

Digital Illness Narratives of Chinese Adults With Coronary Heart Disease on Douyin: A Qualitative Narrative Analysis

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Abstract

Background

Coronary heart disease (CHD) disrupts patients' bodily experiences, everyday routines, social roles, and sense of self. Although digital platforms have become important spaces for sharing illness experiences, seeking support, and negotiating health-related identities, how Chinese patients with CHD construct longitudinal illness narratives on short-video platforms remains underexplored.

Objective

To examine how Chinese patients with CHD construct illness narratives and negotiate bodily confidence, treatment uncertainty, family responsibility, and peer support on Douyin.

Methods

This qualitative study combined inductive thematic coding with culturally and critically informed narrative interpretation. Longitudinal first-person posts were purposively collected from 14 noncommercial Douyin accounts. The dataset included video and image-text posts documenting experiences from symptom recognition and diagnosis through treatment, rehabilitation, follow-up, and daily life with CHD.

Results

Four interrelated narrative types were identified. The alarm and misrecognition narrative captured patients' initial interpretation of ambiguous symptoms as ordinary fatigue or gastrointestinal discomfort and the diagnostic shock that followed. The therapeutic uncertainty narrative reflected patients' concerns about treatment decisions, medication, restenosis, and recurrent symptoms, as well as their efforts to understand and negotiate medical information. The embodied reconstruction narrative illustrated how patients gradually rebuilt bodily confidence through medication routines, symptom monitoring, lifestyle modification, and incremental physical activity. The negotiated responsibility and digital solidarity narrative highlighted the renegotiation of family, work, caregiving, and financial responsibilities, alongside the use of Douyin for illness disclosure, experiential knowledge exchange, and peer support. Across these narratives, CHD was constructed not as a single biomedical event but as an ongoing process of bodily, relational, and identity reconstruction.

Conclusions

This study demonstrates how Douyin mediates culturally situated meaning-making among Chinese patients with CHD. It extends the concept of biographical disruption by showing that postdiagnosis adjustment is a dynamic and relational process shaped by treatment uncertainty, nonlinear rehabilitation, family responsibilities, and digital peer interaction. The findings highlight the need for culturally sensitive and platform-aware approaches to cardiovascular health communication, cardiac rehabilitation, and long-term patient support.

1 Introduction

Coronary heart disease (CHD) remains a major cause of morbidity, mortality, and long-term disability worldwide[1]. Epidemiological evidence[2] indicates that, in 2021, CHD accounted for 48.98% of deaths in rural areas and 47.35% in urban areas. Although advances in percutaneous coronary intervention (PCI), coronary artery bypass grafting, secondary prevention, and cardiac rehabilitation have improved survival, living with CHD continues to affect patients' bodily experiences, emotional well-being, social roles, and everyday routines[3]. Patients must adapt to long-term medication regimens and monitoring, modify their diets and physical activity patterns, and remain vigilant for recurrent symptoms or restenosis[4–6]. These demands can be particularly disruptive when the illness coincides with employment, caregiving, household responsibilities, and financial pressures[7–9]. CHD should therefore be understood not only as a cardiovascular condition requiring biomedical management but also as a chronic illness that may disrupt patients' biographies, identities, and relationships[3,10].

The experience of CHD often begins with uncertainty surrounding bodily symptoms[11]. Chest pressure, back tightness, sweating, dyspnea, fatigue, nausea, epigastric discomfort, or exercise intolerance may be interpreted as tiredness, gastrointestinal discomfort, or ordinary physical strain, particularly when symptoms are intermittent or atypical. Such interpretations can delay medical consultation and intensify the shock associated with emergency care and diagnosis[12]. The transition from being healthy to becoming a cardiac patient may challenge patients' assumptions about bodily safety, autonomy, and future life trajectories. Treatment itself can generate further uncertainty because patients must understand and navigate decisions regarding angiography, stent implantation, bypass surgery, medication, and subsequent rehabilitation[13]. After discharge, patients must rebuild trust in their bodies through gradual physical activity, dietary adjustment, symptom monitoring, and long-term self-management[14,15]. Within the Chinese sociocultural context, these experiences are also embedded in expectations concerning family responsibility, work, caregiving, and reciprocal support[13]. Consequently, CHD management is not simply an individual task but a relational process through which patients and families renegotiate everyday life and responsibilities.

Recent developments in digital media have increased the visibility of patients' lived experiences and created new spaces for documenting illness trajectories, exchanging practical knowledge, and seeking emotional support[16]. Short-video platforms such as Douyin enable users to combine first-person speech, captions, images, hashtags, embodied performance, and audience interaction to construct health-related narratives[17]. Through these multimodal formats, patients can retrospectively interpret

symptoms, describe diagnostic and treatment experiences, document rehabilitation practices, disclose illness identities, and connect with others who share similar conditions[18]. Digital narratives may transform private uncertainty into communicable experience and facilitate peer support, practical learning, and collective belonging[19]. At the same time, platform-mediated health communication may intensify self-surveillance, encourage comparisons among patients, and reinforce expectations that individuals should manage illness through continuous discipline and personal responsibility[20]. Although previous research has examined online illness narratives and digital support in chronic diseases, limited attention has been paid to how patients with CHD construct longitudinal narratives spanning symptom recognition, acute treatment, rehabilitation, and recurrent uncertainty on Chinese short-video platforms.

This study examines how Chinese patients with CHD narrate their illness experiences and negotiate identity, responsibility, and support through longitudinal posts on Douyin. Using qualitative narrative analysis of first-person video and image-text content, we ask the following questions: What recurring narrative patterns emerge from patients' digital accounts of CHD? How do these narratives reflect patients' experiences of symptom recognition, diagnosis, treatment, rehabilitation, family and work responsibilities, and online peer interaction? How does Douyin function as a space for reconstructing bodily confidence and illness identity? By combining inductive analysis with illness narrative theory and culturally informed interpretation, this study identifies 4 interrelated narrative forms. This study contributes to research on digital illness narratives by showing how CHD is experienced not as a single treatment episode but as an ongoing and socially mediated process of biographical adjustment.

2 Methods

Study Design

This study employed a qualitative narrative analysis approach informed by reflexive thematic analysis to examine how Chinese patients with coronary heart disease construct and negotiate illness experiences through longitudinal digital narratives on Douyin, a Chinese short-video social media platform[21]. The analysis combined inductive thematic coding with culturally and critically informed interpretation[22,23]. Rather than treating digital posts as transparent descriptions of patients' experiences, this study conceptualized them as narrative and meaning-making practices shaped by bodily sensations, treatment encounters, family relationships, social responsibilities, and the communicative affordances of short-video media. The analytical framework drew on illness narrative theory, particularly Frank's typology of restitution, chaos, and quest narratives, as well as sociological perspectives on biographical disruption, illness identity, social support, digital culture, and self-management[24,25]. Frank's illness narrative theory served as a sensitizing framework rather than a predetermined coding scheme. The narrative categories were generated inductively through iterative engagement with the data and were further interpreted in relation to symptom recognition, diagnosis, treatment, rehabilitation, family negotiation, and digitally mediated peer interaction within the Chinese context.

Data Source and Sampling Strategy

Data were collected from Douyin, a Chinese short-video platform that enables users to share personal experiences through videos, captions, hashtags, images, and spoken narratives[25,26]. The platform is characterized by highly visual and interactive user-generated content, making it a relevant setting in which to examine how patients publicly document illness experiences, communicate with imagined audiences, and participate in digitally mediated peer communities[27].

A purposive sampling strategy was used to identify information-rich accounts. The sampling process involved iterative searches using Chinese keywords related to coronary heart disease and cardiac rehabilitation, including "coronary heart disease," "myocardial infarction," "stent," "bypass surgery," "PCI," "restenosis," "cardiac rehabilitation," "long-term medication," and "follow-up visit." Accounts were considered eligible if they met the following criteria: (1) the account holder self-identified as living with coronary heart disease or described a clinically recognizable history of coronary heart disease, myocardial infarction, coronary intervention, coronary artery bypass grafting, or long-term secondary prevention; (2) the account contained first-person narratives related to symptoms, diagnosis, treatment, medication, rehabilitation, family life, or illness-related social interaction; (3) the account included longitudinal posts covering more than one stage of the illness trajectory; and (4) the content was noncommercial and not primarily promotional.

The final sample comprised 14 anonymized Douyin accounts, identified as P01 through P14. Sampling and analysis proceeded iteratively until additional accounts no longer generated substantially new narrative patterns, indicating informational redundancy. The account holders ranged in age from 35 to 68 years and included 8 men and 6 women. Five account holders were aged 18–44 years, 6 were aged 45–59 years, and 3 were aged 60 years or older. The observation periods for individual accounts began between January 1, 2023, and November 1, 2024, and all accounts were followed through July 14, 2026. The final dataset consisted of longitudinal video and image-text posts published by the 14 selected accounts. Account-specific demographic characteristics, index event dates, and observation periods are presented in Table 1.

Table 1. Characteristics of the 14 selected accounts.

Account ID	Age, y	Sex	Index event date	Observation period
P01	35	Male	February 18, 2024	November 20, 2023–July 14, 2026
P02	40	Female	June 7, 2024	March 1, 2024–July 14, 2026
P03	45	Male	November 14, 2023	August 20, 2023–July 14, 2026
P04	52	Male	May 9, 2023	February 1, 2023–July 14, 2026
P05	48	Female	March 21, 2024	December 10, 2023–July 14, 2026
P06	58	Male	August 16, 2023	May 1, 2023–July 14, 2026
P07	60	Female	January 12, 2024	October 1, 2023–July 14, 2026
P08	42	Male	October 3, 2023	July 1, 2023–July 14, 2026
P09	37	Male	February 17, 2023	January 1, 2023–July 14, 2026
P10	55	Female	July 26, 2024	May 1, 2024–July 14, 2026
P11	61	Male	September 5, 2023	June 1, 2023–July 14, 2026
P12	46	Female	April 11, 2024	January 1, 2024–July 14, 2026
P13	68	Male	June 20, 2023	March 1, 2023–July 14, 2026
P14	44	Female	February 9, 2025	November 1, 2024–July 14, 2026

Data Analysis

The analysis proceeded through iterative reading, inductive coding, thematic organization, and narrative interpretation[28]. All selected posts were read repeatedly to familiarize the researchers with the longitudinal illness trajectories. Open coding was conducted in Chinese to preserve linguistic and cultural meanings and focused on recurring patterns related to symptom perception, diagnostic delay, treatment experiences, medication and rehabilitation, bodily concerns, family responsibilities, economic pressures, illness disclosure, and online peer interaction. Initial codes were then compared within and across accounts and grouped into broader thematic categories through ongoing discussion. This process remained primarily data-driven and emphasized patterns emerging from patients' narratives rather than the application of predefined categories.

At a later stage, the analysis moved from descriptive themes to interpretive narrative analysis. Drawing on illness narrative theory, particularly Frank's typology, together with perspectives on biographical disruption, illness identity, family responsibility, and digital culture[24], the analysis examined how patients used Douyin to interpret bodily uncertainty, negotiate treatment and social roles, and reconstruct illness identities. Four interrelated narrative types were identified: alarm and misrecognition, therapeutic uncertainty, embodied reconstruction, and negotiated responsibility and digital solidarity. These categories were refined through iterative engagement with the data and treated as overlapping

and dynamic rather than mutually exclusive. Interpretive differences were addressed through repeated comparison with the original posts and collaborative discussion until consensus was reached.

Reflexivity and Rigor

This study adopted a reflexive approach to qualitative rigor, emphasizing transparency and interpretive awareness throughout the analytical process[29]. Credibility was strengthened through repeated reading and comparison of longitudinal video and image-text posts across the 14 accounts. Dependability was supported by documenting sampling decisions, coding procedures, and the development of the 4 narrative categories. The researchers also reflected on how their cultural familiarity, clinical assumptions, and perspectives on family responsibility, rehabilitation, and online peer support might shape the interpretation. Differences in interpretation were addressed through continued discussion and comparison with the original Chinese posts. Transferability was supported by providing contextual descriptions of the patients' illness trajectories and the Douyin platform environment.

Translation and Positionality

All analyses were conducted in Chinese to preserve the integrity of the original narratives, particularly patients' descriptions of bodily symptoms, treatment experiences, family responsibilities, rehabilitation, and peer interaction. Selected excerpts were translated into English by the author (SYT) and independently reviewed by other researchers (LT and WZQ) to ensure conceptual and contextual equivalence. Discrepancies were resolved through discussion. The research team's shared linguistic and cultural background facilitated the interpretation of colloquial expressions, platform-specific forms of address, and culturally embedded meanings related to coronary heart disease and family responsibility, while also constituting a potential source of interpretive bias. Reflexive discussion was therefore incorporated throughout the translation and analytical processes to examine how the researchers' cultural positions and theoretical assumptions shaped the interpretation of patients' narratives.

Ethical Considerations

This study analyzed publicly available social media content and did not involve direct interaction with users. Because this study analyzed only publicly accessible social media content without direct interaction with users, and all potentially identifying information was removed, the study followed institutional guidance for internet-based research ethics and was considered exempt from formal ethical review[30]. All accounts were anonymized using identifiers P01 through P14, and usernames, profile information, locations, and other potentially identifying details were removed. Because the narratives concerned sensitive information about coronary heart disease, treatment, family relationships, and financial pressures, excerpts were selected and paraphrased where necessary to reduce the risk of reidentification while preserving their substantive meaning. The study followed relevant institutional guidance and ethical recommendations for research using publicly accessible social media data and complied with the applicable terms of service of the Douyin platform. There were no human participants in this study, and informed consent was not required.

3 Results

3.1 Overview

Analysis of the longitudinal digital narratives of patients with coronary heart disease identified 4 interrelated narrative types: the alarm and misrecognition narrative, the therapeutic uncertainty narrative, the embodied reconstruction narrative, and the negotiated responsibility and digital solidarity narrative.

3.2 Alarm and Misrecognition Narrative

Overview

The alarm and misrecognition narrative captured how patients initially interpreted chest discomfort, fatigue, dyspnea, sweating, nausea, jaw pain, back tightness, or epigastric discomfort as ordinary tiredness, gastrointestinal discomfort, or temporary physical strain. The disease was initially experienced not as a clearly recognizable medical event but as an ambiguous bodily disturbance that was repeatedly normalized, thereby delaying its recognition.

Bodily Signals Misread as Ordinary Fatigue

Many patients described the period before diagnosis as a phase during which bodily warning signs were present but not recognized as manifestations of coronary heart disease. Chest tightness, shortness of breath, sweating, nausea, shoulder pain, back tightness, and unusual fatigue were repeatedly attributed to ordinary causes such as tiredness, gastrointestinal discomfort, or temporary overwork.

One patient recalled: *It began with chest pain, cold sweats, and a sense of impending doom during exercise. At the time, I simply thought I was tired and would be able to continue after a short rest.* [P08, October 1, 2023]

Another patient described a similar experience: *First, I felt uneasy in my upper abdomen, along with nausea and exhaustion, and then the chest pain began. At the time, I simply told myself that I was worn out and could continue after taking a short break.* [P02, March 1, 2024]

These narratives illustrate that delayed care-seeking was not attributable solely to a lack of medical knowledge. Rather, patients sought to preserve the continuity of everyday life by incorporating unfamiliar symptoms into familiar explanations[12]. As long as the symptoms were intermittent or subsided with rest, patients could continue to occupy the role of worker, parent, spouse, or household member rather than that of a seriously ill person. The intermittent nature of the symptoms further reinforced this misrecognition.

As one patient stated: *The symptoms were not constant during that period; they came and went, which made me feel even more strongly that I did not need to see a doctor.* [P03, August 20, 2023]

In this sense, the body did not immediately present itself as diseased. Instead, it communicated through ambiguous and episodic sensations that patients interpreted according to their existing understandings of fatigue, age, work pressure, or digestive problems. Valasaki et al. suggested that diagnostic delay could be understood as a process of negotiation between bodily signals and the demands of everyday normality rather than as an individual failure of vigilance[31]. Several patients also retrospectively identified risk factors that had been present before diagnosis, including smoking, hypertension, dyslipidemia, sedentary behavior, poor sleep, high-salt diets, metabolic abnormalities, family history, and chronic stress.

One patient reflected: *Looking back, the clues, such as long-term consumption of takeout food, insufficient sleep, and abnormal blood lipid levels, had been present all along. However, I never connected them with coronary heart disease.* [P01, January 4, 2024]

This retrospective reconstruction is important because it changes the meaning of the prediagnosis period. After diagnosis, ordinary details of patients' lifestyles were reinterpreted as previously overlooked clues. The past was reorganized from the standpoint of the present illness, and each patient's life history became a story of warning signs that had existed but remained unread.

From Delayed Recognition to Diagnostic Shock

The transition from ambiguous symptoms to a medical diagnosis constituted a major narrative turning point. Patients described the emergency department as a setting in which electrocardiography, cardiac biomarkers, coronary angiography, physicians' facial expressions, and urgent treatment decisions suddenly revealed the medical seriousness of their previously uncertain bodily experiences.

One patient described the moment of diagnosis as follows: *After my condition worsened, my family insisted that I go to the emergency department. The electrocardiogram, cardiac markers, and the doctor's expression immediately conveyed the seriousness of the situation.* [P01, February 17, 2024]

Another patient stated: *When I actually heard the terms 'myocardial infarction' or 'coronary heart disease,' my first reaction was not pain but disbelief that I had become a patient.* [P02, June 7, 2024]

The significance of the diagnosis lay not only in the medical label itself but also in the identity transformation it produced. Before diagnosis, patients could explain their symptoms as temporary discomfort and continue fulfilling their work and family obligations. After diagnosis, they had to recognize themselves as patients who might require emergency intervention, long-term medication, activity restrictions, and ongoing surveillance.

The emergency care pathway also disrupted patients' existing sense of control. Throughout registration, examination, and medical decision-making, patients continued to think about work, household affairs, and family responsibilities:

During the several hours between making the appointment and undergoing the examination, I was constantly thinking about work and family matters, until the doctor said that we could not delay any longer. [P03, November 16, 2023]

This account indicates that diagnosis was not experienced as an isolated biomedical event[32]. It entered an already structured life and immediately raised questions about work, income, family care, and future functioning. The patient was asking not only, 'What disease do I have?' but also, 'What will happen to my existing responsibilities now that I have become a patient?' This reflects the tension between maintaining everyday normality and acknowledging bodily vulnerability.

3.3 Therapeutic Uncertainty Narrative

Overview

The therapeutic uncertainty narrative reflected the emotional and practical uncertainty that emerged after diagnosis. Patients described disbelief upon hearing terms such as 'myocardial infarction' or 'coronary heart disease,' anxiety surrounding angiography, stent implantation, coronary artery bypass grafting, restenosis, and repeat intervention, and the need for physicians to explain treatment options, risks, and long-term management in an understandable manner.

Treatment Decisions as a Process of Information Negotiation

After diagnosis, patients' central concerns shifted from 'What is happening to my body?' to 'What treatment should I choose, and what will happen after treatment?' Angiography, stent implantation, medication therapy, coronary artery bypass grafting, drug-coated balloon treatment, restenosis, and repeat intervention were not described merely as technical procedures. Instead, patients experienced them as moments that required interpretation, explanation, and personal decision-making.

One patient explained: *Regarding 'coronary angiography and stent selection,' what I truly need is for the doctor to clearly explain the options, risks, and subsequent management, rather than simply naming a procedure.* [P02, June 8, 2024]

Similarly, another patient stated: *While in the hospital, I heard many unfamiliar terms. I wrote down those I did not understand in a memo on my phone and asked about them one by one.* [P03, November 26, 2023]

These accounts illustrate that patients were not passive recipients of medical treatment. They actively sought to translate technical terms into an understandable account of their own illness. Writing down unfamiliar terms, asking questions, comparing treatment alternatives, and requesting explanations became ways of regaining agency in an environment dominated by medical expertise.

The need for explanation was particularly pronounced when patients faced choices involving invasive interventions. The terms 'stent,' 'coronary artery bypass grafting,' 'PCI,' 'restenosis,' and 'repeat intervention' carried implications that extended beyond the immediate procedure. They implied long-term

medication, possible recurrence, changes in activity, economic costs, and altered perceptions of the body.

One patient described the emotional state after treatment: *Completing the treatment does not mean that I can immediately relax. The sounds of the monitor, the wound, and every heartbeat keep me on edge.* [P02, June 20, 2024]

Thus, treatment did not bring the illness narrative to a close. Instead, it opened a new period of uncertainty during which patients had to interpret bodily sensations, monitor for possible complications, and learn to live with the consequences of medical intervention.

Restenosis and Repeat Intervention as a Return of the Original Threat

For several patients, recurrence or possible restenosis disrupted the expectation that treatment would represent a definitive ending. The narratives repeatedly emphasized that having undergone surgery did not mean that the story was over. This statement functions as more than a description of clinical follow-up; it reorganizes the temporal structure of illness. The original treatment is no longer understood as a clear boundary between 'illness' and 'recovery.' Instead, the past illness may return through chest pain, sweating, dyspnea, shoulder discomfort, palpitations, or abnormal indicators.

One patient described the recurrence of symptoms as follows: *Recently, I experienced chest pain, toothache-like discomfort, and shortness of breath. That familiar sensation took me back to the time when I was first hospitalized.* [P09, July 25, 2024]

Another patient similarly stated: *The follow-up examination or reassessment made me realize that coronary heart disease is not something that can be completely resolved with a single treatment.* [P04, January 16, 2025]

These accounts indicate that CHD, as a chronic condition, is not amenable to a one-time cure and that symptoms may recur. Symptom recurrence can trigger anxiety, drawing patients back into the emotional atmosphere of the initial diagnosis. Moreover, awareness of the disease's long-term trajectory undermines patients' belief in the 'controllability' of their physical condition.

One patient described this experience: *At one point, I even considered stopping my medication and trying alternative treatments on my own because I was worried that taking medication over the long term would harm my health. After calming down, I did not act on this idea. Instead, I wrote down my concern and planned to take the medication box with me when consulting a cardiologist.* [P03, December 20, 2024]

This account is analytically significant because it contains both uncertainty and self-regulation. The patient experienced doubt about long-term medication use, considered an alternative course of action, and then redirected the concern toward professional consultation. The narrative does not present adherence as automatic compliance. Instead, medication-taking is constructed as an ongoing process of questioning, hesitation, consultation, and renewed decision-making. Furthermore, patients do not

simply seek recovery; they seek a form of recovery that is understandable, safe, sustainable, and compatible with their own life circumstances.

3.4 Embodied Reconstruction Narrative

Overview

The embodied reconstruction narrative illustrated how patients gradually rebuilt trust in their bodies through medication routines, blood pressure and lipid monitoring, dietary modification, and incremental physical activity. Rather than portraying recovery as a linear return to preillness functioning, patients increasingly described rehabilitation as a process of negotiating fluctuating symptoms, changing indicators, and persistent treatment demands.

Rebuilding Trust in the Body Through Gradual Activity

After discharge, patients' bodies became the central site of uncertainty and reconstruction. Patients described repeatedly checking their heart rate, interpreting minor discomfort, and worrying that physical sensations might signal stent failure, vascular obstruction, or disease recurrence.

One patient stated: *When I had just been discharged from the hospital, I had to check my heart rate repeatedly every few hundred meters. Any abnormality made me worry that there might be another problem with the stent or the blood vessels.* [P01, March 17, 2024]

This account illustrates the loss of embodied confidence after treatment. The patient could walk, but walking was no longer an unproblematic bodily action. It became an activity that required measurement, observation, and interpretation. The body was experienced simultaneously as capable of movement and as a potential source of danger.

Patients responded by dividing rehabilitation into small, measurable actions: *I divided the goal into walking, warming up, resting, and recording my heart rate. I did not aim to walk a long distance all at once.* [P02, July 31, 2024]

The meaning of 'a few hundred steps' extends beyond physical exercise. It represents a strategy for reconstructing bodily trust through manageable experiences. Rather than attempting an immediate return to their previous levels of activity, patients gradually rebuilt their relationship with their bodies by carefully coordinating exertion, rest, symptoms, and clinical indicators.

This process also challenged the ideal of recovery as a linear upward trajectory. One patient reflected: *I gradually came to accept that recovery is not a straight upward process. Sometimes I feel well, but at other times I feel tired, and the indicators also fluctuate.* [P02, November 5, 2024]

Acceptance of fluctuation is a central feature of the embodied reconstruction narrative. Recovery is represented not as a complete restoration of the former body but as the ability to continue living amid variability[33]. Patients learned to interpret temporary fatigue or changes in clinical indicators without

immediately viewing them as evidence of failure. Family protection generated an additional tension. Several patients reported that family members sought to restrict their activities out of concern, but excessive protection could also heighten their fear:

My family wanted to protect me, but doing nothing only made me more afraid. Eventually, I had to begin with very little physical activity. [P01, March 17, 2024]

Care protected patients from perceived physical risks, but it could also communicate that the body was fragile and incapable of ordinary activity. Patients sought a balance between receiving assistance and maintaining bodily autonomy.

Medication, Indicators, and the Routine Management of Uncertainty

Long-term medication use and monitoring became another major mechanism through which patients reconstructed everyday life. Antiplatelet agents, statins, antihypertensive medications, antianginal drugs, β -blockers, angiotensin-converting enzyme inhibitors, angiotensin receptor blockers, glucose-lowering medications, and other treatments were described as part of patients' daily routines. However, medication use was not represented as a simple or effortless form of self-management. Patients repeatedly mentioned side effects, missed doses, medication burden, and the desire to discontinue treatment:

Taking antiplatelet agents, statins, and β -blockers has become routine, but concerns about side effects and the risk of missed doses are also a reality. [P01, February 17, 2024]

The phrase 'With long-term medication, remembering to take it is not the hardest part' captures the emotional and symbolic burden of chronic treatment. The difficulty does not merely involve remembering a medication schedule. It also involves accepting that medication may remain part of one's life indefinitely, tolerating uncertainty about side effects, and continuing treatment even when symptoms are absent.

Patients also recorded their blood pressure, heart rate, lipid levels, left ventricular ejection fraction, and blood glucose levels. Yet these indicators were usually accompanied by a qualification: 'These values represent only this single measurement.' This qualification is narratively meaningful because it prevents a single measurement from being interpreted as a complete account of health. Patients used numbers to stabilize uncertainty, but they also recognized that numerical control could not eliminate all anxiety. A normal or improved measurement did not necessarily restore confidence, whereas a temporary abnormality did not automatically signify definitive deterioration. The practice of preparing records of medications, symptoms, and lifestyle behaviors before follow-up consultations also created a new form of agency:

Before each follow-up visit, I would organize my medications and records of symptoms and daily life, making the brief outpatient consultation more focused. [P01, July 24, 2024]

Through these records, patients transformed fragmented experiences into organized accounts that could be communicated to clinicians. Self-monitoring thus functioned not only as a health behavior but also as a narrative practice[34]. Patients used records to make their changing bodies more legible to themselves and to medical professionals.

The embodied reconstruction narrative encompasses bodily fear, cautious activity, measurement and recording, the gradual rebuilding of confidence, and acceptance of fluctuation. It does not portray patients as having overcome the disease but shows how they reconstruct a livable relationship with a body that remains vulnerable, monitored, and uncertain.

3.5 Negotiated Responsibility and Digital Solidarity Narrative

Overview

The negotiated responsibility and digital solidarity narrative highlighted how coronary heart disease reorganized family labor, employment, caregiving, income, and medical expenses. Patients used digital platforms to disclose their illness identities, seek understanding from peers, evaluate online health information, and distinguish experiential knowledge from professional medical advice[18]. Across these narratives, coronary heart disease was constructed not simply as a biomedical condition, but as an ongoing reorganization of bodily trust, everyday responsibilities, and social relationships.

Family Roles, Work, and the Redistribution of Responsibility

Coronary heart disease disrupted not only patients' bodies but also the organization of family life[35]. Patients repeatedly described work, income, caregiving, household labor, medical expenses, and family responsibilities as concerns that became more difficult to manage once illness became part of everyday life.

One patient stated: *After returning to everyday life following illness, returning to work, coping with financial pressure, and dealing with conflicts in family roles are more difficult than they were during hospitalization because these issues involve income, caregiving, and the division of labor within the family.* [P01, January 4, 2024]

These accounts demonstrated that discharge did not mark the end of illness-related pressures. In the hospital, the primary concerns were immediate survival and treatment. After returning home, patients had to negotiate who would work, who would provide care, who would manage household activities, who would accompany them to follow-up appointments, and how medical expenses would be covered[36]. Illness narratives also varied according to patients' social positions. For some, the disease threatened employment and income. For others, it disrupted responsibilities toward children, older parents, spouses, or grandchildren.

One patient described this constraint: *Caring for older adults and grandchildren leaves little time for follow-up visits and exercise.* [P10, September 10, 2025]

Another patient described limited access to medical resources: *Resources for cross-regional follow-up visits and rehabilitation are limited.* [P06, May 1, 2023]

These accounts suggest that long-term rehabilitation is shaped by social arrangements beyond patients' individual motivation. Regular follow-up, exercise, dietary management, medication use, and symptom monitoring all require time, money, transportation, family coordination, and access to medical services. Patients gradually moved away from bearing all responsibilities alone.

One patient stated: *I discussed work, household chores, and follow-up appointments with my family again and decided not to place all the responsibilities on one person.* [P01, May 13, 2024]

This statement marks a change in the meaning of independence. Before illness, independence may have meant doing everything without assistance. After illness, it came to mean being able to communicate one's needs, define what one could do, accept help when necessary, and coordinate responsibilities with family members. At the same time, family support remained complex. Patients often noted that family members' concern could lead to overprotection:

Spouses, parents, and fellow patients online are currently the main sources of support. However, their concern can sometimes lead to overprotection. [P01, February 9, 2024]

Family care occupied an ambivalent position. It provided emotional and practical support, but it could also limit autonomy and reinforce the image of the patient as fragile. The family was not simply a source of support; it was also a site where care, dependence, responsibility, protection, and autonomy were continuously negotiated.

Disease Disclosure and Reciprocal Digital Support

Patients used digital platforms to reorganize their relationships with illness and with others. They disclosed their illness identities, shared treatment experiences, and sought advice. One patient explained the motivation for disclosing their illness online:

On the platform, I talked publicly about my illness status, hoping to gain understanding from my peers while reminding myself to distinguish fellow patients' experiences from professional advice. [P01, June 18, 2024]

This statement reveals two simultaneous purposes of digital narration. First, disclosure creates opportunities for recognition. Patients can be understood by people who share similar experiences and do not require them to explain every aspect of their condition. Second, disclosure requires patients to establish boundaries around knowledge. Peer experiences may offer emotional support and practical suggestions, but they cannot replace individualized medical advice. Patients repeatedly emphasized this boundary:

Someone online suggested adjusting exercise and medication solely on the basis of one's physical sensations. I was quite tempted by this idea, but I was also concerned that my condition might differ from

that of others, so I decided not to follow the advice blindly. [P01, February 21, 2024]

The digital community did not function simply as a source of reliable information. It was a space of negotiation in which patients compared experiences, evaluated advice, recognized individual differences, and decided what could or could not be applied to their own situations[16]. Patients also used digital platforms to transform individual experiences into collective reminders. Their posts often contained cautionary statements such as: "Personal experience should not be treated as the solution to a problem." "Everyone still needs to make plans based on their test results and their doctor's advice." These statements show that patients did not merely reproduce medical authority or blindly follow peer advice. Instead, they occupied an intermediate position between lived experience and professional knowledge. They shared personal narratives while simultaneously limiting the authority of those narratives.

Digital expression also helped patients construct a public identity that was not reducible to the disease itself. One patient wrote: "Disease alters the pace of life, but it does not take away life itself." This statement represents a process of identity reconstruction. Coronary heart disease changes the pace of life and introduces medication use and health monitoring, but it does not completely erase patients' previous lives, aspirations, relationships, or social roles. Through the digital solidarity narrative, patients transformed isolated experiences of fear and uncertainty into shared accounts of navigating, learning, and continuing to live with coronary heart disease.

Narrative Intersections

The 4 narrative types were closely interconnected rather than mutually exclusive or strictly sequential. A single post could simultaneously contain diagnostic disruption, treatment uncertainty, bodily reconstruction, family negotiation, and digital support.

For example, a patient might describe recurrent chest discomfort, recall the original emergency admission, contact the hospital, record the relevant symptoms, discuss the experience with family members, and share a cautionary reminder online. In this process, recurrence reactivates the alarm and misrecognition narrative, while seeking medical consultation reflects the therapeutic uncertainty narrative. Recording symptoms and contacting clinicians represent embodied reconstruction, while sharing the experience online reflects digital solidarity. The narratives also demonstrated that rehabilitation was not a linear progression from illness to recovery. Patients could appear confident during one period and anxious during another. They could develop stable medication routines while continuing to worry about side effects or recurrence. They could accept family support while resisting overprotection. They could value peer advice while refusing to treat it as a substitute for medical care.

The overall narrative process can be represented as follows: ambiguous bodily signals, delayed recognition, diagnostic shock, treatment negotiation, postdischarge bodily uncertainty, gradual routinization, redistribution of responsibility, digital sharing, and collective meaning-making. However, recurrence could return patients to earlier states of fear and uncertainty, temporarily destabilizing their reconstructed sense of safety.

Across the dataset, patients did not ultimately construct coronary heart disease as an event that could be fully resolved through hospitalization or surgery. Instead, they increasingly described it as a long-term process of negotiation: "I prefer to view recovery as a long-term negotiation rather than as a fight against my body right now." This sentence captures the central narrative transformation in the data. Recovery was no longer defined as defeating the disease or immediately returning to the previous self. It was defined as learning how to coordinate bodily limitations, medical treatment, family responsibilities, work demands, and personal expectations within an uncertain but continuing life[37].

4 Discussion

Principal Findings

This study examined how Chinese patients with coronary heart disease constructed illness narratives on Douyin. Through qualitative narrative analysis of longitudinal short-video posts from 14 patient accounts, 4 interrelated narrative types were identified: alarm and misrecognition, therapeutic uncertainty, embodied reconstruction, and negotiated responsibility and digital solidarity. These narratives demonstrate that coronary heart disease is experienced not only as a biomedical event and a biographical disruption, but also as an ongoing process of rebuilding bodily trust, negotiating treatment and family responsibilities, and reconstructing illness identities through digital interaction[3].

Bodily Warning Signs, Diagnostic Delay, and Biographical Disruption

Patients often attributed chest discomfort, dyspnea, fatigue, sweating, nausea, or back tightness to other conditions, and the intermittent nature of these symptoms further delayed medical consultation. Consistent with the concept of biographical disruption, illness-related disruption began before formal diagnosis, when patients were unable to incorporate ambiguous bodily signals into their existing understanding of everyday life. Through retrospective digital storytelling, previously overlooked lifestyle factors and symptoms were reconstructed as early signs of coronary heart disease. These findings suggest that digital cardiovascular health communication should address not only typical chest pain but also atypical symptoms and the everyday explanations patients use to normalize them. This is consistent with the conclusions of Perona et al.[38]. At the same time, diagnostic delay was not simply an individual failure of awareness; it reflected the tension between recognizing bodily vulnerability and maintaining ordinary work and family roles[12].

Treatment Uncertainty and the Need for Shared Decision-Making

Following diagnosis, patients faced uncertainty regarding angiography, stent implantation, coronary artery bypass grafting, medication therapy, restenosis, and repeat intervention. They described recording unfamiliar medical terms, seeking explanations, and distinguishing individualized medical advice from general online experiences. These accounts indicate that patients were not passive recipients of treatment but actively attempted to regain interpretive control over complex medical decisions, consistent with the findings of Meng et al.[13]. This finding extends research on digital cardiac

rehabilitation and shared decision-making by showing that patients need ongoing explanations beyond the acute treatment encounter. Treatment completion did not immediately restore a sense of safety; concerns about recurrence and unfamiliar bodily sensations could reactivate the fear associated with the original event. Long-term communication should therefore address treatment rationales, potential warning signs, medication management, and follow-up planning.

Rebuilding Bodily Trust Through Nonlinear Rehabilitation

After discharge, patients often experienced their bodies as both capable and potentially dangerous. Engaging in exercise or experiencing fatigue could trigger concerns about stent failure or recurrent disease. Patients responded by monitoring their heart rates and symptoms, incorporating walking, warm-up, and rest into their activity routines, and gradually increasing exertion. These practices suggest that rehabilitation involved not only physical recovery but also the reconstruction of bodily trust. This finding complements previous research by Alpkvist et al.[39] on digital cardiac rehabilitation by highlighting the importance of emotional and embodied adjustment. Patients did not describe recovery as a linear return to preillness functioning. Instead, they learned to live with fluctuating symptoms, clinical indicators, medication concerns, and occasional setbacks. Digital rehabilitation should support gradual activity, symptom interpretation, the management of medication concerns, and the acceptance of nonlinear recovery rather than focusing exclusively on adherence and behavioral targets.

Responsibility Negotiation, Family Roles, and Social Context

Coronary heart disease reorganized patients' work, household labor, caregiving, income, and medical expenses. After discharge, these pressures often became more difficult to manage than the hospitalization itself because patients had to balance long-term treatment with existing family and employment responsibilities. Some patients also described cross-regional follow-up, limited rehabilitation resources, and caregiving responsibilities for older adults or grandchildren as barriers to sustained recovery. Family support was similarly ambivalent. Relatives provided practical and emotional assistance, but their concern could also lead to overprotection and restrict patients' autonomy. Patients gradually described recovery as a process of redistributing responsibilities rather than managing illness alone[40]. These findings suggest that cardiac rehabilitation should consider family coordination, employment, transportation, economic burden, and caregiving demands rather than treating self-management as an individual responsibility detached from social conditions.

Digital Disclosure, Peer Knowledge, and Platform-Mediated Identity

Douyin provided patients with a space to disclose their illness identities, seek recognition, exchange practical experiences, and develop a sense of peer belonging. This enabled patients to integrate coronary heart disease into broader dimensions of identity, including work, exercise, gender, and family life. Digital storytelling therefore helped transform individual uncertainty into a shared experience and supported the reconstruction of illness identity. Patients also recognized that peer experiences could not replace professional advice. They compared online recommendations with their own examination results

and treatment plans and repeatedly warned others not to apply personal experiences directly. These findings are consistent with research by Weddell et al.[41] on the supportive potential of digital health communities, while highlighting the need for platform-aware health communication. Douyin-based interventions should combine experiential support with clear guidance on evaluating information, individualized treatment, symptom recurrence, and the limits of peer advice.

Clinical Implications

The findings suggest that coronary heart disease care should move beyond acute treatment and medication adherence to address patients' difficulties in recognizing ambiguous symptoms, understanding treatment decisions, rebuilding bodily confidence, and managing family and work responsibilities. Clinicians should provide accessible explanations of atypical warning signs, treatment options, medication concerns, recurrence risks, and individualized rehabilitation plans while involving family members without reinforcing overprotection. Digital platforms such as Douyin may serve as complementary spaces for symptom education, cardiac rehabilitation, and peer support; however, professional content should also help patients evaluate online information and distinguish experiential advice from individualized medical recommendations. More broadly, cardiac rehabilitation should adopt a patient-centered and socially informed approach that recognizes nonlinear recovery, emotional uncertainty, caregiving demands, economic burden, and unequal access to follow-up care.

Limitations

This study has several limitations. First, the purposive sample was drawn from publicly available longitudinal content on a single platform, Douyin, and was not statistically representative of all Chinese patients with coronary heart disease. Second, the narratives reflected patients' public self-presentations and may have emphasized experiences considered suitable for short-video sharing while omitting private or less visible forms of distress. Third, because the study did not include interviews with patients, family members, or clinicians, interpretations of treatment experiences, family relationships, and peer interactions were based solely on patients' digital narratives. Fourth, the platform's short-video format and repeated narrative templates may have influenced the content, structure, and emotional expression of the posts. Finally, the study did not independently verify patients' diagnoses, treatments, or reported clinical indicators. Future research should combine digital trace data with interviews, clinical information, audience responses, and cross-platform comparisons to further examine how digital storytelling shapes long-term rehabilitation and illness identity.

5 Conclusion

This study demonstrates that digital illness narratives among Chinese patients with coronary heart disease are shaped by the intersection of bodily uncertainty, family and work responsibilities, treatment experiences, and the communicative environment of Douyin. By identifying 4 interrelated narrative types, the study shows how patients move beyond the initial disruption of diagnosis to reconstruct bodily confidence, negotiate illness identity, and develop forms of self-management and peer solidarity. More

broadly, the findings suggest that digital platforms are not merely spaces for documenting recovery or exchanging health information, but are active sites of meaning-making through which chronic cardiovascular illness is interpreted and managed. Recognizing these dynamics has important implications for health communication and cardiac rehabilitation, particularly for the development of culturally sensitive and platform-aware interventions that address patients' emotional, relational, and socioeconomic concerns alongside biomedical treatment. Rather than viewing coronary heart disease solely as a condition requiring individual adherence and risk-factor control, this study underscores the importance of understanding it as a socially and culturally mediated experience shaped by family expectations, work obligations, medical uncertainty, and online interaction. Future research should compare illness narratives across digital platforms and examine how longitudinal digital storytelling, peer communication, and family negotiation influence rehabilitation experiences, treatment decision-making, and long-term health management.

Abbreviations

CHD coronary heart disease

PCI percutaneous coronary intervention

Declarations

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Authors' contributions

Yating Shi: Data curation, Formal analysis, Methodology, Software, Writing – original draft. Tian Li: Data curation, Investigation, Methodology, Writing – review & editing. Zhiqiang Wang: Data curation, Methodology, Software, Writing – original draft. Yinglin Li: Methodology, Writing – review & editing. Zhongxiang Cai: Methodology, Writing – review & editing. Jiali Zhou: Methodology, Writing – review & editing. Jingjing Tao: Methodology, Writing – review & editing. All authors contributed to the article and approved the submitted version.

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Data availability

Data are available upon reasonable request.

Ethics approval and consent to participate

This study analyzed publicly available social media content and did not involve direct interaction with users. Because only publicly accessible content was analyzed and all potentially identifying information was removed, the study followed institutional guidance for internet-based research ethics and was considered exempt from formal ethical review. Informed consent to participate was not required.

Clinical Trial number

Not applicable.

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

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