

# Decision-Making Processes and Illness Experiences among People with Chronic Hepatitis B Who Discontinued Oral Nucleos(t)ide Analogue Therapy without Medical Advice: A Qualitative Descriptive Study

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## Abstract

**Objective:** This study aimed to investigate how people with chronic hepatitis B make decisions, experience illness, and perceive support needs when they discontinue oral nucleos(t)ide analogue therapy without specialist assessment or medical guidance. **Methods:** We conducted a qualitative descriptive secondary analysis based on bedside semi-structured interview recordings. These interviews were originally collected in the infectious diseases and hepatology wards of a Chinese tertiary hospital between April and May 2026. From nine substantive transcripts, we screened and included seven interviews; two were excluded—one because prior oral antiviral exposure could not be confirmed, and another because the participant repeatedly denied any treatment interruption. Data analysis followed inductive qualitative content analysis, with analytic priority deliberately given to spontaneous narratives elicited before the delivery of health education. We interpreted interviewer prompts, family contributions, and negative cases with appropriate caution. **Results:** Five interconnected themes emerged: 1) Underestimation of risk driven by an illusion of clinical stability; 2) Self-directed trade-offs influenced by treatment burden, medication concerns, and expectations regarding alternative therapies; 3) Insufficient specialist decision support and family involvement; 4) An asymptomatic interval that paradoxically reinforced continued discontinuation and delayed help-seeking; and 5) Reconstruction of treatment beliefs only after severe clinical deterioration. These experiences traced a dynamic pathway: perceived stability, self-directed trade-offs, disruption of support, asymptomatic reinforcement, and ultimately, crisis-driven cognitive reconstruction. **Con-**

**clusions:** Discontinuing therapy without medical advice, as our data show, was rarely a simple matter of forgetting to take a pill. It instead reflected an interplay of misconceptions about disease control, the psychological weight of long-term therapy, beliefs in alternative treatments, gaps in professional and family support, and delayed somatic feedback. For nurses, these findings underscore the need to explicitly communicate that viral suppression is not equivalent to cure, to co-develop scenario-based medication continuity plans, to appropriately engage families, and to ensure proactive post-discharge follow-up.

## Keywords

Chronic Hepatitis B, Nucleos(t)ide Analogues, Treatment Discontinuation, Medication Adherence, Qualitative Research, Content Analysis

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## 1. Introduction

For individuals living with chronic hepatitis B (CHB), nucleos(t)ide analogues (NAs) currently represent the cornerstone of long-term viral suppression. Their consistent use has been shown to meaningfully lower the risks of disease progression, hepatic decompensation, and hepatocellular carcinoma. Leading international and national guidelines—including the 2024 World Health Organization (WHO) guidance, the Chinese Guidelines for the Prevention and Treatment of Chronic Hepatitis B (2022 version), and the 2025 European Association for the Study of the Liver (EASL) clinical practice recommendations—all uniformly emphasize the importance of sustained treatment, continuous monitoring, and retention in care [1]-[3]. It is acknowledged that a small and carefully selected subset of non-cirrhotic patients may stop therapy under strict specialist supervision with close post-treatment surveillance. However, the present study focuses on a different scenario: “discontinuation without medical advice.” This term refers specifically to interrupting or stopping therapy without specialist assessment or a structured monitoring framework—which is distinctly different from guideline-concordant, planned cessation [2]-[4].

Existing evidence indicates that adherence to oral antiviral regimens for CHB is suboptimal. A systematic review placed overall adherence at roughly 74.6%, with forgetfulness, limited appreciation of the rationale for continued treatment, and daily routine disruptions being the most commonly cited barriers [5]. Studies conducted in Chinese patient populations have further pointed to medication costs, personal beliefs about disease and treatment, follow-up logistics, and refill access as relevant contributing factors [6]. Moreover, real-world observations suggest that less-than-perfect adherence can translate into virological breakthrough and unfavorable clinical outcomes [7]. More recently, investigators have drawn attention to the cumulative treatment burden, medication accessibility, and the subjective lived experience of indefinite therapy as critical determinants of treat-

ment persistence [8]-[10].

Despite these insights, much of the previous literature has relied on questionnaires, pharmacy dispensing data, or prescription records to quantify adherence. While such methods can successfully identify who tends to be non-adherent, they offer relatively limited purchase in explaining why individuals who had previously taken their medication regularly, experienced improvements in laboratory values, or even explicitly knew that treatment should be continued, nevertheless decided to stop. Furthermore, they provide scant understanding of how a symptom-free interval immediately following cessation may inadvertently reinforce the decision to remain off therapy. To address these gaps, we designed this qualitative descriptive secondary analysis to explore the decision-making trajectory, illness experiences following clinical deterioration, and support needs among hospitalized CHB patients who had discontinued NAs without medical approval.

## 2. Methods

### 2.1. Study Design

We employed a qualitative descriptive design and used inductive qualitative content analysis to perform a secondary examination of existing interview recordings. The reporting of this study follows the Consolidated Criteria for Reporting Qualitative Research (COREQ) guidelines [11]-[13]; the completed 32-item checklist is provided as **Supplementary Material 2**. Ethical approval was secured from the institutional review board (approval no. A2024-552-01).

### 2.2. Data Source and Eligibility Criteria

The data for this secondary analysis came from audio-recorded bedside interviews conducted in the infectious diseases and hepatology wards of a tertiary hospital in China during April and May 2026. In their original context, these interviews were carried out as part of routine clinical nursing practice, with the dual intention of understanding patients' medication-taking experiences and providing tailored health education. Although the interview guide contained questions about antiviral treatment history and adherence, these conversations were not initially conceptualized as a formal research data collection exercise; rather, they were bedside dialogues that systematically explored medication-related issues in a conversational manner.

Participants were considered eligible if they: 1) were 18 years or older; 2) had a clinically established diagnosis of chronic HBV infection-related liver disease; 3) had a documented history of oral NA therapy; 4) had stopped treatment either continuously or intermittently without receiving an explicit recommendation to do so from a liver specialist; and 5) were able to articulate their reasons for stopping and the associated experiences. For analytic purposes, we operationally defined "discontinuation" as an interruption of oral NA therapy for at least 7 consecutive days, or intermittent gaps adding up to 14 days or more over a 3-month period, all occurring without specialist input (see **Supplementary Material 3** for the full operational definition and exclusion criteria). This definition was applied

retrospectively, drawing on participant and family accounts, complemented by medical record data wherever such information was available. Brief missed doses of 1 - 2 days that were promptly resumed were not categorized as discontinuation; however, participants who reported such brief omissions alongside longer interruptions were included if they met the overall definition.

Exclusion criteria comprised: 1) clinician-directed dose adjustments or planned discontinuations; 2) inability to verify prior oral antiviral treatment from the interview transcript or medical record; 3) explicit and repeated denial of any treatment interruption; and 4) absence of substantive interview content.

A total of nine substantive interview transcripts were initially reviewed. One was excluded because prior oral antiviral treatment could not be reliably confirmed, and another was excluded because the participant consistently denied ever interrupting treatment. This left seven interviews for inclusion. A separate audio file that contained only a recording prompt was not treated as a substantive interview. Since this was a secondary analysis of all available eligible data, prospective data saturation was not employed as a stopping criterion.

### 2.3. Original Data Collection

The original face-to-face interviews were conducted at the bedside by the nurse responsible for the patient when the patient was clinically able to participate. Family members supplemented several interviews. Questions addressed the initiation and continuation of antiviral treatment, immediate reasons for stopping, risk perceptions before and after discontinuation, consultation with health professionals, family involvement, physical changes after stopping, and views about future treatment (the core interview guide is provided as **Supplementary Material 1**). Based on the available audio timestamps, interview duration ranged from approximately 1.4 to 17.7 minutes. Because the interviewers also provided medication education during the encounters, the analysis of discontinuation motives prioritized spontaneous narratives obtained before education. Statements such as “I will never stop again” made after education were used only to illustrate immediate reflection and were not interpreted as evidence of sustained behavioral change.

### 2.4. Data Preparation and Analysis

After transcription, names, bed numbers, hospital identification numbers, and other identifying information were removed, and participants were labeled P1-P7. Cantonese and other dialect expressions were translated into standard written Chinese without changing their intended meaning before the English translation was prepared. Inductive qualitative content analysis was informed by the approaches described by Graneheim and Lundman and by Elo and Kyngas [12] [13]. The researchers repeatedly read the transcripts, identified meaning units related to treatment decisions, triggering situations, sources of support, symptom feedback, and consequences, condensed the meaning units, and assigned open codes. Similar and contrasting codes were compared and grouped into subthemes, which

were then abstracted into overarching themes and an explanatory process model.

Two researchers independently reviewed the complete dataset and recorded preliminary analytic memos. Initial coding was conducted line by line by both researchers independently. Conceptually similar codes were compared continuously, and candidate categories and themes were refined through repeated reference to the source transcripts. The two coders met regularly to compare coding decisions; disagreements were resolved through discussion and, when consensus could not be reached, by consultation with a third researcher (SO). A coding framework, records of theme revisions, and reflexive notes were retained as an audit trail.

To identify material recorded before health education, audio timestamps and transcript markers were used consistently for all seven interviews. Sections of the interview that occurred before the nurse initiated educational content were flagged during transcription and analysis. This allowed the research team to distinguish spontaneous participant accounts from responses that may have been influenced by subsequent educational content.

## **2.5. Strategies to Enhance Rigor**

To enhance credibility, the analysis repeatedly returned to the original quotations and distinguished participants' spontaneous accounts from family additions and interviewer explanations. Interviews that contradicted the initial label of "treatment discontinuation" were examined as negative cases and excluded when eligibility could not be established. Health education delivered by the interviewer was not coded as evidence of the participant's pre-existing beliefs. Theme labels were selected for clinical interpretability and were supported by accounts from multiple participants as well as by divergent experiences within the dataset.

## **2.6. Reflexivity**

The interviewers were registered nurses working in the infectious diseases/hepatology wards who had established therapeutic relationships with participants through routine clinical care. They were responsible for medication education and discharge planning, which created a dual role as both caregivers and data collectors. This relationship may have influenced participants' responses, particularly their expressions of intent to adhere to treatment in the future. The research team acknowledged that participants might have been motivated to present themselves as compliant or receptive to education, and that negative experiences or ongoing reluctance might have been underreported. To address this, the analysis gave priority to spontaneous narratives that occurred before educational content was introduced and interpreted post-education statements cautiously. The nurse-interviewers' clinical knowledge also facilitated accurate interpretation of medical terminology and treatment histories, which was an advantage for data quality. However, their involvement in participants' ongoing care meant that some conversations may have been shaped by existing clinical relationships and the perceived authority of the nurse. The research team discussed these influences throughout

the analysis and maintained reflexive notes to document how these considerations shaped interpretation.

### 3. Results

#### 3.1. Participant Characteristics

Seven participants were included: six men and one woman. Among participants with a recorded age, ages ranged from 30 to 65 years. Treatment interruption ranged from several days and intermittent gaps of 2 - 3 weeks to approximately 2 years. Most participants later developed jaundice, dark urine, fatigue, abdominal distension, vomiting, hepatic encephalopathy, or ascites and re-entered care after clinical deterioration. Participant characteristics are summarized in **Table 1**.

**Table 1.** Participant characteristics and features of treatment discontinuation.

| ID | Sex    | Age, y       | Diagnosis/complications at interview                           | Previous treatment history                                                           | Duration of discontinuation                                                           | Main triggers                                                                                                                                   |
|----|--------|--------------|----------------------------------------------------------------|--------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------|
| P1 | Male   | Not recorded | HBV-related liver disease; hepatic encephalopathy and ascites  | Treatment initiated approximately 1 year earlier                                     | Intermittent interruption for approximately 2 - 3 weeks during episodes of illness    | Concern that medication would increase the burden on the liver; interpreted negative HBV DNA as absence of risk                                 |
| P2 | Male   | 30           | Liver failure                                                  | Treated since adolescence; previously received lamivudine and later switched therapy | More than 1 year                                                                      | No symptoms, optimism bias, psychological resistance to long-term medication; no medical consultation                                           |
| P3 | Male   | 37           | Cirrhosis                                                      | Treated for approximately 3 years                                                    | More than 10 days in the current episode; occasional 1 - 2-day omissions previously   | Belief that taking or not taking treatment made no difference; alcohol use and forgetting; limited risk awareness                               |
| P4 | Male   | 63           | Chronic hepatitis B; hospitalized with abnormal liver function | Treated for approximately 20 years                                                   | Approximately 1 year                                                                  | Felt well; did not discuss the decision with family; disconnect between long-term follow-up and medication decisions                            |
| P5 | Male   | 40           | Chronic hepatitis B; severe liver injury                       | Treated for approximately 2 - 3 years                                                | Stopped abruptly after returning home for the Spring Festival; exact duration unclear | Ran out of medication/refill difficulties while away from home; subsequently self-administered traditional Chinese medicine                     |
| P6 | Female | 65           | Liver failure                                                  | Treated for several years                                                            | Approximately 2 years                                                                 | Normal liver function tests; followed advice from a relative who was not a liver specialist                                                     |
| P7 | Male   | 50           | Liver failure                                                  | Entecavir for 5 - 6 years                                                            | Not reported                                                                          | Refill inconvenience; belief that traditional Chinese medicine could cure the underlying cause; replaced antiviral therapy without consultation |

### 3.2. Theme 1: Risk Underestimation Created by an Illusion of Stability

#### 3.2.1. Equating the Absence of Symptoms with Improvement

Several participants relied primarily on their ability to eat, sleep, and work, and on the absence of obvious discomfort, to judge the severity of their illness. Feeling stable weakened the perceived necessity of long-term treatment and sometimes provided apparent confirmation that missing treatment was safe.

**P2:** *"I was just taking a chance. I had no symptoms... after missing it for a day or two and nothing happened, I stopped worrying about it."*

**P3:** *"It felt the same whether I took it or not."*

**P4:** *"I felt too well."*

#### 3.2.2. Interpreting Negative HBV DNA or Normal Liver Function as Cure

Some participants interpreted favorable test results during treatment as evidence that the disease had disappeared, rather than as an effect of continued viral suppression.

**P1:** *"The viral test was negative, so I thought there was no problem."*

**P6:** *"She said all my test results were good and my liver function was normal, so I did not need to take it anymore."*

This treatment-success paradox—treatment was effective, therefore treatment was believed to be unnecessary—formed an important cognitive basis for discontinuation.

### 3.3. Theme 2: Self-Directed Trade-Offs Driven by Treatment Burden, Medication Concerns, and Expectations of Alternative Therapy

#### 3.3.1. Concern That Medication Would Harm an Already Vulnerable Liver

When participants developed a cold, headache, or other temporary discomfort, some attempted to protect the liver by reducing the number of medicines they took. These decisions were not based on a confirmed adverse drug reaction but on the intuitive belief that taking more medicines would further burden the liver.

**P1:** *"When I caught a cold, I did not dare take it. I thought that because my liver was already bad, taking more medicine would add to the burden."*

#### 3.3.2. Psychological Resistance to Long-Term Treatment and Logistical Burden

Although taking one tablet daily was technically simple, years of continuous treatment created psychological resistance. Refill requirements and travel could convert an underlying wish to stop into an actual interruption.

**P2:** *"Of course I felt resistant to taking it."*

**P7:** *"It was troublesome to keep taking the medicine because I always had to come back for refills."*

P5 stopped abruptly after returning home for the Spring Festival because medication was unavailable and obtaining a refill was difficult, illustrating how travel and inadequate medication reserves can precipitate discontinuation.

### 3.3.3. Trust in Traditional Remedies and Non-Specialist Advice

Some participants believed that traditional Chinese medicine could replace anti-viral suppression, while others placed trust in familiar non-specialist advice or early subjective improvement.

**P7:** *“I heard that traditional Chinese medicine could cure the root cause, so I switched to it myself.”*

P5 first used traditional Chinese medicine after stopping and developing symptoms. P6 discontinued treatment after receiving advice from a relative who worked in a community clinic but was not a liver specialist. Across these experiences, interpersonal trust and cultural beliefs were prioritized over specialist reassessment.

## 3.4. Theme 3: Insufficient Specialist Decision Support and Family Involvement

### 3.4.1. Discontinuation Decisions Bypassed Specialist Consultation

None of the seven participants had obtained an explicit discontinuation recommendation from a liver specialist. Even when participants remembered being told that treatment should not be stopped, they lacked practical plans for common situations such as intercurrent illness, missed doses, travel, medication shortages, pregnancy planning, or suspected adverse effects. General prohibitions were therefore not translated into situation-specific decision-making skills.

### 3.4.2. Family Supervision Was Absent, Ineffective, or Deliberately Avoided

Several participants did not disclose the decision to stop treatment. P1 said the family “did not know,” and P4 stated, “I did not tell my son.” P2 concealed the decision because of concern that a medically knowledgeable sister would be angry. Conversely, P3’s family member regularly obtained medication and encouraged hospital attendance, suggesting that family involvement can be protective but may fail when communication is limited or punitive.

### 3.4.3. Knowledge Remained at the Level of Slogans Rather than Treatment Literacy

Participants could often repeat phrases such as “take it long term” or “do not stop,” but they could not explain why treatment was still necessary when symptoms were absent and test results were normal, nor did they know which indicators required monitoring after interruption. P2 said, “I did not know it could become so serious; this knowledge is not widely understood.” Remembering an instruction was therefore not equivalent to understanding the treatment mechanism.

## 3.5. Theme 4: An Asymptomatic Interval Reinforced Discontinuation and Delayed Help-Seeking

### 3.5.1. The Absence of Immediate Symptoms Provided False Reassurance

Most participants noticed no immediate physical change after stopping therapy.

P1 said, “At first I did not feel anything.” P2 felt well for a prolonged period after stopping for more than a year, and P4 initially experienced “nothing wrong.” This delay between discontinuation and perceptible deterioration encouraged participants to attribute short-term stability to the safety of their decision and reduced their motivation to restart treatment or seek monitoring.

### **3.5.2. Warning Symptoms Were Minimized until Deterioration Became Severe**

Participants later developed fatigue, jaundice, dark urine, abdominal distension, vomiting, poor appetite, or altered consciousness, but some delayed seeking care until eating was impaired or neurological symptoms occurred. P3 sought care only after becoming “bloated and vomiting everything I ate.” P4 developed abdominal distension and abnormal urine color months after stopping. P1 experienced recurrent hepatic encephalopathy and ascites. The combination of a symptom-free interval and limited recognition of warning signs contributed to delayed re-engagement with care.

## **3.6. Theme 5: Severe Consequences Prompted Reconstruction of Treatment Beliefs**

### **3.6.1. Recurrence Imposed Physical, Financial, and Daily-Life Costs**

After discontinuation, participants experienced hepatitis relapse, jaundice, liver failure, ascites, or hepatic encephalopathy; some required transfer to another hospital or artificial liver support. P6 developed fatigue, jaundice, and dark urine approximately 2 years after stopping and did not improve after more than 10 days of hospitalization elsewhere. P7 developed marked jaundice and substantially elevated aminotransferases after replacing entecavir with traditional Chinese medicine. P1 commented that stopping treatment ultimately meant “spending much more money.” Severe deterioration converted an abstract risk into a personal experience.

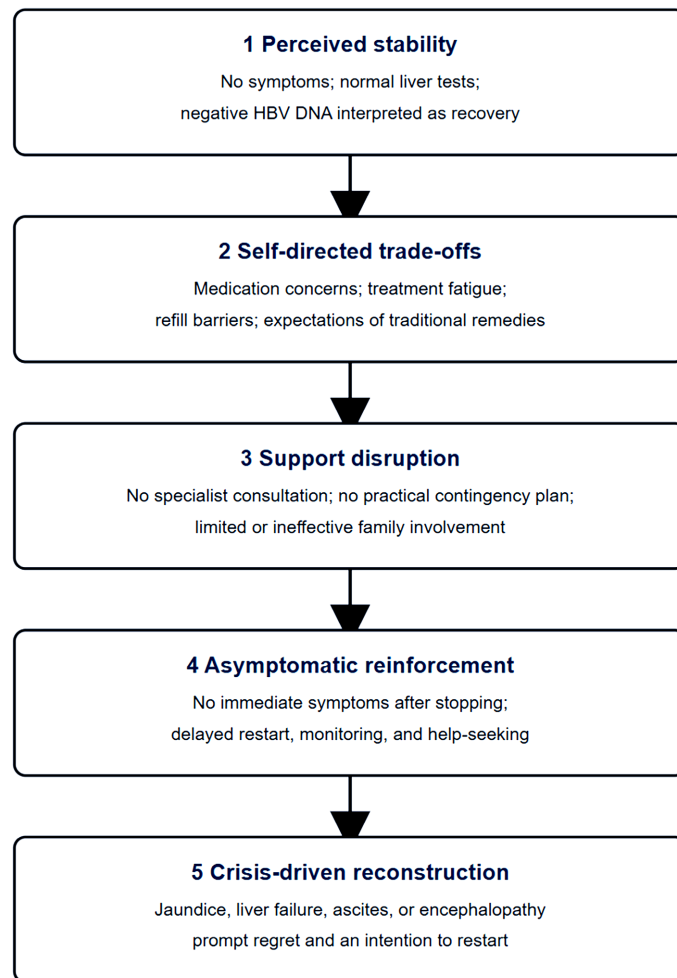
### **3.6.2. Crisis Generated Immediate Regret and an Intention to Restart**

After deterioration and education from the nurse, most participants expressed an intention not to stop treatment again. P6 said, “I will never stop it by myself again; I must listen to a specialist.” P7 said, “I will never experiment on myself like that again.” When P2 was asked whether treatment would be stopped again, the response was, “How could I?” Because these statements were made during hospitalization and after direct education, they represent immediate belief reconstruction rather than evidence of sustained adherence after discharge.

## **3.7. A Dynamic Model of Treatment Discontinuation**

The themes suggest that discontinuation was not a single event but a dynamic process repeatedly reinforced by the absence of immediate symptoms. Treatment-related improvement and perceived clinical stability created the impression of recovery. Medication concerns, treatment fatigue, alternative-treatment expectations, or medication shortages then prompted self-directed trade-offs. Lack of spe-

cialist consultation and ineffective family communication removed opportunities for correction. Short-term well-being after discontinuation appeared to validate the decision, until severe symptoms and hospitalization led participants to reassess the value of antiviral treatment (**Figure 1**).



The pathway illustrates the dynamic process from perceived stability to crisis-driven belief reconstruction.

**Figure 1.** Dynamic pathway of discontinuing oral nucleos(t)ide analogue therapy without medical advice.

## 4. Discussion

### 4.1. The Treatment-Success Paradox Requires Explicit Differentiation between Viral Suppression and Cure

The most prominent finding was that participants interpreted an absence of symptoms, normal liver function, or negative/undetectable HBV DNA as evidence that treatment was no longer necessary. NAs primarily maintain viral suppression, and many people require long-term therapy; discontinuation should be considered only under strict eligibility criteria and close specialist monitoring [1]-[4]. If patients do not understand that favorable results may be a consequence of contin-

ued therapy, successful treatment can paradoxically weaken perceived risk. Education should therefore move beyond repeating “do not stop”. A simple causal explanation can link continued treatment to viral suppression and improved laboratory results, and link discontinuation to possible viral rebound and hepatitis relapse. Teach-back should be used to confirm that the explanation has been understood.

#### **4.2. Discontinuation Was an Active Decision Shaped by Treatment Burden, Health Beliefs, and Life Circumstances**

Previous reviews have identified forgetfulness, limited knowledge, and changes in routine as common adherence barriers [5], while research in China has also highlighted costs, refill access, and beliefs about disease and medication [6]. The present findings add that participants did not always passively forget treatment; instead, they actively weighed perceived risks and benefits during colds, travel, pregnancy planning, alcohol use, medication depletion, or exposure to traditional-medicine advice. Even when medication was affordable and available, psychological resistance to indefinite treatment and the belief that traditional remedies could “cure the root cause” could drive discontinuation. A qualitative study in the United States and Canada similarly described interacting patient-, clinician-, and health-system barriers, including limited access to reliable information and medication [8]. Interventions should therefore address why a person wants to stop and the situations in which stopping becomes most likely, rather than relying only on reminders.

#### **4.3. Professional Support Should Shift from Prohibition to Shared, Scenario-Based Planning**

Most participants remembered a general instruction to continue treatment, but they did not know what to do when practical problems arose. This gap between knowing the rule and knowing how to act suggests that antiviral initiation, stabilization, discharge, and refill visits should include written plans for high-risk situations. These plans should explain that treatment should not be stopped during a cold or another illness without specialist advice; suspected adverse effects should be documented and assessed promptly; medication should be reserved before travel and alternative refill channels identified; missed-dose management should follow product-specific instructions and clinical advice; pregnancy planning, surgery, and traditional medicine use should trigger medication review; and jaundice, dark urine, fatigue, abdominal distension, or altered consciousness should prompt urgent care. The emphasis should be on what the patient can do, rather than solely on the consequences of nonadherence.

#### **4.4. Family Involvement and Continuity of Care May Interrupt the Discontinuation Pathway**

Families played a dual role. Some relatives obtained medication and prompted care-seeking, while other participants concealed discontinuation or followed advice from

a relative without liver expertise. With the patient's permission, a key family member can be included in medication education, with explicit agreement about who monitors refills, who tracks appointments, and whom to contact when disagreements arise. Family involvement should not be reduced to criticism, because a punitive response may increase concealment. People with a history of discontinuation, low health literacy, frequent travel, reliance on alternative treatments, or limited family support may benefit from nurse-led risk stratification, early post-discharge telephone or online follow-up, refill reminders, and coordination across health facilities. The WHO 2024 guidelines likewise identify adherence support and retention in care as essential components of high-quality HBV services [1].

#### **4.5. Crisis Can Change Immediate Beliefs but Does Not Guarantee Long-Term Adherence**

Clinical deterioration during hospitalization led most participants to express regret and an intention to restart treatment. However, the interviewer was also the nurse providing risk education, and responses may have been influenced by the care relationship and social desirability. A recent global survey emphasized the importance of understanding adherence in the context of patients' lived experiences and values [10]. Statements such as "I will never stop again" should therefore not be treated as the endpoint of an intervention. After stabilization, clinicians should reassess unresolved concerns, medication access, and long-term plans, and should verify continuity using refill records, HBV DNA monitoring, and follow-up attendance.

#### **4.6. Limitations**

This study has several limitations. First, it was a single-center secondary analysis of retrospective bedside interviews with hospitalized patients, most of whom had already experienced obvious clinical deterioration. The findings may therefore overrepresent severe consequences and may not reflect people who discontinued treatment without developing a major relapse. Second, the sample was small and included only one woman. Third, several interviews were brief, and some transcripts contained incomplete speech or family responses, limiting the depth of the accounts. Fourth, the interviewers were also the participants' nurses and health educators, and several questions were leading; although the analysis prioritized spontaneous pre-education narratives, social desirability and authority effects could not be eliminated. Fifth, standardized verification of HBV DNA, liver function, cirrhosis stage, specific medication, and exact discontinuation date was not available for all participants. Future research should triangulate interviews with clinical and dispensing records and recruit community and outpatient participants, including people who have not experienced severe relapse.

### **5. Conclusion**

Discontinuation of oral NAs without medical advice among people with CHB

emerged as a dynamic process shaped by an illusion of stability, misconceptions about disease and medication, long-term treatment burden, expectations of alternative therapy, gaps in specialist and family support, and delayed symptom feedback. Clinical deterioration generated immediate regret but did not automatically translate into sustained adherence. Care should therefore emphasize that viral suppression does not equal cure, provide executable medication-continuity plans for high-risk situations, strengthen access to specialist advice, involve families appropriately, ensure medication reserves, and provide proactive follow-up after discharge. The goal should shift from preventing a single missed dose to interrupting the entire decision pathway that leads to discontinuation.

### Author Contributions

Conceptualization, J.W., L.L., and M.Z.; methodology, J.W., L.L., and M.Z.; validation, J.W., L.L., and S.O.; formal analysis, J.W., L.L., and S.O.; investigation, J.W., L.L., and S.O.; resources, M.Z.; data curation, J.W., L.L., and S.O.; writing—original draft preparation, J.W. and L.L.; writing—review and editing, S.O. and M.Z.; visualization, J.W.; supervision, M.Z.; project administration, M.Z. All authors have read and agreed to the published version of the manuscript.

### AI-Assisted Tool Disclosure

During the preparation of this work, the authors used Youdao Translation and ChatGPT solely for language polishing and grammar correction to improve the readability and fluency of the English manuscript. All translation outputs and grammatical suggestions were critically reviewed, verified, and modified by the authors to ensure accuracy, scientific integrity, and fidelity to the original clinical data and patient narratives. The authors take full and ultimate responsibility for the final content, including all interpretations and conclusions presented in this manuscript. No generative AI tools were used to generate the core scientific data, analytical frameworks, or conceptual ideas of this study.

### Conflicts of Interest

The authors declare no conflicts of interest regarding the publication of this paper.

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## Supplementary Material

### Supplementary Material 1: Original Interview Guide

The following core questions guided the bedside interviews. The order and wording were adapted flexibly to the clinical context and patient responses. Questions marked with an asterisk (\*) were included for informational purposes and were not systematically asked of all participants.

#### Medication History

- 1) What antiviral medication were you taking, and for how long?
- 2) When did you start treatment? Who prescribed it?
- 3) Were you taking the medication regularly before you stopped?

#### Reasons for Stopping (asked of participants who reported discontinuation)

- 4) Can you tell me about when you stopped taking the medication?
- 5) What were the main reasons you decided to stop?
- 6) Did you have any concerns about the medication before you stopped?
- 7) Did you experience any side effects or discomfort from the medication?
- 8) Had you been told that you should continue treatment long-term?

#### Risk Perceptions and Decision-Making

- 9) What did you think would happen if you stopped the medication?
- 10) Did you notice any changes in how you felt after stopping?
- 11) Did you discuss stopping with your doctor, nurse, or family members? If not, why not?
- 12) Did you seek advice from anyone else (e.g., family, friends, traditional medicine practitioners)?

#### Health Status and Symptoms

- 13) Did you have any symptoms before you stopped the medication?
- 14) How did you feel in the period after stopping?
- 15) When did you first notice that something was wrong?

#### Family and Social Support

- 16) Does your family know about your hepatitis B treatment?
- 17) Do they help you manage your medication or appointments?
- 18) Did any family member support or influence your decision about treatment?

#### Future Treatment Plans

- 19) How do you feel about restarting treatment now?
- 20) What would help you continue treatment consistently in the future?
- 21) Is there anything that would make it easier for you to take the medication as prescribed?

#### Closing

- 22) Is there anything else you would like to share about your experience with hepatitis B treatment?

Note: The interview guide was designed to explore medication experiences in a conversational manner. In practice, nurses adapted questions based on the clinical situation and the patient's willingness to engage. The guide was not formally pi-

lotted but was developed based on clinical experience and literature review.

## Supplementary Material 2: COREQ Checklist

| Item                                           | Description                                                                                       | Location in manuscript   |
|------------------------------------------------|---------------------------------------------------------------------------------------------------|--------------------------|
| <b>Domain 1: Research team and reflexivity</b> |                                                                                                   |                          |
| 1) Interviewer/facilitator                     | Nurse-interviewers were registered nurses in the infectious diseases/hepatology wards             | Section 2.6              |
| 2) Credentials                                 | Registered nurses                                                                                 | Section 2.6              |
| 3) Occupation                                  | Nurses providing clinical care and medication education                                           | Section 2.6              |
| 4) Gender                                      | Two female interviewers                                                                           | N/A                      |
| 5) Experience and training                     | Experienced in hepatology nursing and patient education; no formal qualitative training specified | N/A                      |
| 6) Relationship established                    | Participants were known to interviewers through clinical care                                     | Section 2.6              |
| 7) Participant knowledge of interviewer        | Participants knew interviewers as their nurses                                                    | Section 2.6              |
| 8) Interviewer characteristics                 | Nurse-interviewers with clinical expertise; dual role as caregivers and data collectors           | Section 2.6              |
| <b>Domain 2: Study design</b>                  |                                                                                                   |                          |
| 9) Methodological orientation                  | Qualitative descriptive design; inductive qualitative content analysis                            | Section 2.1              |
| 10) Sampling                                   | Consecutive sampling of available eligible interview recordings                                   | Section 2.2              |
| 11) Method of approach                         | Bedside interviews during hospitalization                                                         | Section 2.3              |
| 12) Sample size                                | 7 interviews                                                                                      | Section 2.2              |
| 13) Non-participation                          | Not applicable (secondary analysis of existing recordings)                                        | N/A                      |
| 14) Setting                                    | Infectious diseases/hepatology wards, tertiary hospital, China                                    | Section 2.2              |
| 15) Data collection setting                    | Bedside, during hospitalization                                                                   | Section 2.3              |
| 16) Presence of non-participants               | Family members present in several interviews                                                      | Section 2.3              |
| 17) Interview guide                            | Core questions provided as Supplementary Material                                                 | Supplementary Material 1 |
| 18) Repeat interviews                          | No                                                                                                | N/A                      |
| 19) Audio/visual recording                     | Audio-recorded                                                                                    | Section 2.3              |
| 20) Field notes                                | Not systematically recorded                                                                       | N/A                      |
| 21) Duration                                   | 1.4 to 17.7 minutes                                                                               | Section 2.3              |
| 22) Data saturation                            | Not applicable (secondary analysis of all available eligible data)                                | Section 2.2              |
| 23) Transcripts returned                       | Not returned to participants                                                                      | N/A                      |

**Continued**

| <b>Domain 3: Analysis and findings</b> |                                                                           |             |
|----------------------------------------|---------------------------------------------------------------------------|-------------|
| 24) Number of coders                   | Two independent coders (JW, LL); third researcher (SO) for disagreements  | Section 2.4 |
| 25) Description of coding tree         | Coding framework retained as audit trail                                  | Section 2.4 |
| 26) Derivation of themes               | Inductive; data-driven                                                    | Section 2.4 |
| 27) Software                           | Not specified                                                             | N/A         |
| 28) Participant checking               | Not performed                                                             | N/A         |
| 29) Quotations presented               | Yes, with participant identifiers                                         | Section 3   |
| 30) Data and findings consistency      | Theme labels supported by multiple participants and divergent experiences | Section 2.5 |
| 31) Clarity of themes                  | Themes clearly stated and described                                       | Section 3   |
| 32) Negative case analysis             | Examined; excluded cases discussed                                        | Section 2.2 |

### **Supplementary Material 3: Operational Definition of Discontinuation**

For the purposes of this study, “discontinuation without medical advice” was defined using the following criteria:

Definition: Interruption of oral nucleos(t)ide analogue therapy without specialist assessment or recommendation, characterized by:

Continuous period of at least 7 days without taking the prescribed medication,  
OR

Intermittent gaps totaling 14 days or more over a 3-month period

Exclusions from classification as “discontinuation”:

Brief missed doses of 1 - 2 days that were promptly resumed and did not represent a pattern of interruption

Clinician-directed treatment adjustment or planned discontinuation

Treatment interruption due to severe adverse effects that prompted immediate specialist consultation

Application: This operational definition was applied retrospectively based on available information from participant accounts, family reports, and medical records where available. For participants reporting intermittent gaps (e.g., P1, P3), the cumulative duration of interruptions over the relevant period was assessed against the definition.