

Challenges in Accessing Community-Based Rehabilitation and Long-Term Care for Older Adult Stroke Survivors and Their Caregivers: A Qualitative Study

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Background and Objectives: While extensive research has examined the rehabilitation challenges faced by stroke survivors, there is limited literature addressing the difficulties encountered by older adult stroke survivors and their caregivers in accessing rehabilitation and long-term care within the Chinese community. This study aimed to investigate the specific challenges related to access, quality, and coordination of rehabilitation and long-term care experienced by older adult stroke survivors and their caregivers within the Chinese community.

Methods: A qualitative phenomenological design was employed to explore the lived experiences of stroke survivors and their caregivers within the Chinese community. A purposive sampling method was used to recruit participants from June to August 2023. Participants engaged in face-to-face semi-structured interviews. The data were analyzed using an inductive thematic analysis approach to identify and understand key themes and sub-themes.

Results: The study involved 38 participants, consisting of 21 older adult stroke survivors (13 males, 8 females) and 17 family caregivers (7 males, 10 females), recruited from five Chinese community health service stations. The analysis identified four distinct themes and 11 sub-themes that encapsulated the challenges faced by participants. These themes include (1) Difficulties in accessing medical services (insufficient medical resources, lack of rehabilitation resources, and time-consuming processes), (2) Challenges in daily life (inconvenience in daily mobility, inadequate financial support, and difficulties in applying for home care services), (3) Psychosocial stress (loneliness, powerlessness, and worry about burdening others), (4) Insufficient information (lack of awareness of available community services, and limited public health education activities).

Conclusion: Older adult stroke survivors and their caregivers in Chinese communities face significant challenges. To improve their well-being and quality of life, it is crucial to address these challenges through enhanced access to healthcare, better support for daily living, and more effective information dissemination. Meeting these needs requires a coordinated effort from healthcare providers, community stakeholders, and policymakers to develop and implement effective, long-term care solutions.

Keywords: stroke, survivors, caregivers, community, qualitative research

Introduction

Stroke is a significant global health concern, ranking as the second-leading cause of mortality and a major cause of disability worldwide.¹ Its economic impact is significant, accounting for around 34% of the global total healthcare expenditure.² In China, approximately 17.5 million individuals were affected by stroke in 2019,³ with more than 2 million new stroke cases occurring annually.⁴ China bears the largest stroke burden globally,⁵ and the prevalence of

stroke is estimated to reach 34.27 million by 2050.⁶ As a chronic disease, stroke imposes an immense burden on patients, their families, and the Chinese nation.

After being discharged from inpatient care, stroke survivors often transition to community or home-based care, where they may face numerous challenges, including the risk of worsening disabilities due to insufficient rehabilitation.⁷ A lack of communication, particularly regarding the diagnosis and management of conditions such as dysarthria and aphasia, can exacerbate these challenges, increasing the isolation experienced by older adult stroke survivors.⁸ Additionally, infections in stroke survivors can significantly impact long-term cognitive outcomes, raising the risk of post-stroke neurodegeneration and dementia.⁹ During this transitional period, accurate diagnosis and appropriate intervention are crucial for both stroke survivors and their family caregivers. Stroke survivors frequently rely on family caregivers for essential support.¹⁰ Consequently, family caregivers often experience various physical, psychological, social, and economic burdens in their daily lives.¹¹ These challenges underscore the need to investigate the difficulties encountered by both stroke survivors and their caregivers in navigating community-based care.

Previous qualitative studies primarily focused on stroke survivors' rehabilitation challenges, their psychological well-being, and the difficulties of transitioning from hospital to home care.^{12,13} These studies have identified issues such as social isolation, unmet rehabilitation needs, and the importance of transitional care. However, they have provided limited insight into the specific dilemmas faced by both stroke survivors and their family members when seeking rehabilitation and long-term care within the Chinese community. This study addresses this gap by examining the specific barriers encountered by stroke survivors and their caregivers in navigating community-based healthcare, aiming to provide insights to inform the development of stroke-friendly communities in China and enhance the coordination of rehabilitation and long-term care services.

Methods

Design

A qualitative phenomenological methodology was employed to conduct a detailed exploration of the challenges related to access, quality, and coordination of rehabilitation and long-term care faced by stroke survivors and their caregivers within the Chinese community.

Participants and Settings

The study employed purposive sampling to recruit participants by face-to-face invitations from five community health service stations in urban areas of Shanghai, China. These stations were responsible for providing basic medical and public health services for community residents. Semi-structured interviews were conducted between June and August 2023. The inclusion criteria for stroke survivors consisted of individuals who had experienced at least one stroke and were aged 60 years or older.¹⁴ For family caregivers, the inclusion criteria required them to be primarily responsible for caring for a stroke-affected family member. Exclusion criteria were applied to stroke survivors who exhibited severe cognitive impairments, aphasia, or an inability to communicate in Mandarin. Additionally, family caregivers who were unable to communicate in Mandarin were excluded from the study.

Data Collection

During each semi-structured interview, participants were individually invited to a quiet room of the community medical service station to ensure privacy and minimize distractions. The interviews were conducted using a semi-structured interview guide, which was developed by the research team after reviewing the relevant literature and consulting experts in stroke rehabilitation and qualitative research. While the interview guide was not pilot-tested, it was carefully refined to align with the research aims. Two researchers, SN Z and L X, both female nursing postgraduate students with prior qualitative research experience and formal training in qualitative methodology, conducted the interviews. Neither researcher had prior contact with the participants. Each interview lasted 40–60 minutes, was audio-recorded with participant consent, and field notes were taken. We did not give the transcripts to participants for review or correction, and we did not repeat interviews. Participants received a small token of appreciation, including a packet of tissues and

a towel. The interview guide was flexible, allowing the researchers to adapt questions based on participant responses (as outlined in [Appendix 1](#)).

Data Analysis

The research employed inductive thematic analysis,¹⁵ following six steps: 1) familiarization with the data; 2) generating initial codes; 3) searching for themes; 4) reviewing themes; 5) defining and naming themes; 6) writing the report. First, audio recordings were transcribed into text using the Newsmy website (a Chinese Website that converts recorded audio into text) and then imported into Microsoft Office Word for organization and NVivo software for analysis. Two researchers (SN Z and L X) independently familiarized themselves with the data by repeatedly reviewing the transcriptions to gain an in-depth understanding. They then independently generated initial codes using NVivo software, ensuring that key ideas were captured. After initial coding, the two researchers met regularly to discuss their coding frameworks, resolve discrepancies, and reach a consensus on the emerging patterns. In the third step, similar codes were grouped into potential themes, which were discussed among the research team to ensure that the themes accurately reflected the data. The fourth step involved a rigorous review and refinement of themes, ensuring that they were coherent and distinct. This was done through further team discussions and comparisons with the original data to ensure validity. The researchers then worked collaboratively to define and name each theme for clarity in the fifth step, ensuring the themes were articulated and meaningful. Finally, the results and conclusions were developed based on the identified themes, following the sixth step of writing the report. The two researchers continued this six-step process until data saturation was reached, meaning no new themes were emerging, adhering to the Consolidated Criteria for Reporting Qualitative Research (COREQ).¹⁶

Ethics Consideration

The study was conducted following the Declaration of Helsinki and was approved by the Ethics Committee of the Shanghai Tenth People's Hospital of Tongji University (approval number 2020-KN82-01). Before commencing each interview, participants were provided with a detailed explanation of the study's objectives and methodology. Participants' informed consent was obtained, including the publication of anonymized responses and direct quotes. Researchers underscored that all recorded data and personal information would exclusively serve the purposes of this study and be maintained with the utmost confidentiality. To ensure this confidentiality, numerical identifiers (eg, P1, C1) were employed instead of actual names. Moreover, participants retained the freedom to discontinue their involvement in the interview at any point or decide whether to participate. There were no prior relationships or conflicts of interest between the researchers and participants.

Results

A total of 38 participants were recruited through face-to-face invitations, including 21 stroke survivors and 17 family caregivers. Among the stroke survivors, 6 were 60–70, 11 were aged 71–80, and 4 were 80 or older. Of the stroke survivors, 13 were male. Most survivors (57.14%) had experienced one or two strokes, 28.57% had three to four strokes, and 14.29% had five or more strokes. Among the caregivers, 7 were younger than 60, 6 were aged 60–70, and 4 were aged 71–80, with 58.82% being female. The duration of caregiving varied: 8 for 6–12 months, 5 caregivers provided care for 13–24 months, and 4 for over 24 months. None of the participants withdrew from the study or were non-responders. The social demographic details of the selected stroke survivors and family caregivers are presented in [Tables 1](#) and [2](#), respectively.

Participants engaged in extensive discussions regarding the healthcare challenges they encountered within their communities. These challenges encompass difficulties in accessing medical services, challenges in daily life, psycho-social stress, and unmet needs in the community. In total, four themes and 11 codes were derived from the semi-structured interviews. The detailed themes and codes from stroke survivors and family caregivers are reported in [Table 3](#).

Table 1 Socio-Demographic and Clinical Characteristics of Stroke Survivors

| Characteristic | | N | % |
|------------------|----------------------|----|-------|
| Age (years) | 60–70 | 6 | 28.57 |
| | 71–80 | 11 | 52.38 |
| | ≥80 | 4 | 19.05 |
| Sex | Male | 13 | 61.90 |
| | Female | 8 | 38.10 |
| Stroke Frequency | 1–2 | 12 | 57.14 |
| | 3–4 | 6 | 28.57 |
| | ≥5 | 3 | 14.29 |
| Living Situation | Living alone | 4 | 19.05 |
| | Living with spouse | 10 | 47.62 |
| | Living with children | 7 | 33.33 |

Table 2 Socio-Demographic and Clinical Characteristics of Family Caregivers

| Characteristic | | N | % |
|-------------------------|--------|----|-------|
| Age (years) | <60 | 7 | 41.18 |
| | 60–70 | 6 | 35.29 |
| | 71–80 | 4 | 23.53 |
| Sex | Male | 7 | 41.18 |
| | Female | 10 | 58.82 |
| Length of Care (months) | 6–12 | 5 | 29.41 |
| | 13–24 | 8 | 47.06 |
| | >24 | 4 | 23.53 |

Table 3 Themes and Sub-Themes

| Themes | Sub-Themes |
|--|--|
| Difficulties in accessing medical services | Insufficient medical resources Lack of rehabilitation resources Time-consuming processes |
| Challenges in daily life | Inconvenience in daily mobility Inadequate financial support Difficulties in applying for home care services |
| Psychosocial stress | Loneliness Powerlessness Worry about burdening others |
| Insufficient information | Lack of access to community healthcare services Limited public health education activities |

Difficulties in Accessing Medical Services

Insufficient Medical Resources

While basic services such as medical consultations, basic medications, and routine tests (eg, blood, urine, and stool tests) are available within community health service stations, other medical resources are limited, such as X-rays for diagnostic purposes, and the accessibility of a wider range of medications.

Last time, I had to endure a 30-minute taxi ride to the hospital for X-rays, which was quite a hassle compared to the mere 10-minute walk from my home to the community health service station. I hope that in the future, the station can provide X-ray and ultrasound services. (P2)

The range of medications available is limited, and sometimes I have to go to Shibe Hospital to fill my prescriptions after seeing a doctor here. I wish the community health service station could offer a wider variety of medications. (P14)

The process of obtaining medication is quite inconvenient. My husband is paralyzed due to a stroke and unable to walk. So I come to the station on his behalf for medical appointments. But they don't dispense medication in the morning, which means I have to return in the afternoon to pick up his prescriptions. Which is troublesome for me. (C2)

Lack of Rehabilitation Resources

The rehabilitation resources available at community health service stations are limited and include traditional Chinese techniques such as acupuncture, massage, and moxibustion. However, not all stations offer these services. In the absence of resources in communities, stroke survivors with disabilities resulting from strokes often encounter difficulties in obtaining the necessary rehabilitation services. They may be compelled to stay at home to learn rehabilitation skills online, due to have not enough money to pay for rehabilitation in rehabilitation facilities.

I have to learn rehabilitation skills and buy massage devices online because I do not have enough money to pay the cost of rehabilitation facilities. (P20)

When will we be able to access rehabilitation services here? It feels like they are out of reach. (P10)

As I grow older, I find it increasingly difficult to provide proper care and effective rehabilitation for my wife. At times, it feels like my caregiving techniques may not be adequate, and her recovery progress is not as significant as I had hoped. (C3)

Time-Consuming Processes

Complaints about long wait times are common among participants seeking medical care. This situation arises because of the high number of patients crowded in the community health service stations and the pressure on doctors to provide rapid medical treatment.

There is a shortage of doctors here, and every time I need a medical consultation, it takes at least one or two hours. Although it's better than the three-hour wait at the hospital, I still hope the community health service station can reduce the waiting time to 30 minutes. Then, I can do other things after my appointment instead of spending my entire morning here. (P1)

Whenever I come here for a medical consultation for my father, the doctors always seem extremely busy and ask hurried questions. If the doctor had more time and fewer patients were waiting, I could discuss all of my dad's health issues with him. (C6)

I'm unsure of the best time to come, so I have to arrive early and wait a long time before the consultation. (P21)

Challenges in Daily Life

Inconvenience in Daily Mobility

In older residential areas without elevators, residents—especially stroke survivors—face significant daily challenges due to the need to climb multiple flights of stairs, often between 4 and 6 floors. Consequently, they are appealing for government assistance in installing elevators to improve their quality of life.

I live on the fourth floor, and as I am getting older, it's becoming harder for me to climb stairs. I can't afford a new apartment, so I hope that the government can install elevators for older people like us. (P4)

Inadequate Financial Support

Financial strain is a common challenge faced by stroke survivors and caregivers, which is related to accessing necessary rehabilitation services, purchasing assistive devices, and balancing the costs of care with other financial responsibilities.

Each month, the government provides me with 2000 yuan to help cover basic living expenses and medicine costs. I appreciate it, but it's not enough to meet my other needs. I struggle to make ends meet every day. I've tried to apply for more financial assistance, but it's been difficult. (P18)

I have to work to earn a living and don't have much spare time to devote to my mother's rehabilitation exercises. This is a major concern for me because I worry that not being able to provide adequate rehabilitation may lead to a decline in her functionality. (C10)

Difficulties in Applying for Home Care Services

Patients in advanced stages of stroke often struggle with self-care, placing a substantial burden on their families. In many cases, a family member must devote a significant amount of their time to providing care for the stroke patient. One major difficulty is the eligibility criteria, as long-term care insurance is often unavailable to stroke survivors under 60. In addition, due to limited healthcare human resources, not every stroke survivor can access home care services.

I'm almost 80 years old, and my monthly retirement pension is just 4,000 yuan. I can't afford to pay for my son's rehabilitation in rehabilitation facilities, so I have to take care of him myself. It's incredibly tough for me. I've been trying to get long-term care insurance for him for the last five years, but the community workers say he's under 60 and doesn't qualify for it. (C5)

If the community provided in-home healthcare services, it would greatly reduce the stress of caring for my husband. At home, I have to manage household tasks and assist him with eating, dressing, personal hygiene, and rehabilitation, which is quite overwhelming for me. (C1)

Psychosocial Stress

Loneliness

It can not be ignored that patients living alone in the community who lack daily conversations with family members face significant challenges of loneliness. Additionally, they often worry about having to handle emergencies like the onset of a stroke or other difficulties entirely on their own. This situation poses significant challenges for them.

I feel very lonely at home. My children are rarely around because they work outside, and I have no one to talk to daily. Talking to you right now makes me feel happy and relaxed, and I hope the community can provide more opportunities for conversations like this. (P9)

Last time, my neighbors helped call an ambulance when I had a stroke. I was lucky then, but I'm not sure if, next time, someone will be there to help me like that again. (P15)

Powerlessness

The extended rehabilitation process following multiple strokes can exert significant strain on patients. In such circumstances, if patients are unable to access appropriate care services, they may experience a sense of powerlessness. Furthermore, the caregiving stress of family caregivers can not be overlooked as well.

I don't know who I can talk to about my needs, and there's no one helping me with them. I know it's unrealistic to make requests of the community. (P5)

Caring for my husband for so long has left me exhausted. He has multiple health issues, and he often gets upset and yells at me. Sometimes, I feel so powerless. (C6)

Worry About Burdening Others

With the influence of Chinese culture, people often feel reluctant or awkward to burden others, including their families, government, or the community.

My pension is far from enough to cover my medical expenses, and financial stress has become a major issue since my stroke diagnosis. I've had to ask my daughter for financial help, which is quite embarrassing for me. (P12)

As long as I'm not completely incapacitated, I won't trouble the government. (P3)

Insufficient Information

Lack of Awareness of Available Community Services

Obtaining comprehensive services in the community is a challenge for stroke survivors when they return home from the hospital. They express dissatisfaction with the limited accessibility of services.

I wish the community would inform us about the services they offer. I was never made aware of them. (P19)

Other than obtaining medication, I am unaware of any additional services provided by the community. It seems quite difficult to access other rehabilitation services here. (P11)

No one informed me that the center offers services beyond medical consultations and dispensing medicine. There's a need to provide additional healthcare services. (C9)

Limited Public Health Education Activities

Participants are eager to gain comprehensive knowledge about stroke, encompassing areas such as medication, rehabilitation, daily activities, and diet considerations. Additionally, they are interested in learning how to recognize the signs of a stroke and how to respond promptly to assist themselves or their family members in the event of a sudden stroke occurrence.

I experienced a stroke some time ago, and it has been nearly nine months, but I still know very little about it. I am concerned about the possibility of it happening again. How can I prevent it? (P16)

I would like to acquire some knowledge that can enable me to take better care of my wife. I watch videos on Douyin (Chinese TikTok) to learn, and I wish the community could provide some healthcare lectures related to stroke rehabilitation. (C13)

My left hand is weak. What can I do to strengthen it at home by myself? (P17)

Discussion

This study explored the experiences and perspectives of stroke survivors and their family caregivers in Chinese communities when seeking assistance related to rehabilitation and long-term care. The results reveal multiple dilemmas faced by individuals when accessing medical services in the community, including difficulties in accessing medical services, challenges in daily life, psychosocial stress, and insufficient information. These demands encompass a wide spectrum, highlighting the need for governments, society, and healthcare professionals to collaborate in the creation of a stroke-friendly community tailored to the unique needs of these special groups.

The shortage of medical resources in community settings presents significant challenges for older adult stroke survivors and their family caregivers seeking medical assistance. Addressing this issue requires an increase in healthcare personnel and the provision of adequate diagnostic tools and rehabilitation equipment, which are crucial for supporting stroke survivors in community care.¹⁷ Additionally, targeted rehabilitation training is essential. Studies on proprioceptive and dual-task training have demonstrated their effectiveness in improving postural balance, gait, quality of life, and reducing fall risk among stroke survivors.^{18,19} Older adult stroke survivors require not only healthcare but also diverse forms of support, such as improved living arrangements, financial assistance, and community-based services. Although the introduction of Long-Term Care Insurance (LTCI) aims to support stroke survivors,²⁰ our results show that its implementation remains problematic, particularly for caregivers burdened with complex application processes. Streamlining the application process and providing more proactive community health worker support are critical steps to ensure the intended benefits reach stroke survivors effectively. Future research should focus on developing a robust primary healthcare system that enhances the accessibility of medical resources while addressing the daily life needs of stroke survivors.

It is also essential to address the mental health challenges faced by stroke survivors, particularly their feelings of loneliness and powerlessness. These findings align with previous studies, which have noted similar concerns among stroke survivors.^{21,22} Additionally, the influence of Chinese culture may lead to individuals feeling uncomfortable about burdening others.²³ This could contribute to the reluctance of both survivors and caregivers to seek external help, further deepening their isolation. Various strategies can be implemented to assist these individuals, including the organization of routine recreational activities that can bolster social involvement, alleviate depressive symptoms, and promote physical rehabilitation.^{24–26} While current literature emphasizes the importance of community-based psychological support services, large-scale implementation in the community still seems far off. This gap underscores the need for further research into psychological support and community-based resources that are easy to implement.

Accessible healthcare information is crucial for older adult stroke survivors and their family caregivers to effectively navigate rehabilitation and long-term care in communities. Our study highlights a significant gap in awareness about available community healthcare services and underscores the challenge of information dissemination in improving stroke care. This suggests that while public health education is frequently recommended,²⁷ its actual implementation and impact on stroke survivors in diverse settings, including Chinese communities, require further exploration. Additionally, family caregivers of stroke survivors often juggle multiple roles, including caregiving responsibilities, household duties, and sometimes even assuming the role of a care recipient.²⁸ Equipping caregivers with essential skills through targeted training can significantly alleviate their caregiving burden and enhance their overall quality of life.²⁹ Although respite care is proposed as a solution,³⁰ its effectiveness and accessibility need further evaluation, highlighting the need for more comprehensive and culturally tailored approaches.²³ Future research can investigate interventions to improve healthcare information dissemination for older adult stroke survivors and enhance support for family caregivers, such as through respite care and targeted training programs.

Limitations

Our study provided new and valuable insights into the dilemmas faced by stroke survivors and their caregivers in Chinese communities. However, several limitations must be discussed. First, we gathered data from only five community health service stations, mainly from stroke survivors with mild to moderate disabilities who could access these community health service stations and caregivers of bedridden stroke patients. Consequently, our findings may primarily represent the experiences of stroke survivors actively seeking recovery, potentially overlooking the unique needs and challenges faced by those with severe strokes who are unable to access these community health service stations. Secondly, our study did not collect detailed information on the levels of disability, the average costs associated with rehabilitation and long-term care, or specific insurance details for stroke survivors. These are critical factors for comprehensively understanding the challenges faced. The absence of this data may limit the depth of our analysis in capturing how varying levels of disability and rehabilitation costs affect access to and quality of care. Thirdly, all our participants were from Shanghai, an urban area with better healthcare and resources³¹ compared to rural China where stroke rates are higher.³ Therefore, our results may not fully capture the needs and difficulties of stroke survivors and caregivers in less developed areas.

Conclusion

This research highlights the multifaceted challenges faced by older adult stroke survivors and their caregivers within Chinese communities, particularly in accessing medical services, navigating daily life difficulties, and managing psychosocial stress. The lack of sufficient information about available services exacerbates these struggles, with cultural factors often impeding timely help-seeking behaviors. The findings underscore the critical need for a coordinated approach that enhances access to rehabilitation and long-term care, enhances medical resource accessibility, improves daily living support, and disseminates healthcare information more effectively. To address these challenges, we propose an integrated care path that ensures continuous support for stroke survivors and their caregivers. This path should involve the development of a comprehensive primary healthcare system tailored to their specific needs, offering timely, affordable, and convenient services. Governments, healthcare providers, and communities need to collaborate in creating stroke-friendly environments that comprehensively address the needs of survivors and their family caregivers. The

integrated approach should include structured follow-up care, community-based support networks, and the incorporation of cultural considerations into service delivery. Future research should address regional disparities, focusing on the unique challenges faced by stroke survivors and caregivers in rural areas and those with varying levels of disability. Additionally, it should examine the role of insurance in rehabilitation and stroke care to inform the development of more comprehensive, regionally tailored healthcare solutions.

Data Sharing Statement

For the privacy of individuals who participated in the study, the data will be shared on reasonable request to the corresponding author.

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Author Contributions

All authors made a significant contribution to the work reported, whether that is in the conception, study design, execution, acquisition of data, analysis and interpretation, or in all these areas; took part in drafting, revising or critically reviewing the article; gave final approval of the version to be published; have agreed on the journal to which the article has been submitted; and agree to be accountable for all aspects of the work.

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Disclosure

The authors declare no potential conflicts of interest in this work.

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