symptoms and complications turned abstract risk into an immediate reality

A further turning point occurred when illness could no longer remain abstract. Once symptoms or complications appeared, the bodily costs of delay became immediate and difficult to ignore. One participant said, " Before, I really did not want treatment. But when the shingles flared up, it was unbearable, and that was when I truly realized that I could not delay any longer and had to come for treatment" (P9). Another participant described a similar shift from postponement to urgency when symptoms became visible and persistent: " Later, I started to feel unwell. Red spots appeared on my body, and they were very itchy… That was when I felt I could not just leave it alone anymore" (P7).

Subtheme 3.4. Treatment initiation followed a reordering of risk rather than a sudden change of attitude

ART initiation was rarely described as a simple change of mind. Rather, it followed a reordering of risk: as symptoms emerged or the consequences of delay became harder to ignore, continued waiting came to feel more dangerous than treatment itself. One participant reflected this shift clearly: " When I was first diagnosed, I did not feel physically uncomfortable… Only later, when I could no longer hold on, did I realize it was serious" (P13). Another participant expressed the same transition more decisively: "

Before, I really did not want treatment. But when the shingles flared up, it was unbearable, and that was when I truly realized that I could not delay any longer" (P8).

Theme 4. A socially embedded pathway from delay to ART initiation in a border setting

Taken together, the findings suggest that delayed ART initiation in this border setting was neither a static accumulation of barriers nor a simple refusal of treatment after diagnosis. Instead, it unfolded as a socially embedded pathway that moved through concealment, prolonged waiting, and eventual ART initiation. Participants first encountered diagnosis as a problem of social visibility, then remained in a condition of waiting shaped by family negotiation and uncertain treatment urgency, and eventually entered treatment when support emerged, symptoms became harder to ignore, or the risks of continued delay were reappraised.

Subtheme 4.1 From concealment to waiting: delay developed as a staged process

Across participants' narratives, delayed ART initiation did not emerge as a single decision made at one point in time. Rather, it developed in stages. Initial concealment created the conditions for a longer period of waiting, during which postponement became easier to sustain because participants had not yet entered stable treatment routines and continued to manage diagnosis through everyday avoidance. As one participant reflected, " I could never tell other people about this. I did not even dare tell my parents. I had to carry it by myself. What I feared most was that others would find out" (P9). This kind of concealment did not end the process; it opened the way for prolonged non-initiation.

Subtheme 4.2. Social risk, family dynamics, and reappraised urgency operated as linked forces

The pathway from delay to ART initiation was shaped not by isolated factors acting separately, but by closely interconnected forces. Social risk initially made treatment feel dangerous, family relationships sustained both pressure and responsibility, and urgency was continually reinterpreted through symptoms, informal information, and changing life conditions. One participant described this shifting balance clearly: " At first I did not dare take the medicine because I wanted to hide it from my husband. Later, when he found out, he did not abandon me. He encouraged me to get proper treatment, and then I started coming regularly for medication" (P10). Another account showed how urgency was redefined when waiting no longer felt safe: " Before, I really did not want treatment. But when the shingles flared up, it was unbearable, and that was when I truly realized that I could not delay any longer" (P15). Together, these accounts show how social risk, family dynamics, and changing urgency worked together in moving treatment from avoidance to action.

Subtheme 4.3. The border setting functioned as a contextual condition rather than a standalone mechanism

The border setting mattered, but its role was mainly contextual rather than mechanistic. In participants' accounts, this context was reflected in close-knit social environments, population mobility, informal information flows, and socially connected interpretations of treatment timing. These conditions shaped how exposure, trust, and urgency were understood, even when they did not appear as explicit institutional barriers. As one participant explained, " When I was using drugs abroad before, I had already come across this kind of medicine. Some people around me also waited several years before starting it, and nothing seemed to happen, so I felt I could delay for a while too" (P19). This suggests that the border setting influenced the information environment and the perceived acceptability of delay, rather than acting as a single independent cause.

Subtheme 4.4. A process-based explanation beyond knowledge deficits

Overall, delayed ART initiation was better understood as a socially embedded and temporally unfolding pathway than as a simple consequence of insufficient knowledge. Participants were not merely failing to act because they lacked information; rather, they repeatedly weighed social exposure, family consequences, bodily risk, and the possibility of continuing everyday life without treatment. As one participant put it, " When I was first diagnosed, I did not feel physically uncomfortable… Only later, when I could no longer hold on, did I realize it was serious" (P21). This account captures the broader pattern across interviews: ART initiation occurred when the balance of risk shifted and the costs of waiting became greater than the anticipated costs of entering care.

Discussion

Delayed ART initiation was a socially embedded decision-making process rather than a simple knowledge problem

This study suggests that delayed antiretroviral therapy (ART) initiation in a border setting is better understood as a socially embedded decision-making process than as a straightforward consequence of insufficient knowledge, poor treatment motivation, or limited access alone. Participants did not describe delay as a single act of refusal after diagnosis. Rather, they moved through a staged process in which diagnosis first became a problem of social visibility, then evolved into prolonged waiting shaped by family negotiation and uncertain urgency, and finally shifted toward ART initiation when support emerged, symptoms became tangible, or risk was reassessed. This process-based account extends existing research showing that delayed ART initiation remains a substantial problem globally despite the expansion of rapid-treatment policies [33–36].

Previous studies have identified stigma, disclosure concerns, weak social support, fear of side effects, and difficulties engaging with care as important barriers to timely treatment [37–40]. However, these factors are often presented as parallel variables or barrier lists, with less attention to how they become organized into a prolonged process of delay in everyday life. The present study adds to this literature by

showing that delay did not persist because participants simply lacked information. Instead, it persisted because participants repeatedly weighed the anticipated social consequences of treatment against the bodily consequences of continued waiting. This interpretation is consistent with recent qualitative evidence showing that stigma and care engagement are intertwined and that treatment participation often reflects more than an informational deficit alone [41–43]. In this sense, the contribution of this study lies not only in identifying what barriers were present, but also in explaining how delayed ART initiation was formed, sustained, and eventually interrupted. The findings therefore move the discussion beyond obstacle identification toward a more context-sensitive account of how treatment delay unfolds as a socially situated and temporally structured process.

Social risk temporarily outweighed biomedical urgency

One of the central findings of this study is that the early phase of delayed ART initiation was not primarily triggered by ignorance of treatment importance, but by efforts to avoid social visibility. Participants often described the diagnosis first as a threat of being known, judged, talked about, or treated differently, rather than as an immediate medical imperative. In this border setting, ART initiation was not experienced simply as beginning medication. It also implied potential contact with designated services, follow-up arrangements, and forms of recognition that could expose one's HIV status within close-knit social networks [44–45]. This pattern resonates with recent qualitative work showing that care engagement under Treat All can increase the social visibility of HIV and that anticipated, enacted, and internalized stigma may shape whether and how individuals enter care.

This finding helps explain why delayed ART initiation may persist even under long-standing global consensus on early treatment. The issue is not only whether people know that treatment is beneficial, but whether entering treatment is perceived as socially manageable. Where the anticipated costs of exposure, gossip, moral judgment, or relational disruption are high, participants may prioritize the management of social risk over the management of biomedical risk, at least temporarily. In such circumstances, concealment and waiting can appear more tolerable than immediate treatment [46].

Conceptually, this suggests that delayed ART initiation should not be reduced to a health literacy problem alone. Participants were not simply uninformed; they were making decisions within a social world in which treatment itself could carry visible and relational consequences. The findings therefore support a broader interpretation of delay as socially situated decision-making, in which risk is evaluated not only in clinical terms but also in moral, relational, and social terms.

Family dynamics operated as both a sustaining force and a turning point

A second major finding is the dual role of family dynamics. Existing literature often emphasizes family support as a protective factor for HIV care engagement, adherence, and psychological adjustment. While this remains important, the present study suggests that family should not be understood only as a supportive resource. For some participants, family was also a source of concealment pressure,

anticipated shame, and relational burden. Concern about distressing parents, disrupting marriages, or bringing humiliation to the family made treatment more difficult to initiate, not less. This duality is consistent with qualitative evidence showing that close relationships may both facilitate and constrain engagement in HIV treatment and retention [47].

At the same time, family relationships also became one of the strongest drivers of treatment initiation. Responsibility toward children, aging parents, or spouses, together with moments of acceptance and encouragement, could gradually weaken the logic of concealment and waiting. Family therefore functioned not as a one-directional variable, but as a negotiated relational field in which pressure, obligation, care, and acceptance coexisted. This helps explain why treatment decisions were not made once and for all after diagnosis, but were continually revisited as participants reinterpreted the consequences of disclosure, delay, and survival within family life [48].

These findings broaden how family dynamics may be understood in research on HIV treatment decisions. Rather than reducing family to the presence or absence of support, the results suggest the need to consider family honor, disclosure negotiation, role responsibility, emotional dependency, and perceived relational stability. Such a perspective may better capture why family can both prolong non-initiation and create the conditions for treatment to begin.

The border setting shaped the information environment and urgency appraisal

The findings also indicate that the border setting was not merely a neutral background, but an important contextual condition shaping how participants interpreted treatment timing and risk. Participants described living in close-knit social environments characterized by interpersonal familiarity, mobility, informal communication, and exposure to mixed sources of information, including peer narratives, social media, and cross-border experiences. In this environment, judgments about when to start ART were not derived solely from formal clinical advice, but were filtered through everyday comparison, local experience, and socially circulated interpretations. This interpretation is consistent with recent work showing that mobility and movement across places and social environments are closely linked to HIV care engagement and can shape treatment trajectories in important ways [49].

Importantly, the role of the border setting in this study should be interpreted carefully. The data provide clearer support for the influence of cross-border experiences and informal information flows on urgency appraisal than for stronger claims about formal institutional barriers in cross-border continuity of care. In other words, the border setting appears to have shaped how participants understood exposure, whom they trusted, and whether treatment still seemed postponable. It should therefore be understood here primarily as a shaping context for social visibility, information environments, and risk interpretation, rather than as a fully demonstrated institutional mechanism in itself.

This boundary is important for maintaining analytic precision. The present study does not claim to have established a comprehensive model of transnational service coordination or structural cross-border

treatment discontinuity. Instead, it shows that border-related social environments can shape how delayed ART initiation is lived and interpreted. Future research could build on this by examining cross-border care trajectories more directly using multi-site or system-level data.

ART initiation followed a reordering of risk rather than a simple gain in knowledge

The findings further suggest that ART initiation was not an external event that happened after delay, but the outcome of a gradual weakening of the waiting logic that had previously sustained non-initiation. Earlier in the process, anticipated exposure, family shame, fear of treatment side effects, and the absence of symptoms made delay appear acceptable. Later, support from family members or clinicians, the onset of symptoms or complications, and greater awareness of the consequences of continued delay shifted participants' assessment of what was most urgent. This interpretation is consistent with research showing that stigma, family support, and engagement in care can jointly shape treatment participation rather than operate as isolated influences.

This means that ART initiation was not simply a move from ignorance to understanding. Rather, it was a move from one risk hierarchy to another. Initially, participants were attempting to avoid social exposure, relational rupture, and the emotional burden of treatment. Over time, physical suffering, health deterioration, and future uncertainty became harder to ignore. ART initiation occurred when the risks of continued waiting came to outweigh the social and emotional risks of entering treatment. In this sense, the present findings complement evidence that delayed treatment remains common while also suggesting why the transition from diagnosis to ART initiation may be prolonged even when the benefits of treatment are known.

This interpretation has practical importance. It suggests that promoting timely ART initiation requires more than repeatedly emphasizing biomedical benefits. What may matter just as much is whether the social and emotional costs of treatment can be reduced, and whether the consequences of continued delay can be made more understandable, concrete, and meaningful within everyday life .

Practical implications

The findings suggest that interventions aimed at promoting timely ART initiation in border settings should move beyond health education alone. If delayed initiation begins as an effort to avoid social visibility, then improving knowledge without reducing exposure-related concerns may have limited impact. Practical efforts should therefore include strengthening confidentiality protections, reducing patients' fear of being recognized in designated services, and supporting nonjudgmental communication throughout the treatment initiation process [50].

The findings also indicate that family should not be treated as a uniformly positive support system. Family can contribute to delay when diagnosis is tied to shame, concealment, or fear of burdening

others, but it can also become a strong source of treatment motivation. Interventions may therefore need to be more relationally sensitive, distinguishing when privacy should be protected, when key family members might appropriately be involved, and how shame, responsibility, and acceptance can be addressed in communication [51].

In addition, for patients who remain in prolonged states of waiting, general information about treatment benefits may not be enough. More effective support may involve helping them reassess the consequences of continued delay, addressing concerns about side effects, and providing sustained relational contact through clinicians or peers. Such efforts may be especially important in settings where informal information is pervasive and treatment urgency is not self-evident.

Strengths and limitations

This study has several strengths. It provides an in-depth phenomenological account of delayed ART initiation in a border setting and moves beyond a static barrier-based framework by offering a staged and process-oriented explanation of how delay was formed, sustained, and interrupted. In addition, the interpretation of the border setting remains analytically cautious, avoiding stronger claims where direct evidence is limited.

Several limitations should also be acknowledged. Participants were recruited from two HIV-designated hospitals, and all had eventually initiated treatment; thus, the findings may not fully capture the experiences of people who have never entered care or who remain outside treatment systems. Because the study was conducted in a specific border context, transferability to other settings should be considered cautiously. Finally, although cross-border experiences and informal information flows emerged repeatedly in the data, the study did not generate sufficient direct evidence to support stronger claims about institutional barriers to cross-border continuity of care. Future research could address these limitations by including untreated populations, comparative settings, or longer-term treatment trajectories, particularly in relation to mobility and care engagement across contexts [52–53].

Conclusions

This study adopted descriptive phenomenology to explore experiences and causes of delayed ART initiation among people living with HIV in southwestern border areas. It revealed this as a socially embedded process shaped by social risk, family dynamics and contextual uncertainty, and underscored that interventions should integrate confidentiality, stigma-sensitive support and relational contexts.

Abbreviations

ART
Antiretroviral therapy
COREQ
Consolidated Criteria for Reporting Qualitative Research

HIV
Human immunodeficiency virus
WHO
World Health Organization

Declarations

Ethics approval and consent to participate

This study was approved by the Ethics Committee of the First Affiliated Hospital of Dali University (Approval No. DFY20240726001). All procedures involving human participants were conducted in accordance with the standards of the institutional ethics committee and the Declaration of Helsinki and its later amendments. Written informed consent was obtained from all participants prior to data collection.

Consent for publication

Not applicable.

Competing interests

The authors declare that they have no competing interests.

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Author Contribution

Authors' contributions QH conceived and designed the study.YZ and XH conducted the interviews and collected the data. ML, HY, SK L and LC assisted with participant recruitment and coordination. YZ and QH analyzed the data and drafted the manuscript. QH critically revised the manuscript. All authors read and approved the final manuscript.

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Data Availability

Availability of data and materialsRelevant excerpts supporting the findings are included in the body of the manuscript. Full interview transcripts are not publicly available because they contain sensitive personal narratives that, even when de-identified, may carry a risk of deductive identification. In addition, permission for public dissemination of raw transcript data was not obtained during the consent process and was not approved by the ethics committee. De-identified data may be available from the corresponding author on reasonable request and subject to approval by the relevant ethics committee.

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