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Influencing factors of self-advocacy in stroke patients from multiple perspectives: a qualitative study

Zhixin Zhao[1,2], Beilei Lin[1], Zhenxiang Zhang[1*], Chunhui Zhang[1*], Yongxia Mei[1], Zhiwei Liu[1], Hu Jiang[1] and Xiaoxuan Wang[1]

Abstract

Background Self-advocacy can help stroke patients actively participate in disease management and maximize health benefits, which is a central issue in chronic disease management. The aim of the study was to explore the influencing factors of self-advocacy in stroke patients from multiple perspectives.

Methods A descriptive qualitative interview study was performed. Semi-structured in-depth interviews were conducted with 19 stroke patients, 6 caregivers, and 8 medical staff from two hospitals in Henan province between October 2023 to February 2024. This study analyzed interview data using a Social Ecological Model (SEM) and content analysis strategies.

Results Factors associated with stroke patients' self-advocacy were categorized using the social ecological model: (1) individual factors: influence of individual cognitive and psychological factors (weak sense of autonomy, insufficient disease cognition, severity of the disease, self-perceived burden, concerns about deteriorating doctor-patient relationship). (2) interpersonal factors: influence of family, peers and medical staff (insufficient family support, lack of peer support, authority of medical staff dominates). (3) community factors: influence of socio-environmental factors (shortage of medical staff, incomplete rehabilitation equipment, limited channels for information). (4) policy-economic factors: influence of existing policy (insufficient support from medical insurance, long-term financial burden).

Conclusion This study's application of a social ecological model helped to illuminate the complex and multilevel factors that may influence self-advocacy in stroke patients. Stroke patients' self-advocacy was influenced by the patients themselves, interpersonal relationships, community factors, and policy-economic factors. These findings can be used to guide the development of a multi-pronged intervention strategy to increase the level of self-advocacy for stroke patients in the self-management process.

Keywords Self-advocacy, Stroke, Influencing factors, Qualitative research, Social ecological model

*Correspondence:
Zhenxiang Zhang
zhangzx6666@126.com
Chunhui Zhang
zhangchunhui0617@zzu.edu.cn

[1] School of Nursing and Health, Zhengzhou University, Henan 450000, China
[2] School of Nursing, Inner Mongolia Medical University, Hohhot, Inner Mongolia 010000, China

Background

The Global Burden of Disease (GBD) study indicates that stroke is the second leading cause of disability and death worldwide and the third leading cause of disability-adjusted life years (DALY) [1]. In China, stroke is the leading cause of death and disability among adults [2]. Stroke patients, as their primary caregivers, need effective self-management. However, the current self-management status of stroke patients is not optimistic. In addition to poor control of risk factors such as hypertension, diabetes, and dyslipidemia, stroke patients also face issues such as smoking, alcohol consumption, unhealthy eating habits, insufficient physical activity, and low medication adherence [3–5]. This makes stroke prevention and control a significant challenge. The Self-advocacy in the health domain represents a philosophical approach that fosters active participation in healthcare interactions and caregiving to improve the health outcomes of individuals grappling with chronic diseases. International Self-Care Research Center emphasizes that patients must actively engage in self-care and take full advantage of their own initiative, enhancing health and well-being, the reduction of incidence and mortality rates, and the mitigation of medical expenses [6]. Self-advocacy may offer a breakthrough in the self-management of stroke patients.

Self-advocacy refers to the ability of patients to advocate for their interests in managing their disease [7, 8]. Self-advocacy is designated as a critical skill involving the acquisition of pertinent information and the effective conveyance of individual needs and preferences to healthcare providers [9, 10]. It can directly or indirectly encourage healthier behaviors in patients, thus enhancing health outcomes. Studies have shown that self-advocacy reduces patients' disease burden, improves treatment adherence, quality of life, and satisfaction with care [8, 11]. Through self-advocacy, individuals receive the information and support they need to manage their associated illnesses. Individuals through self-advocacy are able to actively seek solutions to problems that affect their life status [12], all of which greatly improve the overall well-being of patients in terms of physical, mental, social, and emotional functioning.

Currently, foreign studies on self-advocacy mainly focus on conceptual analysis [13, 14], scale design and validation [15–17], exploration of influencing factors [18–22], and interventions for self-advocacy [23]. Although studies [18–22] have examined the correlation between socio-demographic factors, disease-related factors, psychological factors, and social support and patients' self-advocacy, the research data are mainly focused on foreign countries, and due to racial, geographic, and cultural differences, the relevant results may not be fully applicable to domestic patients. Domestic research on self-advocacy is still in its infancy. Feng et al. [24] introduced the concept of self-advocacy into China in 2021 and Chineseized the self-advocacy assessment tool. Zhang et al. [25] reviewed the research progress of self-advocacy. He et al. [26] and Zhang et al. [27] explored the current status of self-advocacy and influencing factors in cancer patients. However, research on self-advocacy among stroke patients is still in its exploratory stages, and the factors influencing it are not yet well understood. Existing studies on the factors affecting self-advocacy, both domestically and internationally, primarily focus on cancer, heart disease, and the elderly [20, 26, 28], and the process of disease management varies among the study populations. How these factors impact and further influence the health outcomes of stroke patients remains unclear, thus highlighting the need for further research in this area.

The Social Ecological Model (SEM) combines systems theory, sociology, and ecology, emphasizing the interaction between individual development and the surrounding environment to form a complete ecosystem [29]. Given that it suggests the importance of individual, interpersonal, community, and public policy factors in determining health behavior, the SEM appears to be a suitable framework [30]. It has been used widely in chronic disease management and health promotion research [31, 32]. Hence, this study focuses on the framework of the social ecological model and employs semi-structured interviews with stroke patients, caregivers, and medical staff to comprehensively and systematically analyze the multilevel factors influencing self-advocacy among stroke patients from the perspectives of different stakeholders. The objective of this study was to guide the development of self-advocacy assessment tools for stroke patients and to inform the development of a multi-pronged self-advocacy intervention strategy for stroke patients.

Methods

Study design and research framework

A qualitative descriptive study was designed to explore the influencing factors of self-advocacy among stroke patients, caregivers and medical staff. The social ecological model was used as the research framework for this study. The SEM was then used to present the themes that emerged from the analysis of the data.

Participants and recruitment

This study used purposive sampling to recruit participants. Nineteen stroke patients, six caregivers, and eight medical staff were selected from two hospitals (Zhengzhou city central hospital and Luoyang city central hospital) in Henan, China. The inclusion criteria were as follows: (1) stroke patients: survivors of various types of stroke [33]; with communication ability (Token test ≥ 17 points) [34] and self-care capability (activities of daily living ≥ 40) [35]; individuals without cognitive dysfunction (mini mental state examination ≥ 17 points) [36]. (2) caregivers: informal caregivers were ≥ 18 years of age [37]; had no prior history of psychiatric illness or cognitive impairment, had normal speech, and were literate enough to understand the questions; and gave informed consent. (3) medical staff: employees of the neurology and rehabilitation departments of the hospital with at least 10 years of service; intermediate or higher professional and technical title; informed consent.

Data collection

Individual interviews were conducted between October 2023 to February 2024. The demographic information of the participants was obtained by using a structured questionnaire. The initial interview guide was developed on the basis of thorough literature reviews and exploratory interviews. Following a group discussion, the study team identified and engaged three relevant specialists in the fields of nursing management, psychological care, and stroke care research to formulate the interview guide. Prior to the formal interviews, two stroke patients were pre-interviewed, and the content and form of the presentation of the interview outline were revised and improved. The interview guiding questions at this stage including three parts (Supporting Information: File 1).

A semi-structured face-to-face individual interviewing strategy was used in this study. The first author, a PhD candidate in nursing, conducted the interviews. She is a passionate, outgoing person with the ability to do qualitative research and has practical internship experience working with stroke patients. Records and interviews should only begin with the patient's permission. Throughout the interview, it was crucial to pay attention to and document the patient's nonverbal cues, including their tone, intonation, facial expressions, and movements. When a participant is deemed unsuitable, the interview data gets saturated, or no new topic emerges, the interview may be ended [38]. To ensure consistency, a group discussion on data saturation was undertaken when no new topics surfaced. The interviews are best set up in a relatively quiet consultation room or ward of a hospital.

Data analysis

Directed content analysis was employed [39, 40], which involves utilizing existing theories to preliminarily identify key concepts or frameworks before coding. In this study, the social ecological model served as the theoretical framework for data coding. The steps were as follows: within 24 h after the interviews, the recordings were repeatedly listened to, and the interview transcripts and memos were thoroughly reviewed. The audio recordings were transcribed into text by using Nvivo 11.0 software. Relevant statements were identified, analyzed and refined word by word and then coded according to the theoretical framework. Similar codes were integrated to form relevant topics and finally return to the interviewed participants for verification. To maintain a continuous analysis and ascertain whether data saturation was achieved, data collection and analysis were carried out simultaneously. Two researchers independently conducted the data analysis. Any disagreements were resolved through group discussions to ensure the reliability of the conclusions.

Rigor

This study used several of strategies (credibility, dependability, confirmability, and transferability) to establish rigour [41, 42]. First, this study selected different participants to be interviewed until data saturation was reached, and ongoing discussions with team members during data analysis increased the credibility and dependability of the findings. Second, the original words of the interviewees were quoted in the results of the study to help the readers to make judgment on the accuracy of the analysis results, which strengthened the confirmability of the study. Finally, this study increased the translatability of the study by attempting the maximum difference method of sampling and providing detailed descriptions of the respondents' information. Meanwhile, we report the results based on the COREQ checklist [43].

Ethical considerations

This study was approved by the Ethics Committee of Zhengzhou University (ZZUIRB2023-277). For formal interviews, the participants were explained the purpose and procedure of the research and invited to sign an informed consent form. All participants gave verbal or written consent and permission to use the recording device. In order to protect their privacy and confidentiality during the study and for the results to be published, each participant was purposefully assigned a sequential number (P1 to P19; C1 to C6; A to H). Interviewees had complete autonomy to discontinue participation in the study at any time and to seek clarification.

Results

Demographics of participants

In total, 19 stroke patients, 6 caregivers and 8 medical staff were interviewed in this study. The characteristics of the participants are shown in Tables 1, 2 and 3. The duration of the interview ranged from 26 to 48 min, and there were no direct professional or personal ties between the research team members and the interviewees.

Thematic analysis

Based on the social ecological model, the influencing factors of self-advocacy of stroke patients were identified

Table 1 The characteristics of stroke patients ($N = 19$)

No	Gender	Age (years)	Educational level	Employment	Marital status	Diagnosis	Stroke event number	Duration of stroke (month [M]/year [Y])	ADL
P1	Male	47	Middle school	Cooker	Married	IS	1	1 M	Independence
P2	Male	65	College	Officer	Married	IS	2	2.5Y	Minimal dependence
P3	Male	60	Primary school	Farmer	Married	IS	1	6 M	Independence
P4	Female	59	Middle school	Worker	Married	HS	2	3Y	Minimal dependence
P5	Female	53	Primary school	Worker	Married	IS	1	1 M	Independence
P6	Male	33	Master degree	Officer	Married	IS	2	6 M	Independence
P7	Female	70	College	Teacher	Married	IS	3	6Y	Partial dependence
P8	Female	65	Primary school	Farmer	Married	IS	2	7 M	Minimal dependence
P9	Male	71	Middle school	Driver	Married	HS	3	11Y	Partial dependence
P10	Male	60	Middle school	Farmer	Married	IS	2	6Y	Minimal dependence
P11	Female	69	High school	Farmer	Married	IS	1	5 M	Minimal dependence
P12	Male	49	High school	Driver	Married	IS	1	1 M	Independence
P13	Female	60	Middle school	Farmer	Married	IS	1	8 M	Independence
P14	Male	47	College	Hotel manager	Married	IS	3	5Y	Minimal dependence
P15	Female	53	College	Officer	Married	IS	1	1 M	Independence
P16	Female	60	Middle school	Farmer	Married	IS	2	8Y	Partial dependence
P17	Female	38	College	Officer	Unmarried	IS	1	1 M	Independence
P18	Male	59	High school	Worker	Married	IS	1	2 M	Independence
P19	Male	55	Middle school	Self-employed	Married	HS	1	3 M	Minimal dependence

IS ischemic stroke, *HS* haemorrhage stroke, *ADL* activity of daily life, the maximal score of Barthel Index is 100 points, with scores of 80–100 representing independence, scores of 60–79 points representing minimal dependence, scores of 40–59 representing partial dependence, and scores less than 40 denoting severe dependence

Table 2 The characteristics of caregivers ($N = 6$)

No	Gender	Age (years)	Educational level	Monthly family income (thousands of yuan/RMB)	Relationship with patients	Daily care hours
C1	Female	46	High school	5–10	Couples	2
C2	Male	60	Three-year college	5–10	Couples	3
C3	Male	65	High school	5–10	Couples	3
C4	Female	57	College	≥ 10	Couples	4
C5	Female	52	Middle school	5–10	Father and daughter	2
C6	Male	67	Middle school	5	Couples	3

Table 3 The characteristics of medical staff ($N = 8$)

No	Gender	Age (years)	Educational level	Title	Positions	working experience (year)
A	Female	34	College	Middle level title	Neurology nurse	10
B	Female	36	College	Middle level title	Neurology nurse	12
C	Male	48	College	Associate title	Neurology physician	24
D	Female	53	Three-year college	Associate title	Neurology nurse manager	32
E	Male	38	Master degree	Middle level title	Rehabilitation nurse	12
F	Female	33	College	Middle level title	Rehabilitation nurse	10
G	Male	56	Master degree	High professional title	Rehabilitation physician	30
H	Female	48	College	Associate title	Rehabilitation nurse manager	26

and categorized, as shown in Fig. 1. We found 4 major themes: (i) individual factors; (ii) interpersonal factors; (iii) community factors; (iv) policy-economic factors. Each of the major themes was further divided into 13 sub-themes. Selected quotes taken verbatim from the participants were used to highlight the various themes. The results were shown in Table 4.

Theme 1: individual factors

Sub-theme 1: weak sense of autonomy

Some interviewees exhibited a lack of autonomy during their treatment and rehabilitation, failing to report symptoms promptly and not actively participating in disease management. P2: "I usually don't mention minor ailments; they don't really matter or affect anything." C4: "This person is very strong-willed and doesn't take

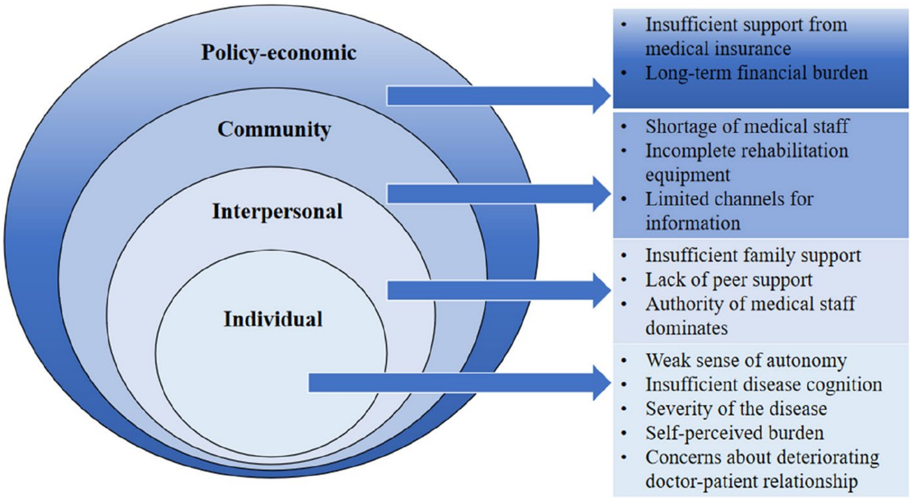

Fig. 1 Influencing factors on self-advocacy based on the social ecological model

anything seriously. I was the one who noticed the symptoms and rushed to the hospital." Furthermore, most patients did not proactively express their needs or preferences for nursing care. P5: "When I'm at the hospital, I answer the doctor's questions, but if they don't ask, I don't mention anything to them (family/friends)." C: "I've noticed that many patients lack this awareness and simply follow whatever we (medical staff) say."

Sub-theme 2: insufficient disease cognition

Insufficient understanding of their condition is considered a significant factor affecting stroke patients' ability to advocate for themselves and actively manage their illness. Many stroke patients grapple with the challenges posed by the disease itself or its treatment, yet they lack adequate awareness of their condition, which is characterized by a deficit in disease knowledge and health perspectives. Some interviewees admitted to lacking knowledge about their illness, not comprehending the diagnosis, treatment, or rehabilitation processes, and feeling unsure about what aspects they should learn about. P3: "I don't understand it at all, and I don't know how to manage it. I've just stopped asking." P11: "Getting sick is just part of growing old; it's nothing special." A: "Despite the increasing awareness of health issues, many people still lack understanding about their illnesses and how to deal with treatment and management." D: "Despite extensive efforts on popular science, there are still individuals who are unfamiliar with stroke, and some may struggle to identify even the most basic symptoms."

Sub-theme 3: severity of the disease

Most stroke patients consider the severity of the illness to be a significant factor influencing their self-advocacy. The more severe the condition, the more pronounced the patients' self-advocacy tends to be, with some actively seeking information related to their condition. P1: "Since I became ill, I've been paying attention to information about (strokes). Whenever I have free time, I use my phone to look it up." P19: "My leg on one side isn't quite as agile, so I search online to find some good ways to do exercises." B: "Often, patients with more severe conditions have more concerns; they closely monitor their health status."

Sub-theme 4: self-perceived burden

The majority of interviewees reported experiencing varying degrees of functional impairment after the acute phase, leading to a decline in their ability to care for themselves. Increased dependence on others and the burden placed on caregivers due to the illness resulted in feelings of anxiety, self-blame, and shame for the patients. P7: "Because of my illness, my whole family revolves around me. Seeing them so tired, I truly feel like a burden (sigh)." P9: "Now that I have difficulty moving, I have to rely on my family for everything, which brings them a great burden." C3: "Since falling ill, she always says she doesn't want to trouble us as if she's dragging us down." Some patients also adopt an attitude of avoidance, believing that understanding information about their illness not only offers them no help but also increases their psychological burden. P10: "What's the use of knowing all this? I don't understand it anyway. What's the point of knowing so much?" P16: "Thinking about it too much makes me feel terrible (shaking head, sigh). I don't want to deal with anything. Whatever the doctor tells me to do, I'll just do it."

Sub-theme 5: concerns about deteriorating doctor-patient relationship

Some interviewees expressed worries that their inquiries or doubts might negatively impact their relationship

Table 4 The summary of the interview themes

Themes	Sub-themes	Representative quotations
Individual factors	Weak sense of autonomy Insufficient disease cognition Severity of the disease Self-perceived burden Concerns about deteriorating doctor-patient relationship	I usually don't mention minor ailments; they don't really matter or affect anything (P2). I don't understand it at all, and I don't know how to manage it. I've just stopped asking (P3). Despite the increasing awareness of health issues, many people still lack understanding about their illnesses and how to deal with treatment and management (A). Often, patients with more severe conditions have more concerns; they closely monitor their health status (B). Since falling ill, she always says she doesn't want to trouble us as if she's dragging us down (C3). Last time, the doctor prescribed this medication for us, but I feel it's not very effective. However, I didn't dare to ask. We don't understand, and I'm afraid that if we ask too many questions, they (the doctor) will think we don't trust them (C2).
Interpersonal factors	Insufficient family support Lack of peer support Authority of medical staff dominates	My family takes good care of me, but we rarely discuss matters related to the illness because none of us really understand it (P18). We lack knowledge about it, so we mainly focus on ensuring his well-being in daily life and rely on the doctors and nurses for the rest (C5). While in the hospital, there was a kind lady who had been ill for a long time and had a lot of experience. She often encouraged me to move around more and exercise. Now that she's been discharged, I don't have anyone to exercise with (P4). Patients and their families have a lot of trust in us (the medical staff). They follow our instructions, showing a high level of cooperation (G).
Community factors	Shortage of medical staff Incomplete rehabilitation equipment Limited channels for information	Doctors and nurses are swamped. Although I see them every day during rounds, we can hardly exchange more than a few words. I haven't dared to ask many questions (P17). The workload is heavy every day. Sometimes I wish I could chat with patients about their specific needs, but time is scarce (sigh) (D). After being discharged, we stay at home, but there is no rehabilitation equipment in our village. We simply take her out for walks and exercises when we have free time (C2). During check-ups, many patients express concerns about not knowing how to exercise after discharge. They're hesitant to rely on information found online due to potential lack of credibility, so they simply opt out of learning (B).
Policy-economic factors	Insufficient support from medical insurance Long-term financial burden	As soon as I see the rehabilitation costs, I feel like giving up. I didn't discuss my thoughts with the doctor again. I just can't afford these costs (shake head with a wry smile) (P11). Some patients are quite concerned about the cost of rehabilitation. If they find it expensive, they simply give up after asking (F). He's the sole breadwinner in our family. With him falling ill, the pressure is immense. He doesn't even mention any discomfort or symptoms, simply out of fear of the expenses (C1). I spent a significant amount right after being hospitalized, and there are further expenses for follow-up check-ups and rehabilitation guidance. Sometimes, I think, if it's not a major issue, I'd rather not seek further treatment (P4).

with medical professionals, fearing they might be seen as uncooperative or disobedient patients. P8: "Sometimes, I have thoughts but hesitate to voice them, unsure if it's appropriate. Will the doctors (and nurses) think I'm not cooperating with treatment?" C2: "Last time, the doctor prescribed this medication for us, but I feel it's not very effective. However, I didn't dare to ask. We don't understand, and I'm afraid that if we ask too many questions, they (the doctor) will think we don't trust them." P14: "Sometimes, I have many questions I want to understand, but seeing how busy the doctors/nurses are, I don't dare to disturb them too much. I'm afraid they'll get annoyed with too many questions (wry smile)."

Theme 2: interpersonal factors

Sub-theme 1: insufficient family support

Family stands as the most significant social support for stroke patients, and family caregivers play a crucial role in their treatment and recovery. However, family members tend to focus more on the patient's daily life, with limited involvement in disease management. P18: "My family takes good care of me, but we rarely discuss matters related to the illness because none of us really understand it." C5: "We lack knowledge about it, so we mainly focus on ensuring his well-being in daily life and rely on the doctors and nurses for the rest." While family members are earnest in tending to the patient's everyday needs, many lack an understanding of how to engage in disease management. E: "Often, not only are patients unclear, but family members are also clueless about the illness." H: "Patients' families often don't see the importance of understanding the illness; they simply leave everything to the medical staff."

Sub-theme 2: lack of peer support

Some interviewees indicated that mutual communication among fellow patients can contribute to disease treatment and management, but there is a lack of support from particular groups of people after discharge. P4: "While in the hospital, there was a kind lady who had been ill for a long time and had a lot of experience. She often encouraged me to move around more and exercise. Now that she's been discharged, I don't have anyone to exercise with." P13: "During my hospitalization, I had daily conversations with fellow patients and learned many skills. But now that I've been discharged, I no longer have such opportunities (sigh)."

Sub-theme 3: authority of medical staff dominates

Some interviewees expressed the belief that medical staff are professionals and should be trusted implicitly. They feel that as long as they follow the advice of medical staff, they'll be fine. This perception of the authoritative expertise of medical staff leads to patients overly relying on them, neglecting to articulate their own needs and a lack of proactive communication between patients and medical staff. P15: "When you come to the hospital, you just listen to what they (the medical staff) say; they're all professionals." C6: "Once you're at the hospital, you have to follow the doctor's instructions. Whatever they tell you to do, you do it. We may not understand everything, but trusting the doctor is always the right approach." G: "Patients and their families have a lot of trust in us (the medical staff). They follow our instructions, showing a high level of cooperation."

Theme 3: community factors

Sub-theme 1: shortage of medical staff

The care and support provided by medical staff can enhance trust between doctors and patients, facilitating patients to actively express their needs and promoting health. However, the reality in China is that there is a scarcity of medical staff. Medical personnel are overwhelmed with their workload, often prioritizing treatment-related issues while overlooking other needs of patients. This results in a lack of a conducive environment for effective communication between doctors and patients, and some patients' needs go unmet. P8: "When I was first admitted, nurses asked me many questions and gave me a small booklet when I was discharged. They are busy every day and don't have much time to talk." P11: "During ward rounds, doctors quickly glance at images, advise me to eat less of this and more of that without specifying the amount, and then rush off (shake head and wry smile)." P17: "Doctors and nurses are swamped. Although I see them every day during rounds, we can hardly exchange more than a few words. I haven't dared to ask many questions." D: "The workload is heavy every day. Sometimes I wish I could chat with patients about their specific needs, but time is scarce (sigh)."

Sub-theme 2: incomplete rehabilitation equipment

Most interviewees noted that primary healthcare facilities lack adequate rehabilitation equipment. After experiencing a stroke, most patients return to their communities or homes for rehabilitation. However, there is a shortage of infrastructure available to provide rehabilitation exercises for these patients. P16: "There is very little rehabilitation equipment in our county hospital, and it's always crowded. Going to a larger hospital is inconvenient, so I just don't bother." C2: "After being discharged, we stay at home, but there is no rehabilitation equipment in our village. We simply take her out for walks and exercises when we have free time."

Sub-theme 3: limited channels for information

Most interviewees complain that while there are numerous sources of information, the quality varies, making it difficult to ascertain its accuracy. P6: "Often, I search on my phone, but I'm uncertain if the information on the Internet is reliable." C6: "Despite the abundance of channels for accessing disease knowledge, we lack the expertise to discern, sometimes leading to potential misinformation." Additionally, some stroke patients highlighted the necessity for long-term outpatient rehabilitation after discharge, yet often lack professional guidance for rehabilitation. P10: "Our neighborhood is quite distant from the hospital. Occasionally, the community hosts events for stroke awareness, but they are often overcrowded, and time is limited, leaving many questions unanswered." B: "During check-ups, many patients express concerns about not knowing how to exercise after discharge. They're hesitant to rely on information found online due to potential lack of credibility, so they simply opt out of learning."

Theme 4: policy-economic factors

Sub-theme 1: insufficient support from medical insurance

Currently, not all rehabilitation programs are fully covered by medical insurance. Some require out-of-pocket expenses, which, to some extent, limits the implementation of self-advocacy among stroke patients. Some stroke patients have their own ideas about rehabilitation, but due to financial constraints, access to rehabilitation programs is restricted. Patients cannot make choices based on their own care needs. P11: "As soon as I see the rehabilitation costs, I feel like giving up. I didn't discuss my thoughts with the doctor again. I just can't afford these costs (shake head with a wry smile)." E: "For some rehabilitation programs not covered by insurance, patients with limited financial constraints choose to give up and return home. We don't even know their specific needs." F: "Some patients are quite concerned about the cost of rehabilitation. If they find it expensive, they simply give up after asking."

Sub-theme 2: long-term financial burden

The treatment duration for strokes is prolonged, which amplifies the financial strain on patients' families. Some interviewees indicated that they are the primary financial support in their households. However, falling ill has diminished their ability to generate income. They are hesitant to voice their own needs or advocate for themselves, fearing it would exacerbate the financial burden on their families. P12: "My family relies on my earnings. Now that I'm sick and spending so much money, sometimes I feel like giving up treatment altogether. What's the point of mentioning any needs (sigh)?" C1: "He's the sole breadwinner in our family. With him falling ill, the pressure is immense. He doesn't even mention any discomfort or symptoms, simply out of fear of the expenses." Some interviewees indicated that the economic burden caused by treatment and rehabilitation costs also hinders their ability to advocate for themselves. P4: "I spent a significant amount right after being hospitalized, and there are further expenses for follow-up check-ups and rehabilitation guidance. Sometimes, I think, if it's not a major issue, I'd rather not seek further treatment."

Discussion

Stroke rehabilitation is a long-term process, and self-management can help maximize the health benefits of stroke patients, thereby reducing the burden of disease and improving health outcomes. Therefore, taking “self-advocacy” as a breakthrough point and exploring the factors influencing self-advocacy in stroke patients can help to clarify the key role of self-management in stroke patients, and may provide new perspectives for solving the challenges of self-management and enriching related theories.

This study explored the influencing factors of self-advocacy in stroke patients from the perspectives of different stakeholders, with a wide range of study populations. In addition, the application of social ecological modeling helps to explore the influencing factors from different levels, which makes the research results more comprehensive and accurate. Specific details are presented below.

Prioritizing patients and enhancing their awareness and ability for self-advocacy

In this study, the patients themselves emerge as critical factors influencing self-advocacy. Among these factors, the severity of the illness impacts patients' capacity for self-advocacy, aligning with previous research findings. Hagan et al. [44]. revealed a positive correlation between illness severity and self-advocacy; as the illness becomes more severe, patients tend to exhibit higher levels of self-advocacy. Typically, patients with severe illnesses proactively seek out relevant disease-related information and communicate with healthcare providers, potentially enhancing their self-advocacy. These interviews uncovered that some patients exhibit weak self-awareness and insufficient understanding of their condition. Additionally, psychological factors such as feeling burdened or fearing deterioration in doctor-patient relationships contribute to a lack of awareness and ability for self-advocacy in some patients.

Research indicates that individuals with strong self-awareness, a sense of responsibility, and a positive attitude towards health information are more likely to engage in self-advocacy, incorporating disease-related information they acquire into their decision-making and communication [13]. Throughout the experience of illness, patients with accurate disease cognition can prioritize their own needs at different stages, which is crucial for effective disease management [45]. Additionally, negative self-perceptions such as anxiety and depression are associated with difficulties in decision-making and can also hinder patients' ability to advocate for themselves [14, 46]. In this study, factors such as the busy schedules of healthcare professionals contribute to patients' reluctance to initiate communication, as they fear that their questions or challenges might influence the doctor-patient relationship, consistent with Hagan et al. [47]. Self-advocacy necessitates patients seeking support and assistance through communication with others, empowering them in the process. By advocating for themselves, individuals can gain access to the information and support necessary for managing their health conditions effectively. Therefore, recognizing the significant role of individual patients in self-advocacy and enhancing their awareness and capacity for it is crucial.

Enhancing social support networks to strengthen patients' interpersonal environment

In this study, some interviewees noted a lack of sufficient family support for patients, with caregivers primarily focused on daily life rather than actively engaging in the patients' disease treatment and rehabilitation processes. Existing research has made numerous efforts to encourage family involvement in patients' treatment and rehabilitation, such as empowerment guidance for family caregivers [48] and family-centered nursing modes [49].

These interventions aim to improve caregivers' disease-related knowledge and skills, ultimately increasing family participation. Moreover, intervention strategies based on communication within family systems can foster a proactive approach among family members of stroke patients in addressing the disease [50]. Additionally, some interviewees emphasized the crucial role of peer support in patients' self-advocacy. As a vital form of social support, peer support has been found to enhance patients' confidence in rehabilitation through supportive peer relationships and education [51]. However, interviewees noted challenges in sustaining this support after discharge, and this underscores the need for healthcare professionals and communities to recognize the importance of peer support. They should implement multifaceted measures to help patients establish connections beyond the hospital. Furthermore, this study reveals that the authority of healthcare professionals might impede patient self-advocacy. Some patients lack confidence in the knowledge they acquire due to the influence of healthcare professionals' expertise. Consequently, they hesitate to raise questions or doubts, fearing to challenge their authority, which is consistent with Ruggiano et al. [52].

Rehabilitation is a complex and long-term process that requires support and collaboration from various sources, including patients, family members, peers, and healthcare professionals. Fenn et al. [22] have shown that patients provided with higher social support are more likely to access relevant knowledge through various channels, thereby enhancing their self-advocacy. According to Calderon et al. [53], effective social support can boost patients' wellbeing and encourage them to adopt proactive strategies in coping with their disease. Therefore, it is crucial to recognize the importance of patients' social environment and assist them in establishing a solid support network.

Optimizing organizational resources within the community to meet patients' healthcare service needs

In this study, due to a shortage of healthcare personnel, most interviewees noted that healthcare professionals tend to focus more on the symptoms of the disease, neglecting other aspects of patients' needs. Additionally, because of the busy clinical workload, patients lack an environment for communication with healthcare professionals, which hampers the realization of self-advocacy. Research indicates that the information and emotional support provided by healthcare professionals can positively influence the patient's rehabilitation. Patients' trust in healthcare professionals motivates them to actively maintain their own health [54]. Therefore, it's crucial to acknowledge the role of healthcare professionals in promoting patients' self-advocacy and to increase opportunities for communication between them. Furthermore, some interviewees mentioned that primary medical facilities within their community lack the instruments and equipment necessary for stroke rehabilitation, thereby diminishing patients' enthusiasm to participate in rehabilitation exercises and impeding their ability to express their own needs. Research has shown that supplementing medical institutions and community health service centers with equipment to assist patients' rehabilitation exercises, such as electric standing beds, standing frames, walkers, and weight reduction training frames, can encourage patients to engage in early activities [55]. This helps them actively participate in self-management and achieve self-advocacy. Due to economic and medical conditions, 80% of stroke patients return to their families and communities after the acute phase and stabilization of their condition. Some interviewees mentioned that after discharge, access to information is limited. Despite numerous sources of information, the quality varies, making it difficult to ascertain the accuracy of the information, thereby affecting patients' self-advocacy.

Managing the health of stroke patients is a systematic, ongoing, and intricate endeavor that demands collaboration between medical practitioners and patients. Therefore, it's vital to optimize the allocation of medical personnel, enhance the professional training of healthcare providers, and furnish them with appropriate, safe, and feasible diagnostic and rehabilitation facilities tailored to the rehabilitation needs of patients. Through various channels like media, the internet, and other platforms to disseminate knowledge about stroke prevention and treatment, while also considering the individual needs and care preferences of patients, conducting suitable stroke-related health seminars is of paramount importance. Through the judicious optimization of resources from multiple angles, meeting the healthcare service needs of patients becomes feasible, thus significantly contributing to the realization of patients’ self-advocacy.

Increase policy support and ease patients' financial burden

In this study, the majority of interviewees indicated that realizing self-advocacy relies on policy support and financial security. The development of any medical service into a benign and scalable system requires robust policy backing and financial resources, as well as a comprehensive management mechanism to ensure its orderly operation. The rehabilitation of stroke patients is a time-consuming, labor-intensive, and costly process. While various rehabilitation projects have been gradually incorporated into China's basic medical insurance coverage at the national level, the system regarding reimbursement scope and payment mechanisms remains incomplete. Some rehabilitation projects are still not covered, and they place a heavy economic burden on patients and their families. It is hoped that China's medical security system can be further improved in the future. For instance, combining the degree of patients' functional recovery with the proportion of medical insurance reimbursement could establish a rehabilitation evaluation system based on functional outcomes [56], thus further enhancing the preferential treatment of medical insurance policies for stroke patients participating in health management services.

Implications for practice

This study identified multi-level factors related to self-advocacy in stroke patients, and different groups play a crucial role in this process. These findings help patients, caregivers, and healthcare professionals gain a comprehensive understanding of the factors influencing self-advocacy, thereby further improving self-advocacy among stroke patients. For patients, it is crucial to increase their knowledge of the disease and enhance their awareness and ability to advocate for themselves. At the interpersonal level, it is important to help patients obtain more family support, peer support and support from health-care workers, as a good interpersonal environment will help patients establish a solid social support system. At the community level, the needs of patients for health care services should be met by strengthening healthcare human resources, rehabilitation equipment and access to information. At the organizational level, the most important thing is to increase policy support.

Strengths and limitations

To our knowledge, this is the first study to use a social ecological model to explore the factors that influence self-advocacy in stroke patients from the perspectives of patients, caregivers, and medical staff. The application of the social ecological model provides a basis for analysis of key personal, interpersonal, community, and policy-economic elements. However, this study still has some limitations. First, participants were those people with a disability score of over 40, so the findings may not be generalized to people with more severe stroke. Second, the two hospitals involved in this study were city-level hospitals, and the sample was not representative enough. In the future, it is necessary to expand the scope of the interview participants to comprehensively analyze the influencing factors of self-advocacy in stroke patients.

Conclusion

This study explored the influencing factors affecting self-advocacy in stroke patients through qualitative interviews based on the social ecological model. The results of the study showed that the local healthcare system and policies had an impact on stroke patients' self-advocacy in addition to personal and interpersonal characteristics. To improve patients' self-advocacy, multiple social ecological factors must be recognized and addressed. A classified guidance program should be designed according to the individual characteristics and needs of patients, focusing on self-advocacy and implementing a precise and comprehensive education program to improve the level of self-advocacy in stroke patients. This study provides a reference for the development of comprehensive intervention strategies to improve self-advocacy in stroke patients.

Supplementary Information

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Supplementary Material 1.

Supplementary Material 2.

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Authors' contributions

Conceptualization, ZZX, and ZZX*; methodology, ZZX, LBL, and ZCH*; formal analysis, ZZX, and LBL; investigation, ZZX, LZW, JH, and WXX; writing—original draft preparation, ZZX; writing—review and editing, ZZX, LBL, and MYX; supervision, ZZX* and ZCH*; project administration, ZZX*. All authors reviewed the manuscript.

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Data availability

The data supporting the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

Declarations

Ethics approval and consent to participate

A full compliance with ethical guidelines and regulations was observed in all methods used in this study. The Zhengzhou University Ethics Committee gave its approval to this study, and the subjects gave their informed consent before their data was collected.

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

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