

BMJ Open Needs and rights awareness of stroke survivors and caregivers: a cross-sectional, single-centre questionnaire survey

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ABSTRACT

Objectives The needs and rights awareness of stroke survivors have not been reported in China. This study investigated the needs and rights awareness of stroke survivors and caregivers in Tianjin, China.

Setting A survey launched by the World Stroke Organization was conducted in Tianjin, China. The questionnaire included demands for psychological support, treatment and care, social support and information. Stroke survivors and their caregivers were interviewed face to face for the questionnaire. Between June 2014 and February 2015, stroke survivors were invited to participate if they were more than 18 years old and had experienced a stroke. Exclusion criteria were patients who had disorders of consciousness, significant cognitive impairment, aphasia, communication difficulties or psychiatric disorders. Only caregivers who were family members of the patients were chosen. Paid caregivers were excluded.

Participants Two hundred and forty-eight stroke survivors and 212 caregivers were enrolled.

Primary outcome measures The correlations between levels of needs and potential effect factors were analysed. Levels of different needs were compared by age, gender and time since stroke.

Results Among the cohort, 95.6% stroke survivors and 92.5% caregivers agreed to each question in the questionnaire. The participants prioritised the needs for psychological support (99.4%), treatment and care (98.6%), social support (98%) and information (96.2%). The total score was negatively correlated with age ($r=-0.255$, $p<0.01$). Patients below 65 years old had higher scores than those 65 years or older ($p<0.01$), while male patients had higher scores than female patients ($p<0.01$).

Conclusions The needs for psychological and emotional support, individual treatment, social support and information about stroke were eagerly reported by most survivors. The Bill of Rights must be recognised by the Chinese society, providing appropriate stroke care to every patient to optimise stroke outcomes.

INTRODUCTION

Stroke is the major cause of death and disability worldwide. The burden of stroke is particularly serious in Asia,¹ and its mortality is higher than that in Europe or North

Strengths and limitations of this study

- Stroke survivors and caregivers did not have their own bill of rights when this study was performed, and their needs and rights awareness have not been reported in China.
- The demands for psychological and emotional support, individual treatment, social support and information were eagerly reported by most stroke survivors.
- The stroke survivors in China had the strongest demand for emotional and psychological support, which should be recognised.
- Limitations include potential bias due to the exclusion of patients with severe language or cognitive impairment. The number of participants was also limited. Further multiple-centre and large-sample research studies may be needed.

America.² In China, it is the leading cause of death and disability.³ Stroke survivors cope with significant physical, cognitive and emotional deficits, and 25%–74% of these survivors require some assistance or are fully dependent on their caregivers for activities of daily living.⁴ Although much has been done to control the disease, the stroke survivors' needs and rights have not received adequate attention. Bills of patient rights for several diseases have been developed to achieve higher degrees of patient satisfaction, such as for cancer⁵ and chronic obstructive pulmonary disease.⁶ Stroke survivors did not have their own bill of rights until the World Stroke Organization (WSO) realised this urgent need and framed a global bill of rights for patients with stroke.⁷ The WSO has numerous strategies to increase stroke awareness, including influencing policies for stroke prevention and improved health services, providing education, and fostering the development of systems and organisations for the long-term support of stroke survivors and their families.⁸ To determine what stroke survivors



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and caregivers require, the WSO has launched an online survey (<https://www.surveymonkey.com/s/WSOStrokeSurvivor-Chinese> and <https://www.surveymonkey.com/s/WSOStrokeCarer-Chinese>) (see online supplementary file).

This survey was used in this study to investigate the needs and rights awareness in Chinese stroke survivors and caregivers. This study was aimed to provide a reference for the improvement of stroke-related laws and bills, which could provide the stroke survivor with physical, mental and emotional support.

METHODS

Study population

This study was approved by our local Ethics Committee at the Second Hospital of Tianjin Medical University. All patients and their caregivers gave informed consent.

Between June 2014 and February 2015, 248 stroke survivors and 212 caregivers from the Stroke Clinical Registry and Follow-up Database of the Second Hospital of Tianjin Medical University were enrolled. According to the Kendall sample size determination method of the questionnaire, at least 70–140 samples were needed; therefore, we recruited more participants than the sample size determined. Stroke survivors were invited to participate if they were more 18 years old, had experienced stroke and agreed to participate in the study. The exclusion criteria were patients who had disorders of consciousness, significant cognitive impairment, aphasia, communication difficulties or psychiatric disorders.

Caregivers who had been taking care of the patients with stroke who met the above criteria were recruited. Only caregivers who were family members of the patients were chosen. Paid caregivers were excluded.

Development of the survey

The questionnaire was adapted from that designed by the WSO. Stroke survivors and caregivers were interviewed face to face during the patients' follow-up by well-trained neurologists who were not the patients' treating doctors.

The final questionnaire included 17 questions covering age, gender, level of education, time since the first stroke, and demands for treatment and information about stroke and psychological and social support. Fourteen of the questions had five choices for each question. The five choices were strongly agree, agree, neutral, disagree and strongly disagree. The Likert five-grade score method was used to assign 1–5 points; higher scores indicated a greater degree of demand. The purpose of the survey and the procedure were explained fully to all participants.

The questionnaire translated to Chinese was tested again for the reliability in our population. The scales reliability of the stroke survivors' questionnaire was assessed with a total Cronbach's α of 0.910, corrected by interitem correlation above 0.70. The scales reliability of the stroke caregivers' questionnaire was assessed with

Table 1 Characteristics of stroke survivors and caregivers

	Stroke survivors n (%)	Stroke caregivers n (%)
Total	248	212
Age		
<45	3 (1.2)	49 (23.1)
45–54	29 (11.7)	69 (32.5)
55–64	54 (21.8)	65 (30.7)
65–74	63 (25.4)	21 (9.9)
75–84	73 (29.4)	5 (2.4)
≥85	26 (10.5)	3 (1.4)
Gender		
Male	125 (50.4)	95 (44.8)
Female	123 (49.6)	117 (55.2)
Time since stroke, years		
<1	170 (68.5)	132 (62.3)
1–3	41 (16.5)	37 (17.5)
4–7	13 (5.2)	22 (10.4)
8–10	6 (2.4)	8 (3.8)
>10	18 (7.3)	13 (6.1)
Education, years		
<3	19 (7.7)	2 (0.9)
3–6	44 (17.7)	13 (6.1)
6–9	70 (28.2)	56 (26.4)
9–12	88 (35.5)	93 (43.9)
>12	27 (10.9)	48 (22.6)
Type of stroke		
Ischaemic stroke	192 (77.4)	170 (80.2)
Haemorrhagic stroke	56 (22.6)	42 (19.8)
NIHSS score		
<4	115 (46.4)	90 (42.5)
4–15	127 (51.2)	116 (54.7)
>15	6 (2.4)	6 (2.8)

NIHSS, National institutes of Health Stroke Scale.

a total Cronbach's α of 0.817, corrected by interitem correlation above 0.70. The Cronbach's α values were good for all scales for the study.

Statistical analysis

Frequencies and proportions were used to summarise levels of answers. The Spearman rank relational coefficient was used to analyse the correlations between levels of needs and potential effect factors. Levels of different needs were compared by age, gender and time since stroke. Categorical variables are displayed as frequencies and percentages. Categorical variables were analysed using a χ^2 test. Comparisons between groups were made

Table 2 The correlations between levels of needs and potential effect factors

	Total		Psychological support		Information		Treatment and care		Social support	
	Rho	p Value	Rho	p Value	Rho	p Value	rho	p Value	Rho	p Value
Age	-0.255	<0.001	-0.211	0.001	-0.221	<0.001	-0.197	0.002	-0.245	<0.001
Gender	-0.14	0.027	-0.184	0.004	0.052	0.419	-0.130	0.041	-0.131	0.039
Time since stroke	-0.044	0.487	0.095	0.135	-0.063	0.324	-0.127	0.046	-0.029	0.647
Education	0.099	0.121	-0.000	0.998	0.051	0.427	-0.067	0.293	0.010	0.879
Type of stroke	-0.089	0.162	-0.017	0.791	0.075	0.242	-0.044	0.494	0.005	0.932
NIHSS Score	-0.088	0.169	0.010	0.877	-0.059	0.352	-0.087	0.172	-0.036	0.578

NIHSS, National institutes of Health Stroke Scale.

Table 4 Needs of rural stroke survivors by gender

	Total	Psychological support	Information	Treatment and care	Social support
Male	4.3 (4.0–5.0)	4.5 (4.0–5.0)	4.0 (4.0–5.0)	4.4 (4.0–5.0)	4.4 (4.0–5.0)
Female	4.1 (4.0–4.9)	4.0 (4.0–5.0)	4.0 (4.0–5.0)	4.2 (4.0–4.8)	4.2 (4.0–4.8)
Z	-2.210	-2.893	-0.810	-2.043	-2.063
P	0.027	0.004	0.418	0.041	0.039

using the Mann-Whitney U test. Statistical tests were performed at the 95% CI level.

RESULTS

Study population

The descriptive characteristics of stroke survivors and caregivers are summarised in [table 1](#).

The 248 stroke survivors included 123 women and 125 men between the ages of 33 and 92 years, with a mean age of 69.5 years. The 212 caregivers included 117 women and 95 men between the ages of 20 and 88 years, with a mean age of 52.6 years. Stroke survivors they cared for were aged between 45 and 92 years, with a mean age of 72.2 years.

Among the cohort, 95.6% of the stroke survivors approved of each question in the questionnaire. The results of the survey showed that participants prioritised the need for psychological support (99.4%), treatment and care (98.6%), social support (98%) and information (96.2%). The total score and every aspect of need were negatively correlated with age ($p < 0.01$). There were no correlations between needs and type of stroke or National Institutes of Health Stroke Scale score ($p > 0.05$) ([table 2](#)).

The total needs and every aspect of the needs of patients below 65 years old were higher than those of older patients

(65 years or older) ($p < 0.05$). Moreover, male patients had higher scores for total needs, psychological needs, needs for treatment and care and needs for social support than female patients ($p < 0.05$) ([tables 3](#) and [4](#)).

Caregivers' opinion

Among the caregivers, 92.5% approved of each question in the questionnaire. Timely diagnosis and treatment appeared to be uppermost in caregivers' minds (99.1%). They also cared about financial support to aid in the patient's recovery (98.6%). The total score of caregivers was negatively correlated with the age of the caregivers ($r = -0.197$, $p = 0.004$), while positively correlated with levels of education ($r = 2.259$, $p < 0.001$). No correlation was found between the scores and gender or time that the patients they cared for experienced their first stroke ($p > 0.05$).

DISCUSSION

In this study, 95.6% stroke survivors and 92.5% of caregivers approved of each question, which showed that most patients were eager for a formal declaration of their rights. The Global Stroke Bill of Rights, developed by the WSO, sets out the right of each stroke survivor to receive

Table 3 Needs of stroke survivors by age

	Total	Psychological support	Information	Treatment and care	Social support
<65	4.7 (4.1–5.0)	5.0 (4.0–5.0)	4.5 (4.0–5.0)	4.6 (4.0–5.0)	4.6 (4.0–5.0)
≥65	4.2 (4.0–4.7)	4.0 (4.0–5.0)	4.0 (4.0–4.5)	4.2 (4.0–4.8)	4.0 (4.0–4.8)
Z	-4.179	-3.314	-3.477	-3.090	-3.855
P	<0.001	0.001	0.001	0.002	<0.001

the best stroke care, be informed and prepared, and be supported in their recovery.⁹

Factors that influenced the awareness of needs and rights

This survey showed that patients below 65 years old had more needs than younger patients. The needs and awareness of rights were negatively correlated with the age of the patients. Because of different social and domestic duties between younger and older patients, younger patients yearned for a higher quality of life after experiencing stroke. They seemed keener to acquire knowledge of stroke and appropriate therapies as well as emotional and social support. This result did not match the findings of a similar survey conducted in the UK,¹⁰ which reported that there was no relationship between needs and age. Patients more than 65 years of age constituted 47.5% of the subjects in the British survey, while in this survey, 65.3% of the patients were above 65 years old. In addition, unlike other surveys, this survey found that male patients had a stronger demand for and were more conscious of their rights. This phenomenon could be due to the traditional thought of 'male superiority to female' in Chinese tradition society. A study in China showed that there was a sex difference in the social participation domain in Chinese patients with stroke, and male patients had higher social desires.¹¹

Our study is consistent with the UK study,¹⁰ where no significant correlation was found between the total scores and levels of education. There was also no correlation between the needs and the time since the first stroke. Similarly, Walsh *et al.*¹² found no significant difference in time since stroke between those who reported multiple unmet needs and those who reported one or no unmet needs.

Psychological support

As shown in our results, the questions related to psychological needs received the highest score and the highest support rate, suggesting that stroke survivors in China had the strongest demand for emotional and psychological support. A sudden attack and poor prognosis had an appreciable effect on the psychology of stroke survivors. Some surveys have demonstrated that emotional problems among stroke survivors would be prejudicial to treatment and rehabilitation after stroke.^{13–15} As physicians, we usually pay more attention to treating the disease, rather than the emotional needs of the patients. A national survey carried out in Ireland showed that 77% of respondents suffered from emotional problems after stroke, while only 10% of the respondents had received community psychological service.¹² Since emotional and psychological needs are liable to be neglected, poststroke depression was a common complication which seriously impairs quality of life.^{16 17} Psychological expertise and formal psychological support were needed by stroke survivors.¹⁸ The newest version of the Chinese Stroke Guidelines goes further, recommending psychological support.

Needs for treatment and care

The needs for diagnosis, treatment, care and rehabilitation were second only to the need for psychological support. The strategies should vary depending on the cause, pathophysiological mechanisms, severity and prognosis to reduce the risk of a recurrent event.¹⁹ Patients should be assessed for individual risks, such as atrial fibrillation, in which case antithrombotic therapy or anticoagulation may be needed for effective stroke prevention.²⁰ Most stroke survivors suffer from different residual deficits; individualised and optimised care is also needed during inpatient and in chronic care and end-of-life settings.⁴ Rehabilitation was usually ignored in busy clinical settings prior to discharge from hospital in China, and there was also a lack of postdischarge rehabilitation services. The patients perceived nurse-led coordination of rehabilitation and ongoing changes of rehabilitation goals in different stages of recovery.²¹ A considerable unmet need for poststroke rehabilitation services was also found in other low-income and middle-income countries, such as India.²² As stroke is an emergency and disastrous disease, a timely and appropriate diagnosis and therapy made by specialised neurologists is vital to the survival and recovery of the patients. A well-organised continuing medical education system for community doctors and non-neurologists covering stroke should be established in China,²³ as well as a stroke services system in accordance with the WSO Global Stroke Services Guidelines and Action Plan,²⁴ reminding us that stroke awareness, education, prevention and treatment should always be feasible.

Social support

In this study, the stroke survivors exhibited a desire to return to their full range of activities and roles they had before their stroke, playing an active role in their own lives and in their community. However, there is often a gap between their aspiration and what they actually experience. A cross-sectional study showed that stroke survivors had more participation restrictions.²⁵ Physical/structural and services/assistance were considered the dominant barriers to and participation in activities of daily life for stroke survivors in China.²⁶ This research also found that needs had a negative correlation with age. In Ireland, only 23% of those below the age of 66 obtained a full-time or part-time job after stroke.¹¹ Those under retirement age would face a higher financial burden and social responsibility. The age-specific burden of stroke in low-income and middle-income countries is greater than in high-income countries.²⁷ In our survey, 97.6% of all the stroke survivors expected to receive financial support, much higher than in the Irish survey.¹¹ Social support should be provided to stroke survivors, including barrier-free facilities and financial support; furthermore, the social security system for stroke survivors needs to be improved in low-income and middle-income countries such as China.

Information needs

In this study, most individuals wanted more information about the signs of stroke, as well as what changes they would face afterwards. With more knowledge of stroke, they could identify the disease immediately, resulting in a decrease in the time from symptom onset to hospital arrival and increase in the number of patients who may receive appropriate interventions.²⁸ Knowing the individual's abilities and limitations would help them to prepare adequately for the future. Although stroke is a devastating disease for the individual, family and society, many times their knowledge about stroke goes unheeded. Individuals had an extremely limited knowledge of stroke, which was also reported in other countries.^{29–32} A survey among patients with previous stroke or transient ischaemic attack in China showed that only 3.3% of patients knew all the stroke warning signs, and only 9.2% indicated that they would seek emergency service.³² In this study, we also found that younger patients had a stronger need to know about the changes they would face after stroke. Stroke survivors had to adapt to changes in their bodies as a result of stroke and adjust their expectations, including roles within the home and community, particularly for those of working age. Another discovery in our research was that as the level of education increased, so did the request for more information on stroke. Well-educated patients had the desire to learn all they could about stroke. Those with the least understanding of stroke were participants in an Irish survey that only had a primary level of education.³³

Educational strategies to increase stroke knowledge are urgently needed to combat and prevent disease. We have made efforts to educate physicians and patients about stroke to improve the recognition of this condition in China, especially in our hospital. Educational activities have been held every world stroke day over the past few years and once a month this year. Local and regional healthcare workers should put a high premium on health education about stroke to meet the needs of patients and to disseminate the knowledge to the public, policymakers and health professionals.³⁴

The stroke caregivers' opinions

A stroke in the family can cause many shifts, whether it is relationship dynamics, finances, home modifications or role changes. The views of caregivers of stroke survivors would provide a valuable reference about the needs and rights of these patients, as the caregivers provide physical and psychological support in the daily life of stroke survivors. Not consistent with the stroke survivors, the caregivers' ultimate concern was treatment and financial support, which revealed the heavy burden the family suffered due to stroke and need for social support. The scores for these questions were negatively correlated to their age, while positively correlated to their level of education. A longitudinal study of caregivers' perspectives found that family caregivers expected to obtain assistance and care-related information.³⁵ Providing caregivers with

relevant information and counselling would be beneficial to the recovery and rehabilitation of stroke survivors.

Limitations

First, patients who were not able to express their views due to severe language or cognitive impairment were excluded from this study. The results could not reflect their needs, which may lead to some bias. Second, nearly 70% of stroke survivors who participated in this survey experienced their stroke less than 1 year ago; therefore, their long-term needs might not have been met accurately. Finally, the number of participants was limited, and data were only collected from one site, which may limit the generalisability of our results. In addition, we did not use in-depth interviews or focus groups to explore the reasons behind the patients' needs. Further multiple-centre and large-sample research studies may be needed in the future to explore the needs of stroke survivors using these techniques.

CONCLUSION

The demands of psychological support, treatment and care, social support and information about stroke in China were much more than we expected. Stroke services should consider each individual stroke survivor's needs for psychological and physical care in the whole course of their condition, from the onset of stroke through rehabilitation and reintegration into the community, which requires a more concerted effort across specialists in stroke units, communities and social supports. The Bill of Rights must also be recognised by Chinese society, providing appropriate stroke care to every patient to optimise stroke outcomes.

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