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Living with an Open-Ended Risk of Stroke: A Qualitative Study of Adults Identified as Being at High Risk of Stroke Without Prior Stroke or TIA in China

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Abstract

Background

Stroke screening can identify adults without previous stroke or transient ischaemic attack (TIA) as being at high risk and bring them into preventive care. Yet little is known about how people without a cerebrovascular event interpret and live with this risk status. Guided by the “patients-in-waiting” concept, this study explored how adults at high risk of stroke understood their risk classification, integrated risk management into everyday life, and sustained prevention over time.

Methods

This qualitative descriptive study, informed by naturalistic inquiry, used individual semi-structured interviews. Using maximum-variation purposive sampling, we recruited 21 adults without previous stroke or TIA from two community health centres in Chengdu, China. Interviews conducted from May to June 2026 were analyzed using theory-informed thematic analysis guided by Braun and Clarke’s six-phase framework. The “patients-in-waiting” concept informed interpretation while the analysis remained open to findings beyond the concept.

Results

Three themes were identified. Making sense of being at high risk showed that participants accepted, distanced themselves from, or recalibrated the classification according to bodily experience, family history, perceived control, and uncertainty about future stroke. Fitting risk management into everyday life showed that participants incorporated manageable practices into routines, negotiated recommendations against enjoyment, relationships, work, and personal priorities, and sometimes made prevention a shared family practice. Maintaining direction in ongoing risk management showed that sustaining prevention depended on accessible care, actionable guidance, usable information, and follow-up feedback that helped participants interpret changes in modifiable risk factors and health indicators over time.

Conclusions

High-risk classification did not automatically produce a stable patient identity. Instead, participants lived with an open-ended and negotiated risk state in which future stroke remained uncertain and prevention had to be continually interpreted and fitted into everyday life. Primary stroke prevention should extend beyond risk identification by providing accessible, tailored, actionable, and sustained follow-up support.

1. Background

Globally, stroke is the second leading cause of death and the third leading cause of death and disability combined, as measured by disability-adjusted life-years (DALYs), and its absolute burden continues to rise [1]. In response, the World Health Assembly adopted its first stroke-specific resolution, emphasising prevention, acute care, rehabilitation, and health-system readiness [2]. In China, stroke remains a leading cause of death and disability, with an estimated 4.09 million new cases and 2.59 million deaths in 2021 [3]. Because much stroke risk is attributable to modifiable vascular and behavioural factors, primary prevention through early identification and management of elevated risk is increasingly important [4]. In 2011, China launched the China Stroke High-Risk Population Screening and Intervention Program (CSHR Program), which targets community residents aged 40 years and older. Under the programme's screening criteria, individuals are classified as being at high risk if they have three or more of the eight major stroke risk factors or a history of stroke or transient ischaemic attack (TIA). Since its establishment, the CSHR Program has screened more than 13 million people across mainland China [3]. However, the population level benefit of risk screening depends not only on identifying individuals at elevated risk, but also on whether risk information can be translated into sustained preventive action in everyday life.

Evidence suggests that this translation remains challenging. Individuals identified as being at high risk of stroke continue to report physical inactivity, smoking, unhealthy dietary practices, and other gaps in preventive behaviours[5]. Guo et al.[6] reported ongoing health-management difficulties related to limited knowledge, lack of confidence, management complexity, financial burden, and insufficient social support. More recently, Akosile et al.[7] identified low risk perception, misconceptions about stroke risk, socioeconomic constraints, competing everyday priorities, and difficulties sustaining lifestyle changes among community-dwelling adults at high risk of stroke.

Existing research has largely focused on knowledge, adherence, health behaviour, and the effectiveness of health-management interventions [8]. However, an important distinction remains insufficiently examined: studies of populations classified as being at high risk of stroke have not consistently separated individuals with no history of stroke or TIA from those who have already experienced a cerebrovascular event [6, 8, 9]. Consequently, less is known about how individuals without prior stroke or TIA understand and experience being classified as being at high risk of a future stroke. This distinction is important because risk-based screening identifies future vulnerability in people who may have few or no disease-specific symptoms, potentially altering how they understand their present health in relation to future illness [10]. For individuals without prior stroke or TIA, high-risk classification is based on combinations of established risk factors rather than on a previous cerebrovascular event, raising questions about how individuals interpret their current health and manage the possibility of future stroke.

The concept of "patients-in-waiting" offers a useful perspective for examining these experiences. Timmermans and Buchbinder [11] introduced patients-in-waiting as an umbrella concept to highlight iatrogenic liminality: the shared experience of being caught between health and illness when facing

diagnostic uncertainty. This perspective is particularly relevant to risk-based screening, where individuals may be asked to act on future disease risk despite experiencing themselves as currently healthy. Subsequent work has also questioned whether risk classification necessarily produces patienthood. Among people with elevated cholesterol, Jauho [12] found considerable resistance to patienthood, with many participants continuing to describe themselves as healthy. This tension is also relevant to stroke risk screening, where individuals without prior stroke or TIA must reconcile their present sense of health with an identified risk of future stroke. Such information may orient individuals towards ongoing monitoring and risk management, but how they interpret this high-risk status—whether as evidence of illness, as an uncertain position between health and illness, or as compatible with remaining healthy—remains an empirical question. Their situation also differs from the original formulation of "patients-in-waiting". For this population, ongoing monitoring is oriented primarily towards reducing future risk rather than resolving diagnostic uncertainty. Their high-risk status may therefore persist over time rather than serving as a temporary stage before a definitive diagnosis. Rather than assuming that these individuals become "patients-in-waiting", the concept is used as a sensitising lens for interpreting their accounts.

This qualitative study aimed to explore the experiences of individuals classified as being at high risk of stroke who had no history of stroke or TIA. It addresses the following questions: How do individuals understand their high-risk classification? How do they experience this classification in everyday life? What conditions shape their efforts to sustain stroke risk management over time?

2. Methods

2.1 Study design

This study used a qualitative descriptive design informed by naturalistic inquiry [13, 14]. This approach enabled a close account of how individuals without prior stroke or TIA experienced being classified as high risk of stroke, while allowing moderate interpretation in relation to the research questions. The study was reported in accordance with the Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist [15]; the completed checklist is provided as Additional file 1.

2.2 Setting and sampling

The study was conducted between May and June 2026 at two community health centres in Chengdu, Sichuan Province, China. Both centres participated in the CSHR Program and routinely conducted stroke-risk screening and follow-up management for residents in their catchment areas. Under the programme criteria, individuals with three or more of eight major risk factors, or a history of stroke or TIA, are classified as being at high risk of stroke [3]. The eight risk factors comprise hypertension, dyslipidaemia, diabetes, atrial fibrillation or valvular heart disease, smoking, physical inactivity, overweight or obesity, and a family history of stroke. Screening databases were reviewed by ND and SW together with family doctor teams to identify individuals who had been classified as being at high risk of stroke through the CSHR Program and had no prior history of stroke or TIA. Maximum variation purposive sampling was

used to capture a range of experiences across sex, age, and education [16]. Family doctors initially approached potentially eligible individuals during outpatient or home visits. Those who expressed interest received further information about the study from ND by telephone or in person, and their eligibility was reconfirmed. Two individuals declined participation because of scheduling conflicts. A total of 21 participants were included in the final sample.

Participants were eligible if they had been classified as being at high risk of stroke under the CSHR Program on the basis of three or more of the eight major stroke risk factors, were aware of their high-risk classification, and were able to participate in the interview and communicate their experiences. Individuals were excluded if they reported a previous physician diagnosis of stroke or TIA, cognitive or communication difficulties that prevented meaningful participation in an interview, or an acute or unstable medical condition that precluded participation.

2.3 Data collection

Data were collected through individual, face-to-face, semi-structured interviews. The interview guide was developed collaboratively by the research team, drawing on the research questions, the “patients-in-waiting” concept, and relevant literature on individuals at high risk of stroke. The interview guide was developed collaboratively by the research team, including its alignment with the “patients-in-waiting” concept. It included open-ended questions such as “Could you tell me about your experience from the time you first learned that you were at high risk of stroke?” and “What does being identified as at high risk of stroke mean to you?” Follow-up probes were used to clarify participants’ meanings and encourage more detailed descriptions of their experiences. Pilot interviews were conducted with three eligible participants to assess the clarity, sequence, and overall flow of the questions. Data from the pilot interviews were not included in the final analysis. Based on feedback from the pilot interviews, technical terms and abstract wording were simplified to improve clarity. The full interview guide is provided in Additional file 2.

To maintain consistency across interviews, all interviews were conducted by ND, while SW took field notes on participants’ non-verbal cues and relevant contextual observations. Both researchers were female master’s students in nursing who had received training in qualitative research methods and had relevant knowledge in chronic disease management and stroke prevention. Neither researcher had a prior social or clinical relationship with any participant. Each participant was interviewed in a private room at the community health centre from which they were recruited, with only the participant and the two researchers present. Before each interview, ND explained the study procedures, confidentiality, and voluntary participation, and encouraged participants to speak openly. All interviews were audio-recorded with participants’ consent. Interview duration ranged from 27 to 64 minutes. No repeat interviews were conducted. Within 24 hours of each interview, QH and JG shared responsibility for verbatim transcription, and ND checked each transcript against the original recording for accuracy. Identifying information was removed during transcription. Data collection and preliminary analysis proceeded concurrently. Recruitment and interviewing ceased when later interviews added little substantive variation to the

developing analysis and the sample was judged sufficient to address the research questions and planned variation in participant characteristics[17].

2.4 Data analysis

A theory-informed thematic analysis was conducted within the qualitative descriptive design, guided by Braun and Clarke's [18] six-phase framework, with NVivo 15.0 used for data management. Analysis was led by ND and BL, whose nursing and neurological perspectives provided complementary approaches to interpreting the data. ND conducted the initial coding, while BL critically engaged with codes and interpretations to broaden and challenge the developing analysis; both repeatedly engaged with the transcripts and discussed emerging interpretations. Differences in interpretation were discussed to challenge assumptions and refine the developing analysis, with repeated reference to the transcripts. The "patients-in-waiting" concept informed subsequent interpretation while the analysis remained open to findings beyond the concept. Related codes were grouped into candidate themes and subthemes, which were iteratively reviewed against the coded extracts and the full dataset and refined through team discussion. Themes were then refined and named, and representative quotations were selected to illustrate the final findings.

2.5 Rigour

Rigour was supported through ongoing reflexive and multidisciplinary engagement across the research team. Team members brought complementary perspectives from nursing, neurology, health management, community and public health, qualitative methodology, and theoretical research. Regular team discussions were used to challenge emerging interpretations, consider alternative explanations, and examine how professional backgrounds, prior knowledge, and the "patients-in-waiting" concept might shape interpretation. ND and SW maintained reflexive journals throughout the analytic process to document and critically examine how their assumptions, professional perspectives, and engagement with the theoretical concept might influence interpretation. After the preliminary themes were developed, ND contacted all 21 participants by telephone and invited them to comment on whether the interpretations resonated with their experiences. Nineteen participants indicated that the findings broadly reflected their experiences, while two provided further clarification about receiving stroke risk feedback. The relevant transcripts were subsequently re-examined, and the corresponding theme was refined accordingly.

2.6 Ethical considerations

This study was approved by the Ethics Committee of Sichuan Provincial People's Hospital (approval No. 431 [2026]) and conducted in accordance with the Declaration of Helsinki. Before all interviews, participants received oral and written information about the study, audio recording, data use, confidentiality, and voluntary participation, and provided written informed consent. They could decline any question or withdraw without penalty, with no effect on their routine healthcare. Interview data were de-identified during transcription and stored on encrypted devices accessible only to authorised research

team members. Data will be retained and securely destroyed in accordance with institutional and ethical requirements.

3. Results

3.1 Characteristics of participants

A total of 21 participants (9 men, 12 women) were interviewed, ranging in age from 53 to 80 years (mean = 66.71, SD = 8.23). Participant characteristics are presented in Table 1.

Table 1. Characteristics of study participants (n = 21)

Participant	Age (years)	Gender	Educational attainment	living arrangement	Employment status	Stroke risk factors								
						Hypertension	Dyslipidaemia	Diabetes Mellitus	Atrial fibrillation or valvular heart disease	Active Smoking	Physical Inactivity	Overweight /obesity	Family History of Stroke	Number of risk factors
N1	79	Female	Primary school	With spouse	Retired	Yes	Yes	Yes	No	No	No	Yes	No	4
N2	75	Female	Primary school	With spouse	Retired	Yes	Yes	No	No	No	Yes	Yes	No	4
N3	73	Female	Junior high school	With spouse	Retired	No	Yes	No	No	No	No	Yes	Yes	3
N4	75	Female	Primary school	With children	Retired	Yes	Yes	No	No	No	No	Yes	No	3
N5	62	Female	Junior high school	With spouse and children	Employed	Yes	Yes	No	No	No	Yes	Yes	No	4
N6	80	Male	Senior high school or equivalent	With spouse and children	Retired	Yes	Yes	Yes	No	No	Yes	No	No	4
N7	53	Male	College	With spouse and other family members	Employed	Yes	Yes	Yes	No	No	No	Yes	Yes	5
N8	68	Male	College	With spouse	Retired	Yes	No	Yes	Yes	No	No	No	No	3
N9	57	Male	College	With children	Employed	Yes	Yes	Yes	No	Yes	No	Yes	No	5
N10	64	Male	Primary school	Living alone	Employed	Yes	Yes	No	No	Yes	No	No	Yes	4
N11	59	Male	Junior high school	With children	Employed	Yes	Yes	Yes	No	No	Yes	Yes	No	5
N12	62	Female	College	With spouse	Retired	Yes	Yes	No	No	No	No	No	Yes	3
N13	61	Female	Senior high school or equivalent	With spouse	Employed	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	7
N14	69	Female	College	Living alone	Retired	No	Yes	No	No	No	Yes	Yes	No	3
N15	65	Female	College	Living alone	Retired	Yes	Yes	No	Yes	No	Yes	Yes	Yes	6
N16	73	Female	Senior high school or equivalent	With spouse and children	Retired	Yes	Yes	No	Yes	No	No	No	Yes	4
N17	61	Male	College	With children	Employed	Yes	Yes	No	No	Yes	Yes	Yes	No	5
N18	69	Male	Senior high school or equivalent	With spouse	Retired	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	7
N19	56	Female	Junior high school	With spouse and children	Employed	Yes	No	No	No	No	Yes	Yes	No	3
N20	80	Male	Primary school	Living alone	Retired	Yes	No	No	Yes	No	Yes	No	No	3
N21	60	Female	Junior high school	With spouse	Employed	Yes	Yes	No	No	No	No	No	Yes	3

Note: Stroke risk-factor data were extracted from participants' existing CSHR screening records and were not re-assessed for this study. "Yes" indicates that the risk factor was recorded as present at the time of screening.

3.2 Themes and Subthemes

3.2.1 Theme 1: Making Sense of Being at High Risk

This theme describes how participants made sense of being classified as high risk of stroke. Three patterns were identified: Accepting the High-Risk Label, Keeping the Label at a Distance, and Recalibrating What “High Risk” Meant. For some, screening confirmed an already meaningful sense of vulnerability. Others acknowledged the classification without allowing it to redefine their current health, while others accepted some degree of risk but modified its meaning or magnitude through their own reasoning.

3.2.1.1 Accepting the High-Risk Label

For some participants, the high-risk classification matched concerns that had developed before screening. Previous bodily experiences or family history had already made stroke seem possible in their own lives. The screening result therefore confirmed an existing sense of risk rather than introducing a completely new concern.

Participants who had experienced physical sensations that they associated with stroke had already begun to worry about the possibility of having a stroke before they were identified as being at high risk:

"My hand has been numb for two or three years, and quite often, when I'm talking, I suddenly feel a little dizzy. I had already suspected that I might be going to have a stroke." (N10)

Family history was another reason why the classification seemed reasonable. When close family members had experienced stroke, some participants had already expected that they might also be at high risk:

"Both my grandfather and my father died from stroke, and they both had high blood pressure. Before the community health workers told me, I had already prepared myself for it." (N12)

3.2.1.2 Keeping the Label at a Distance

Some participants acknowledged the high-risk classification but did not incorporate it into how they understood their current health. Although they recognised that they had been labelled as being at high risk, they continued to experience themselves as relatively healthy, controlled, or uncertain that the classification fully applied to them.

The absence of symptoms was one reason why the classification felt distant. Although participants knew that they had been identified as being at high risk, feeling physically normal made the possibility of stroke seem less immediate in everyday life:

"I was identified as high risk through last year's screening. But going by how I actually feel, I'm perfectly normal—I don't have any pain or discomfort." (N17)

"I know I'm at high risk of stroke, but I don't really think about it day to day. I don't have any physical symptoms, and I just don't feel it really has anything to do with me yet." (N14)

For participants who were already managing conditions such as hypertension or dyslipidaemia, the high-risk classification did not always bring a new sense of threat. Instead, stroke risk was understood as something that could be managed by continuing what they were already doing, such as taking medication and keeping their blood pressure under control:

"As long as I take my tablets regularly and keep my blood pressure under control, I don't think there'll be any big problem. I just take it as it comes—I'm not really worried about having a stroke." (N11)

A different form of distance came from uncertainty about the screening result itself. When health measurements differed between home and the clinic, some participants were unsure whether the high-risk classification accurately described them. Rather than rejecting the result completely, they remained uncertain about whether it applied to their own situation:

"The community clinic told me I have high blood pressure and am at risk of stroke, but I don't think I necessarily do. I have a monitor at home. Every time I go to the clinic, my reading is higher, but at home it's normal. I'm just confused." (N4)

3.2.1.3 Recalibrating What “High Risk” Meant

Some participants accepted that they had an increased risk of stroke but adjusted what the high-risk classification meant for them personally. Unlike participants who kept the classification at a distance, these participants accepted that stroke risk was personally relevant but reinterpreted its degree, seriousness, or certainty. Rather than taking the label at face value, they considered their own health condition or their beliefs about whether stroke would occur. In this way, they acknowledged the risk while reducing its perceived seriousness or certainty.

Some participants judged risk according to the actual severity of their health problems. They felt that being placed in the same high-risk category did not mean that everyone faced the same level of risk. When their own indicators were only mildly abnormal or their condition seemed stable, they saw themselves as being at the lower end of the high-risk group:

"Although I'm classified as high risk, my blood lipids are only slightly elevated and I don't have any plaque. After looking into it, I judged from my physical condition that I'm not someone who is about to have a problem. I'm relatively stable within the high-risk group—essentially low-risk among those at high risk… A high-risk assessment should use more detailed and comprehensive indicators. In a case like mine, I don't think I should be called 'high risk'. That term is frightening." (N7)

Another way of adjusting the meaning of risk was to view stroke as something that could not be predicted with certainty. Some participants understood stroke as partly a matter of chance or fate. From this perspective, being classified as high risk meant that stroke was possible, but did not mean that it would necessarily happen:

"As I see it, stroke is a matter of probability. If it's going to happen, it will happen; if not, then God has protected you." (N8)

3.2.2 Theme 2: Fitting Risk Management into Everyday Life

This theme shows that rather than reorganising their lives entirely around stroke prevention, participants incorporated manageable practices into existing routines and negotiated how far prevention would alter valued aspects of everyday life. Within households, risk management could also become embedded in shared family routines.

3.2.2.1 Incorporating Risk Management into Existing Routines

Participants often incorporated risk-management practices into routines that were already familiar and manageable. Medication taking, exercise, and health monitoring were easier to sustain when they could be fitted into established schedules without substantially disrupting everyday life.

For some participants, medication taking became integrated into an existing daily routine and was treated as an ordinary part of everyday life rather than as something requiring deliberate attention:

"I was identified as high risk of stroke 3 years ago when I registered for the special hypertension outpatient service… I've been taking my tablets every day ever since." (N10)

Exercise was incorporated in a similar way. Rather than adopting highly structured exercise programmes, some participants chose activities such as walking or badminton that could be fitted around their usual schedules. In this way, physical activity could become part of ongoing health management without requiring substantial changes to everyday routines:

"After I was told I was at high risk, I started walking a lot—every day, really—and I play badminton sometimes too. My blood lipids have improved a lot over the last few years. It's not all down to the medication." (N13)

Health monitoring was also fitted around existing routines. Although some participants monitored indicators such as blood pressure regularly, the timing was often flexible rather than fixed, allowing monitoring to remain compatible with other daily activities:

"I check my blood pressure at home every day. Sometimes I do it in the morning, sometimes in the evening —it depends on my schedule." (N9)

3.2.2.2 Negotiating How Far to Change Everyday Life

Not all risk-management recommendations could be readily accommodated within participants' existing ways of living. When prevention competed with personal preferences, valued relationships, or other everyday demands, participants negotiated how far they were willing or able to change their lives in response to stroke risk.

Dietary change clearly illustrated this negotiation. Participants could recognise the need to restrict certain foods while still finding it difficult to give up foods they enjoyed:

" I know fatty meat, organ meats, animal fat—all that stuff—I should stay away from it, but I just can't resist." (N16)

"The hardest thing is still diet. I really enjoy good food, so cutting down is hard for me." (N18)

For some participants, how far they were willing to change was also shaped by their stage of life. Strict dietary control was weighed against a preference to maintain familiar ways of eating and to avoid excessive restriction in later life:

"I have high blood pressure and high blood sugar, but I don't avoid much. Older people do need some oil and meat for nourishment. I'm already old, so I might as well eat what I want and take things as they come." (N1)

Dietary recommendations were also negotiated within family relationships. Restrictions that participants maintained in other circumstances could become more difficult to sustain when shared meals formed part of family interaction. In these situations, adherence to preventive advice was balanced against participation in valued family occasions:

"I'm usually careful about what I eat. When my children ask me to go out for hotpot, I know it's not healthy, but it's hard to say no sometimes." (N10)

In other circumstances, participants had limited scope to act on risk-management recommendations because these practices competed with the practical demands of everyday life. Work schedules, for example, could restrict the time and opportunity available for regular exercise:

"After a night shift, I come home, sleep during the day, and then work another night shift. My wife sometimes tells me to exercise more, but I just don't have the time." (N17)

3.2.2.3 Making Risk Management a Shared Family Practice

Risk management often took place within everyday household routines rather than remaining an entirely individual activity. Practices such as taking medication, monitoring blood pressure, and modifying diet were visible to family members and, in some households, became activities in which spouses or adult children actively participated.

For some participants, family members became directly involved in medication use and health monitoring. Their involvement included reminding participants about particular practices, checking whether these had been carried out, and responding when changes in health were noticed. Risk management therefore became embedded within routine family interactions rather than being managed solely by the individual:

"My daughter is a nurse—she takes charge of my health. If I feel unwell, she's the first person I tell. She also makes sure I take my medication and check my blood pressure." (N11)

Risk management also became embedded in shared household practices such as preparing and eating meals. Because food was prepared and consumed within the household, dietary change was not always something participants could manage independently. Family members could influence what was eaten and how food was prepared, while also encouraging other management practices such as blood pressure monitoring:

"My wife is always on top of health issues. She keeps pushing me to measure my blood pressure and all that. I prefer my food saltier, but she cooks very lightly, so I have no choice but to eat the same way." (N8)

3.2.3 Theme 3: Maintaining Direction in Ongoing Risk Management

This theme shows that sustaining risk management depended not only on participants' own efforts, but also on the care, information, and feedback available to them over time. These resources helped participants understand what they could do, find workable ways of managing risk, and assess whether their efforts were making a difference. Whether this support was accessible, clear, and well matched to their needs shaped whether participants could maintain a sense of direction in managing stroke risk over time.

3.2.3.1 Securing Access to Care

Participants' ability to continue managing stroke risk was shaped by how readily they could access consultations, medication, and follow-up care. When access involved substantial practical demands or uncertainty, however, maintaining risk management practices became more difficult.

For some participants, difficulties obtaining medication were compounded by inconsistent advice across healthcare providers. When treatment changed without a clear or stable management plan, participants could become uncertain about how to proceed and feel less able to manage their condition effectively:

"Getting the special outpatient status is such a hassle. The community clinic sometimes can't supply my medication, so I have to go to other hospitals. And then one doctor tells you one thing, another tells you something completely different—I don't know whose advice to follow. My blood pressure used to be under control, but after they kept switching me from one drug to another, it just stopped responding. Now it's been unstable for a while, and there's really nothing I can do about it." (N13)

For some participants, access to care depended not only on the availability of services but also on whether they had someone who could help them manage the practical demands of attending hospital. When family support was limited, accessing care could require additional financial and organisational resources:

"We're a one-child family, so my child has their own life and can't really look after me. Every hospital visit means lots of tests and running around to get everything stamped. I just can't manage all that on my own. I have to hire someone to help me for 200 yuan each time, but even then, I often end up with no one to turn to." (N15)

3.2.3.2 Receiving Actionable Guidance

Guidance after screening varied in how clearly it helped participants translate stroke-risk information into everyday management.

For some participants, being informed that they were at increased risk did not come with sufficiently specific guidance about what they should do in response. In the absence of more specific advice, they had to infer for themselves what the risk message meant for their daily management, without being sure whether their interpretation was appropriate:

"After looking at my report, the community staff told me I was at relatively high risk and should be more careful. I guess they meant I should rest more and keep my blood pressure and blood sugar under control. They didn't really give me anything specific." (N6)

Even when a general behavioural direction was provided, however, the advice did not always contain enough detail to guide its implementation in everyday life. Advice such as “eat less and move more” indicated the direction of behaviour change but left questions about what changes to make, how much change was appropriate, and whether recommendations should vary according to individual circumstances:

"I hope I can do enough on the lifestyle side to avoid having a stroke. After the screening, all they said was 'eat less and move more'—but what does that actually mean? What should I be eating? How much exercise should I be doing? It must depend on your age as well, surely? To be honest, I still don't really know." (N21)

3.2.3.3 Making Information Work

Beyond clinical encounters, participants encountered stroke-related information in different forms and settings. Its usefulness depended not simply on availability, but on how well the way information was provided fitted their circumstances and preferences. Relationships, existing routines, preferred frequency, perceived credibility, and accessibility all shaped how participants engaged with health information.

Engagement with community health information was sometimes shaped by participants’ existing relationships with local healthcare staff, rather than by informational needs alone. Familiarity with community providers could itself encourage participation in health education activities:

" If the community asks me to come to something, I always go. I'm there for check-ups all the time anyway, and they put these things on for us. I just want to support my family doctor's work as much as I can." (N3)

Participants' everyday relationships also shaped where they turned for experiential information:

"I share experiences with a few good friends I've met in the community. We learn from each other about anything that seems useful." (N2)

Information could also be easier to engage with when its delivery fitted into healthcare routines participants already followed, reducing the need to attend separate activities:

"I think a lot of people don't really want to come to these talks or events. People don't know each other like they used to, so gathering with strangers isn't always appealing. Since we're already coming to the community clinic every month to pick up our medication anyway, they could just give us some health information then." (N16)

Digital peer groups also allowed participants to benefit from information without necessarily taking an active role in the exchange, making passive participation another way of learning from others:

"It helps to hear other patients share their experiences in the group chat too. I think having a peer group chat is quite useful. Even if you don't post anything yourself, you can still pick things up from others and think about whether you need to change what you're doing." (N14)

The preferred frequency of health information also differed between participants. The same frequency of communication could therefore be experienced as supportive by some participants but excessive by others:

"Older people tend to forget things now and then. A daily reminder about what I should do and what to watch out for could help me keep my condition under control." (N13)

"I feel I already know most of the relevant health information. Getting frequent messages about stroke would just make me feel pressured and anxious." (N12)

Generative AI provided another way of addressing information needs outside healthcare encounters. Its immediacy allowed them to seek explanations at the point when questions arose:

"These AI tools are very handy now. Sometimes I forget to ask the doctor something during my appointment, so I ask on Doubao instead. I just type in my question and get an answer straight away." (N16)

At the same time, participants did not necessarily accept AI-generated information uncritically, and some distinguished between information they considered useful and advice they were unwilling to trust:

"I now have three generative AI apps on my phone. Sometimes they give different answers, so I ask all three the same question to cross-check. I only look at the basic principles—like why something happens. Sometimes AI can steer you wrong. For example, it might recommend medication, I wouldn't trust that." (N8)

These digital options, however, were not equally accessible to all participants:

"My phone is only for calls. I don't understand all these newfangled things. I'd rather go to a lecture." (N20)

3.2.3.4 Tracking Change Over Time

Because risk management continued over time, participants looked for follow-up feedback that could show whether their risk or health indicators were changing and whether their efforts were making a difference.

For some participants, long gaps between screening and follow-up made it difficult to know whether changes in management had improved their risk and allowed the issue to fade from attention:

"At the moment, once the screening is done, that's it. I think the community should check in with me after a couple of months to see if my risk has improved after I've made some changes. Otherwise, I have to wait a whole year for the next screening. That's too long—I'll easily forget about it." (N18)

Even when screening was repeated regularly, the same categorical result could provide little sense of movement over time. When changing clinical indicators continued to produce the same "high-risk" classification, participants found it difficult to judge whether their risk was improving or worsening:

"I get screened every year, and every year they tell me I'm at high risk of stroke. But my test results have changed over the years, while the conclusion has stayed the same. That makes it hard for me to tell whether my risk management is working. I think the doctor should tell me clearly whether my risk has gone down or up compared to last year—and if it's up, by how much. The way it is now, I'm just going round in circles." (N7)

4. Discussion

Drawing on Timmermans and Buchbinder's [11] concept of "patients-in-waiting", his study shows that being medically classified as being at high risk of stroke does not necessarily produce a corresponding sense of patienthood. The concept is useful because it draws attention to the ambiguous position created when people who feel healthy are nevertheless asked to understand and manage their health in relation to the possibility of future illness. However, the experiences identified here also depart from the original formulation. For people at high risk of stroke, follow-up is not primarily intended to resolve diagnostic uncertainty, and the high-risk status may have no clearly defined endpoint. Instead, individuals may remain in an open-ended high-risk status, in which the meaning and everyday relevance of risk must be repeatedly interpreted while preventive practices need to be sustained over time.

A central finding is that biomedical risk classification did not necessarily lead participants to understand themselves as patients. For participants who accepted the high-risk classification, screening often confirmed and gave biomedical meaning to a vulnerability already recognised through bodily sensations or family experiences of stroke. Such experiences provided an interpretive framework through which an otherwise abstract risk classification became personally credible, consistent with evidence that lay

understandings of illness are grounded in bodily experience and familiar illness narratives [19]. By contrast, participants who felt well or considered their existing conditions controllable could acknowledge the classification while continuing to regard themselves as healthy. Perceived control over conditions such as hypertension may therefore help explain why some participants acknowledged the high-risk classification without seeing it as incompatible with being healthy [20]. As Jauho [12] similarly found among people with elevated cholesterol, resistance to patienthood need not imply denial of risk: individuals may recognise future vulnerability while maintaining a present identity as healthy. Participants also treated the "high-risk" classification as something to be interpreted rather than accepted as a fixed statement about their future. These findings resonate with Gillespie's [21] concept of "measured vulnerability", which shows how biomedical assessments of future risk acquire meaning through lived experience and social context, and with Lorenc et al.'s [22] observation that individuals may supplement formal risk assessments with their own informal judgements. Such recalibration should therefore not be understood simply as rejection or minimisation of medical advice, but as interpretive work through which individuals reconcile biomedical vulnerability with their experience of feeling well and their sense of control over existing conditions. In this sense, stroke risk screening may create a liminal position without necessarily producing a stable sense of patienthood. Being a "patient-in-waiting" is therefore better understood here as a contingent and negotiated position rather than a status automatically conferred by risk classification.

A second key finding is that stroke prevention had to be made workable within participants' existing lives. Rather than reorganising daily life around future stroke risk, participants were better able to sustain preventive practices when these could be incorporated into established routines with limited disruption. This is consistent with research showing that health-related self-management is often fitted around competing everyday demands and priorities [23], and with minimally disruptive medicine, which argues that healthcare work should remain workable within people's everyday lives [24].

This negotiation became more visible when prevention competed with valued aspects of everyday life. Food, for example, involved not only health but also pleasure, familiar practices, family interaction, and culturally shaped understandings of nourishment. Previous research in China has similarly shown that eating practices are intertwined with family relationships, hospitality, and beliefs about food and health[25, 26]. Dietary change could therefore require participants to alter activities that were both enjoyable and socially meaningful. Similar tensions appeared among some older participants, who weighed the possible future benefits of stroke prevention against present enjoyment and a desire to avoid excessive restriction in later life. This is consistent with evidence that older adults may weigh health outcomes against quality of life, independence, and other personally valued goals, including the balance between present and future quality of life[27, 28]. Such decisions should therefore not be understood simply as dismissing risk, but as judgements about how much present life should be changed for a future health benefit. Practical capacity also shaped how far participants could engage in prevention. This aligns with Shippee et al.'s [29] Cumulative Complexity Model, which proposes that self-management depends on the balance between the demands placed on individuals and the capacity

available to meet them. Preventive practices may therefore become difficult to sustain when they compete with other demands on limited time, energy, and practical capacity. What may appear as “non-adherence” can instead reflect constraints on what individuals can realistically accommodate in everyday life, rather than simply insufficient knowledge or motivation.

Family involvement was important not only because relatives provided practical support, but because they helped create a social environment in which preventive practices could be sustained. As Whitehead et al. [30] suggest, family relationships can help to normalise and contextualise self-management by embedding it within everyday routines and interactions. In this sense, prevention was not simply carried out by the individual at risk, but was incorporated into shared family life. At the same time, participants’ accounts suggest that family involvement could sometimes become directive, potentially shaping how much autonomy individuals retained in everyday management [31].

Third, the findings extend the “patients-in-waiting” perspective by showing that, for individuals at high risk of stroke, long-term risk management involves not only living with uncertainty but also maintaining direction in prevention over time. Unlike forms of surveillance that aim to clarify an uncertain diagnosis, stroke risk monitoring is primarily directed towards reducing the likelihood of a future event. This means that preventive action may need to be sustained even when there is no obvious clinical transition marking progress or resolution. This is particularly challenging because many factors contributing to elevated stroke risk can remain asymptomatic before an acute event occurs[32, 33]. Research on hypertension similarly shows that feeling well can reduce the perceived need for treatment when symptoms are used to judge whether attention is needed [34]. The challenge is therefore not only recognizing risk, but maintaining clarity about what to do, why preventive action remains necessary, and whether those efforts are making a difference over time.

Maintaining direction also depended on whether screening was followed by accessible care and guidance that participants could translate into action. Continued contact with healthcare professionals may help individuals adapt to living with elevated health risk[12], but its usefulness depended on care being accessible, coherent, and linked to a clear management pathway. In such circumstances, individuals and families were left to coordinate care and reconcile differing recommendations themselves. Difficulties also arose when advice remained broad, with limited guidance on how to put it into practice. Risk information is more useful when linked to modifiable factors and clear preventive options rather than communicated through risk categories alone [35]. The problem identified here was therefore not simply whether individuals understood their risk, but whether risk identification was accompanied by clear and actionable guidance. Supporting long-term prevention therefore requires not only identifying elevated risk, but providing guidance that helps individuals translate that risk into feasible and sustained action.

The findings further suggest that information supported prevention when it was usable within participants’ circumstances, rather than simply more abundant. Preferences varied by source, format and frequency, consistent with evidence that support is more acceptable when its form and intensity are

tailored to individual needs [36]. Generative AI illustrated this tension particularly clearly: it offered immediate explanations outside clinical encounters but required users to judge the credibility of variable information and remained inaccessible to some participants [37, 38]. Beyond usability, maintaining direction also depended on feedback that helped participants interpret change over time. When elevated risk may persist over an extended period, repeatedly receiving the same categorical label can confirm that risk remains while offering little indication of whether preventive efforts are making a difference. A static risk classification may therefore indicate current risk status without conveying a sense of trajectory. Follow-up may therefore be more meaningful when changes in modifiable risk factors and clinical indicators are explained in relation to previous results and ongoing preventive efforts, rather than communicated through repeated categorical classification alone [35]. For individuals who may remain at elevated risk for many years, the purpose of follow-up may be less to resolve uncertainty than to help them remain oriented within a long-term process of prevention.

In summary, these findings extend the “patients-in-waiting” concept by showing that stroke risk classification may place individuals in an open-ended state of future health risk without producing a stable patient identity. Living with this risk involved not only interpreting what the classification meant, but also making preventive practices workable in everyday life and maintaining direction over time in the absence of a clear endpoint. This shifts attention from risk identification alone towards the conditions that make long-term prevention sustainable. Accessible care, actionable guidance, usable information, family support, and interpretable follow-up feedback may reduce the practical and interpretive burden placed on individuals and families in sustaining long-term stroke prevention.

5. Limitations

This study has several limitations. First, while the analysis identified variation in how participants interpreted and managed stroke risk, the study was not designed to systematically compare experiences across participant subgroups. Education, for example, appeared relevant to how health information was understood and used. Future research could examine more systematically how educational and socioeconomic circumstances shape the interpretation and management of stroke risk. Second, recruitment through family doctor teams may have favoured individuals already engaged with community health services, potentially underrepresenting people who were less engaged with follow-up or prevention, including those who did not accept or prioritize the high-risk classification. Future studies should use broader recruitment strategies to include participants with different levels of engagement. Third, all participants were recruited in Chengdu, and their experiences were shaped within a particular healthcare, community-service, and sociocultural context. Multi-site studies could help examine which aspects of these findings are context-specific and which may be transferable to other settings.

6. Conclusions

This study shows that being classified as at high risk of stroke does not necessarily produce a stable sense of patienthood. Instead, living with elevated stroke risk involves an open-ended and negotiated

relationship with possible future illness, shaped by personal experience and everyday life. Sustained prevention depends not simply on risk awareness, but on whether recommended actions are workable within existing routines, relationships, and practical constraints. Primary stroke prevention programmes should therefore link risk identification with accessible follow-up, actionable guidance, and support that helps individuals interpret changes in relevant risk factors over time. The value of screening therefore depends not only on identifying risk, but on whether people are supported to understand and manage that risk sustainably in everyday life.

Abbreviations

AI
Artificial intelligence
COREQ
Consolidated Criteria for Reporting Qualitative Research
CSHR
China Stroke High-Risk Population Screening and Intervention Program
DALYs
Disability-adjusted life-years
TIA
Transient ischaemic attack.

Declarations

Ethics approval and consent to participate

This study was approved by the Ethics Committee of Sichuan Provincial People's Hospital (approval No. 431 [2026]) and was conducted in accordance with the Declaration of Helsinki. Before the interviews, participants received oral and written information about the study, audio recording, data use, confidentiality, and voluntary participation, and all participants provided written informed consent.

Consent for publication

Written informed consent was obtained from all participants for the use of their interview data in this study. Only de-identified quotations are reported.

Data availability

The interview data are not publicly available because the qualitative transcripts contain sensitive information that could compromise participant confidentiality. Requests for access may be directed to the corresponding authors and will be considered subject to relevant ethical and institutional requirements.

Competing interests

The authors declare that they have no competing interests.

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Authors' contributions

ND: Conceptualization, Data curation, Methodology, Investigation, Formal analysis, Writing - original draft. SW: Conceptualization, Methodology, Investigation, Data curation, Writing - original draft. BL: Conceptualization, Methodology, Investigation, Formal analysis. QH: Data curation, Investigation, Formal analysis. JG: Data curation, Formal analysis. JJ: Conceptualization, Methodology, Supervision, Resources, Project administration, Writing - review and editing. XM: Conceptualization, Methodology, Writing - review and editing. All authors read and approved the final manuscript.

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Use of generative AI and AI-assisted technologies

During manuscript preparation, the authors used Gemini 2.5 Pro and ChatGPT (OpenAI) to assist with English-language editing and adaptation of the manuscript to journal formatting requirements. All AI-assisted output was reviewed and edited by the authors, who take full responsibility for the final content.

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