

**ORIGINAL RESEARCH**

# Barriers to Activity and Participation for Stroke Survivors in Rural China



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## Abstract

**Objectives:** To investigate environmental barriers reported by stroke survivors in the rural areas of China and to determine the impact of environmental barriers on activity and participation relative to demographic characteristics and body functioning.

**Design:** Cross-sectional survey.

**Setting:** Structured interviews in the participants' homes.

**Participants:** Community-dwelling stroke survivors in the rural areas of China (N=639).

**Interventions:** Not applicable.

**Main Outcome Measures:** Activity and participation (Chinese version of the World Health Organization Disability Assessment Schedule 2.0), environmental barriers (Craig Hospital Inventory of Environmental Factors), neurological function (Canadian Neurological Scale), cognitive function (Abbreviated Mental Test), and depression (6-item Hamilton Rating Scale for Depression).

**Results:** Physical/structural barriers are the major impediment to activity and participation for these participants (odds ratio, 1.86 and 1.99 for activity and participation, respectively;  $P<.01$ ). Services/assistance barriers primarily impede participation rather than activity (odds ratio, 1.58 in participation;  $P<.05$ ).

**Conclusions:** Physical/structural and services/assistance barriers were considered the dominant barriers to activity and participation for stroke survivors in the rural areas of China. Attitudinal/support and policy barriers did not emerge as serious concerns. To generate an enabling environment, physical/structural and services/assistance barriers are the environmental barriers to be decreased and eliminated first.

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Stroke is notable for its high incidence and mortality rate and for the long-term disability it can cause, which are more serious in the rural areas of China.<sup>1</sup> In recent decades, the age-adjusted mortality rate from cerebrovascular diseases in the rural areas of China has increased dramatically from 78 per 100,000 population in 2000 to 197 in 2009.<sup>2</sup> Persons surviving a stroke usually face long-term disability, used here as "...an umbrella term for impairments, activity limitation and participation restriction."<sup>3(p3)</sup> Activity limitation and participation restriction can contribute to depression, social isolation, and poor quality of life.<sup>4-6</sup> These outcomes often

influence each other and form a vicious circle.<sup>6</sup> Regaining activity and participation is an important goal of rehabilitation.<sup>7</sup>

Activity limitation and participation restriction are due to the imbalance of people's capacity and environmental demands.<sup>8</sup> Both strengthening capacity and eliminating or decreasing environmental barriers can improve activity and participation. The World Health Organization's International Classification of Functioning, Disability and Health (ICF)<sup>3</sup> emphasizes environment as an important element influencing activity and participation and points out that environmental factors could be barriers or facilitators to hinder or enhance activity and participation. Environmental factors here refer to "all aspects of the external or extrinsic world that form the context of an individual's life and, as such, have an impact on that person's functioning."<sup>3(p213)</sup>

Although environmental effects on participation have been widely treated theoretically,<sup>3,8</sup> empirical studies have been

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relatively few.<sup>9,10</sup> Whiteneck et al<sup>9</sup> studied 2726 participants after spinal cord injury and showed that environmental barriers accounted for 4% of the variance in participation. However, such studies of community-based stroke survivors have been scarce. Stroke leads to various impairments and disabilities in motor, sensory, cognitive, and emotional functioning. This can result in a great burden on stroke survivors, their families, and society. At the same time, the environmental barriers that stroke survivors experience may be different from those affecting persons with spinal cord injury. This study was designed to investigate the environmental barriers stroke survivors perceived in the rural areas of China and to determine their effects on activity and participation.

To exclude the effects of confounding factors, the potential variables that might influence activity and participation were included in the study. According to the ICF, activity and participation may be affected by body structure and functions, health condition, and personal and environmental factors. For stroke survivors, in addition to the primary variable of environmental factors, neurological function, cognitive function, emotional status were evaluated, which were viewed as confounding factors in this study. Therefore, the main objective of this study was to explore the effects of environmental barriers on activity and participation after adjusting neurological and cognitive functions, depression, and demographic data.

## Methods

### Study design and participants

This was a cross-sectional study conducted from September 2013 to June 2014 in China's Guangdong province. Multistage cluster sampling was used. A stratified convenience sample of stroke survivors was drawn by first selecting 1 county in the east of the province, 1 in the west, 1 in the north, 1 in a mountainous area, and 2 in the Pearl River Delta. In each county, 5 townships were selected at random and convenience samples were drawn from 4 to 8 villages in each township on the basis of the number of stroke survivors in each village. In total, 6 counties, 30 townships, and 202 administrative villages were sampled. All the stroke survivors in each village were included if they had been diagnosed with a stroke (confirmed by computed tomography or magnetic resonance imaging) or had exhibited typical symptoms of stroke at least 3 months previously and were willing to participate. Participants were excluded if they suffered from subarachnoid hemorrhage, transient ischemic attacks, and lacunar infarction or exhibited dementia or another psychiatric disorder before the stroke. Only those with normal language comprehension and an Abbreviated Mental Test (AMT) score of  $\geq 6$ <sup>11</sup> were included in this study.

#### List of abbreviations:

|            |                                                                    |
|------------|--------------------------------------------------------------------|
| AMT        | Abbreviated Mental Test                                            |
| CHIEF      | Craig Hospital Inventory of Environmental Factors                  |
| CNS        | Canadian Neurological Scale                                        |
| ICF        | International Classification of Functioning, Disability and Health |
| OR         | odds ratio                                                         |
| WHODAS 2.0 | World Health Organization Disability Assessment Schedule 2.0       |

The study protocol was approved by the Ethics Committee of the School of Nursing of Sun Yat-sen University. Informed consent was obtained from all participants. The investigators were trained to explain the meaning and objectives of the study to the participants, and a card with the related information about the study was shown to each participant and/or to their significant others. The literate participants signed their consent forms themselves, but the illiterate needed one of their family members to sign on their behalf. If no family member could sign, such as the participant living alone and having no family, the village doctor signed as a witness to the consent. (This was one of the requirements of the ethics committee.)

## Procedures

Ten postgraduate students in rehabilitation or nursing, including 2 of the authors (L.Z., K.L.), collected the data. They were members of 2 research groups mentored by the other 2 authors (L.Y., T.Y.). The students were first trained with a 3-hour lecture on the topic, the study, and the questionnaire. They then invested 3 hours in role playing pertaining to interviewing and evaluating and watched a 1-hour video of one of the authors interviewing a stroke survivor with disability. There was a training manual that each interviewer needed to study. Then, on-site, the 10 investigators were divided into 2 groups led by 2 authors separately. The 5 members of each group conducted 2 interviews as a group under the author's supervision before beginning the actual data collection interviews to help ensure consistency.

All the doctors working in the sampled villages were invited to participate in the research. They were familiar with the participants living in their villages and were responsible for screening participants with stroke and introducing the investigators to them. After obtaining consent, the investigators visited each participant at home. The interviews lasted 20 to 60 minutes, depending on the participant's condition.

Most of the stroke survivors were elderly and illiterate, and many suffered from degraded hearing and/or eyesight, so all were interviewed face to face. A private interview setting was demanded so that the information related was as uninhibited as possible. While completing the self-rated instruments—the World Health Organization Disability Assessment Schedule 2.0 (WHODAS 2.0) and the Craig Hospital Inventory of Environmental Factors (CHIEF)—to avoid bias introduced by the interviewer, the investigators questioned the participants using standard wording and then offered response options on a flashcard (or read them out) and invited the participants themselves to choose the most appropriate option.

The average number surveyed per day was 30. The investigators were required to write up each interview individually. This write-up was later checked against the replies to the entire questionnaire. The authors collected and checked all the questionnaires immediately at the end of each day. If problems were found, the investigator was reminded and guided at once.

## Measures

### Demographic and stroke-related data

The participants' demographic and stroke-related characteristics involved the common variables such as age, sex, occupation, marital status, and pathological subtype. "Retired" was recorded as the occupation of a participant older than 65 years who was not doing any work or household chores. Participants who had a distinct stroke history but did not know the abnormality were recorded as "undetermined."

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