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Needs and rights awareness of stroke survivors and caregivers: a survey in China

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Needs and rights awareness of stroke survivors and caregivers: a survey in China

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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 in current Chinese stroke survivors and caregivers.

Setting: A survey launched by the World Stroke Organization (WSO) was conducted in Tianjin China. The questionnaire included demands of psychological support, treatment and care, social support, and information. Stroke survivors and their caregivers were interviewed face to face for the questionnaire. From June 2014 to February 2015, stroke survivors were invited to participate if they were over 18 years old, had suffered 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: 248 stroke survivors and 212 caregivers were enrolled.

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

***Results*:** 248 stroke survivors and 212 caregivers completed the survey. 95.6% stroke survivors and 92.5% caregivers approved of each question listed in the questionnaire. The participants prioritized the needs for psychology 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）. The patients under 65 years old had higher scores than the elderly (65 years or older) (P<0.01), while the male patients also got higher scores than the female

patients (P<0.01).

Conclusions: The demands of psychological and emotional support, individual treatment, social support and information were eagerly reported by most stroke survivors. The Bill of Rights is also needed to be recognized by the society in China, providing an appropriate stroke care to every patient for optimizing stroke outcomes.

Strengths and limitations of this study

- Stroke survivors and caregivers do 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 of psychological and emotional support, individual treatment, social support and information were eagerly reported by most stroke survivors.
- The stroke survivors in China had strongest demand for emotional and psychological support, which should be recognized.
- Limitations include potential bias due to severe language or cognitive impairment patients excluded. And the number of participants was limited. Further multiple central and large sample research studies may be needed in the future.

INTRODUCTION

Stroke is a 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 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% to 74% of these survivors require some assistance or are fully dependent on 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 right's for several diseases have been developed to achieve higher degrees of patient satisfaction, such as for cancer[5] and Chronic Obstructive Pulmonary Disease (COPD)[6]. Stroke survivors didn't have their own bill of rights, until the World Stroke Organization (WSO) have realized this urgent need and framed a global bill of rights for stroke patients[7]. WSO have numerous strategies in increasing stroke awareness, influencing policies for stroke prevention and improved health services, providing education and fostering the development of systems and organizations for the long-term support of stroke survivors and their families[8]. To determine what stroke survivors and caregivers require, the WSO has launched an online survey.

This survey was used 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 in the Second Hospital of Tianjin Medical University. All the patients and caregivers gave informed consent.

From June 2014 to February 2015, 248 stroke survivors and 212 caregivers at the Department of Neurology of the Second Hospital of Tianjin Medical University were enrolled. Stroke survivors were invited to participate if they were over 18 years old, had suffered a stroke, and agreed to participate in the study. 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 stroke patients 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 one designed by the WSO. Stroke survivors and caregivers were interviewed face to face 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, demands of treatment and information about stroke, 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 purpose of the survey and the procedure was 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 inter-item correlation above 0.70. The scales reliability of the stroke caregivers' questionnaire was assessed with a total Cronbach's α of 0.817, corrected by inter-item correlation f above 0.70. The Cronbach's α values were good for all scales for the study.

Statistical Analysis

Frequencies and proportions were used to summarize levels of answers. The Spearman

Rank Relational Coefficient was used to analyze the correlations between levels of needs and potential effect factors. Levels of different needs were compared by age, gender, and time since stroke. Comparisons between groups were made using the Mann–Whitney *U* test. Statistical tests were performed at the 95% confidence level.

RESULTS

Study population

The descriptive characteristics of stroke survivors and caregivers were summarized in Table 1.

248 stroke survivors included 123 women and 125 men between the ages of 33 and 92 with a mean age of 69.5. 170 (68.5%) patients had experienced their first stroke within one year. 115(46.4%) patients had been educated for more than 9 years.

212 caregivers included 117 women and 95 men between the ages of 20 and 88 with a mean age of 52.6.Stroke survivors they cared for were aged between 45 and 92 years with a mean age of 72.2. The duration of care for 132 (62.3%) of the patients was less than one year. 141(66.5%) caregivers had been educated for more than 9 years.

Table 1 Characteristic 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			
	<1y	170(68.5%)	132 (62.3%)
	1-3y	41(16.5%)	37(17.5%)
	4-7y	13(5.2%)	22(10.4%)
	8-10y	6(2.4%)	8(3.8%)
	>10y	18(7.3%)	13(6.1%)
Education			
	<3y	19(7.7%)	2(0.9%)
	3-6y	44(17.7%)	13(6.1%)
	6-9y	70(28.2%)	56(26.4%)
	9-12y	88(35.5%)	93(43.9%)
	>12y	27(10.9%)	48(22.6%)

95.6% of the stroke survivors approved of each question listed in the questionnaire. The right to receive treatment by a specialized team at all the stages of the disease, as well as psychology support was mostly favored by the stroke survivors (99.6%). The next most common demand was the right to receive treatment as an individual, taking into consideration their age, gender, culture and changing needs over time (99.2%).

The total score was negatively correlated with age（r=-0.255， P<0.01）and gender(r=-0.14，P=0.027). Weighing the total score of all questions, the patients under 65 years old scored higher than the older (65 years or older) (P<0.001), while male patients got higher scores than female patients (P=0.027). There were no differences in the total scores

based on level of education (P=0.434) and time since first stroke (P=0.588).

All the needs in the questionnaire were divided into needs for psychological support, treatment and care, social support and information. The results of the survey showed the participants prioritized the needs for psychology supports (99.4%), treatment and care(98.6%), social support (98%) and information (96.2%).

Psychological support

More than 99% of stroke survivors reported the need for psychological and emotional support. Scores for physiological needs were higher in patients under 65 years old (P<0.001), as well as in male stroke survivors (P=0.004). There was no difference in the request for psychological needs based on the level of education (P=0.420) or time since first stroke (P=0.466).

Needs for treatment and care

Over 98% of stroke survivors reported the needs for diagnosis, treatment, care and rehabilitation. 99.6% of patients prioritized the need for treatment by a specialized team at all stages of their journey (in hospital and during rehabilitation). The next most common request of stroke survivors, at 98.8%, was the need of individual treatment based on their age, gender, culture, goals and changing needs over time. Patients under 65 years old had greater needs related to stroke treatment and care than those 65 years or older (P=0.002). Male patients had higher scores than female patients (P=0.041). There was no difference between needs related to treatment and education (P=0.408) or time since first stroke (P=0.474).

Social support

98% of stroke survivors had the will to connect with other stroke survivors to gain and

provide support in recovery from stroke. Although stroke survivors suffered from different disabilities, 97.6% of them still want to participant in all aspects of society. Financial or other forms of social support for longer-term care was also demanded by 97.6% stroke survivors. The scores of needs related to social participation and support in stroke survivors under 65 were higher than those of 65years or older (P<0.001). The male patients got higher scores than female patients (P=0.045). There was no difference between social needs and education (P=0.963) or time since first stroke(P=0.652).

Information needs

97.6% of stroke survivors reported wanting information about what had happened and living with stroke, while 94.8% of stroke survivors reported wanting information about the signs of stroke. As with the other needs, information needs in patients under 65 were greater than those 65 years or older (P<0.001). Unlike other needs, the desire to be fully informed about what has happened and about living with stroke was positively correlated with education level (P=0.04). There was no difference between information needs and gender (P=0.311) or time since first stroke (P=0.348).

Caregivers' opinion

92.5% of caregivers approved of each question listed 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 participants prioritized the needs for psychology support (99.4%), treatment and care (98.6%), social support (98%) and information (96.2%). The Global Stroke Bill of Rights developed by the World Stroke Organization, which sets out the right of each stroke survivor to: receive the best stroke care, be informed and prepared, be supported in their recovery[9].

The factors influencing the awareness of needs and rights

This survey showed that patients under 65 years old had more needs than those 65 years or older. The needs and awareness of rights were negatively correlated with the age of the patients. Because of different social and domestic duties between the younger and the older, the younger yearned for a higher quality of life after stroke. They seemed keener on requiring knowledge of stroke, appropriate therapies, as well as emotional and social support. In China, the older population's beliefs were more likely to follow traditional Chinese ideas and not demand much, while the younger population had a stronger awareness of their rights. This result did not match the findings of similar survey conducted in the UK[10], which had reported that there was no relationship between needs and age. In our survey, this cultural difference between the generations might be the cause of the different results. Patients over 65 age constitute 47.5% of the subjects in the British survey, while in this survey, 65.3% of the patients were above 65 years old. Also unlike other surveys, this survey found that male patients had a stronger demand 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.

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[11] 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 is shown in our results, the questions related to psychological needs got the highest score and the highest support rate, suggesting that the stroke survivors in China had 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 the treatment and rehabilitation after stroke[12-14]. As a doctor, we usually pay more attention to the therapy of 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[11]. Since emotional and psychological needs are liable to be neglected, post-stroke depression was a common complication after stroke, which seriously impairs quality of life[15 16]. Psychological support has been gradually recognized, and recommended in the newest version of the Chinese Stroke Guidelines in particular. The results in this study remind us that psychological needs of stroke survivors shouldn't be ignored, and we should provide more

psychological and emotional support to our patients, which is essential for their recovery and rehabilitation.

Needs for treatment and care

The needs for diagnosis, treatment, care and rehabilitation were second only to the need for psychological support. Patients were anxious for individualized treatment by a specialized team, taking into consideration their age, gender, culture, goals and changing needs over time. The strategies should vary depending on the cause, pathophysiological mechanisms, severity and prognosis to reduce the risk of a recurrent event[17]. Patient's individual risk should be assessed, such as those with atrial fibrillation, then antithrombotic therapy oral anticoagulation may be needed for effective stroke prevention[18]. Most stroke survivors suffer from different residual deficits; individualized and optimized care is also needed during inpatient and in chronic care and end-of-life settings[4]. As stroke is an emergency and disastrous disease, a timely and appropriate diagnosis and therapy made by specialized neurologists is vital to the survival and recovery of the patients. A well-organized continuing medical education system covering stroke for community doctors and non-neurologists should be established in China[19], as well as a stroke services system in accordance with World Stroke Organization Global Stroke Services Guidelines and Action Plan[20] which remind us stroke awareness, education, prevention, and treatment should always be feasible.

Social support

In this research, the stroke survivors exhibited their desire to return to the full range of activities and roles they had before their stroke, playing an active role in their own lives and

in their community. But in fact 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[21]. Physical/structural and services/assistance barriers were considered the dominant barriers to activity and participation for the stroke survivors in China[22]. This research also found that the needs had a negative correlation with age. In Ireland only 23% of those under the age of 66 got a full or part-time job after their 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[23]. In our survey, 97.6% of all the stroke survivors expected to get financial support, much higher than the Irish survey[11]. Social supports should be provided to stroke survivors, including barrier-free facilities and financial support, and what's more, social security system for stroke survivors needs to be improved in developing countries such as China.

Information needs

In the present study, most individuals wanted more information about the signs of stroke, as well as what changes they would face after stroke. With more knowledge of stroke, they could identify the disease immediately, thus 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[24]. 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 the knowledge about stroke is going unheeded. Individuals had extremely limited knowledge of stroke, which was reported in different countries[25-28].

A survey among patients with previous stroke or TIA in China showed that only 3.3% of the patients knew all the stroke warning signs, and only 9.2% indicated they would get emergency service[28]. In this study, we also found that the younger patients had stronger needs to know 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 included 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. The 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 education[29].

Educational strategies to increase stroke knowledge are urgently needed as a major part to play in preventing and combating disease. As we had noticed this problem, efforts to health education about stroke have been made to improve the recognition in China, especially in our hospital, the education activities were held every world stroke day over the past few years to once a month this year. Local and regional healthcare workers should put a high premium on health education about stroke, not only to meet the needs of patients, but also to disseminate the knowledge to the public, policymakers, and health professionals[30].

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 the stroke caregivers would provide a valuable reference about the needs and rights of the stroke survivors, as the caregivers provide the physical and psychological support in the daily life of stroke survivors.

92.5% caregivers thought that stroke survivors should have the rights listed in our questionnaire. Not consistent with the stroke survivors, treatment and financial support for care was the ultimate concern of the caregivers, which revealed the heavy burden of stroke their family suffered and needs for social supports. 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 related care information[31]. Relevant information and counseling provided to caregivers would be beneficial to the recovery and rehabilitation of stroke survivors.

Limitations

Firstly, patients that were not able to express their views due to severe language or cognitive impairment were excluded in the present study. The results could not reflect their needs, which may lead to some bias. Secondly, nearly 70% of stroke survivors who participated in this survey experienced their stroke less than one year ago, which fails to accurately identify long-term needs. Finally, the number of participants was limited, and data was only collected from one site, which may limit the generalizability of our results. Further multiple central and large sample research studies may be needed in the future.

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 starting from the onset of stroke all the way through to 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 is also needed to be recognized by the society in China, providing an appropriate stroke care to every patient for optimizing stroke outcomes.

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Contributorship statement

Xin Li contributed significantly to conceived and designed the study and revise manuscript. Ming Liu contributed to the conception of the study and revised the manuscript. Xin Li and Ming Liu are co-correspondence authors. Xiaoshuang Xia performed the data analyses and wrote the manuscript. Peilu Wang collected the data from the survey. Shuting Zhang helped collect the data. Lin Wang helped perform the analysis with constructive discussions.

Competing interests

None declared.

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Data sharing statement

No additional data are available.

Disclosures:

None

References

1. Bo Norrving BK. The global burden of stroke and need for a continuum of care. Neurology 2013;**80**(Suppl 2):S5-S12
2. JS K. Stroke in Asia: a global disaster. International Journal of Stroke 2014;**9**(7):856-57
3. Qian Jia L-PL, Yong-Jun Wang. Stroke in China. Clinical and Experimental Pharmacology and Physiology 2010;**37**:259-64
4. Miller EL ML, Richards L, Zorowitz RD, Bakas T, Clark P & Billinger SA. Comprehensive overview of nursing and interdisciplinary rehabilitation care of the stroke patient: a scientific statement from the American Heart Association. Stroke 2010;**41**:2402-48
5. Lawler M LCT, Banks I, Conte P, De Lorenzo F, Meunier F, Pinedo HM, Selby P, Murphy MJ, Johnston PG; European Cancer Concord (ECC). A Bill of Rights for patients with cancer in Europe. Lancet Oncol 2014;**15**(3):258-60
6. L. N. A Bill of "Rights" for patients with COPD: the "right" therapy for the "right" patient at the "right" time. Thorax 2010;**65**(1):2-3
7. Damrow J, Gaarder K, Chopra S, et al. Global stroke bill of rights. Int J Stroke 2014;**9**(8):964 doi: 10.1111/ijs.12399[published Online First: Epub Date]|.
8. Davis S, Norrving B. World Stroke Day: one world voice for stroke. Int J Stroke 2013;**8 Suppl A100**:2-3 doi: 10.1111/ijs.12185[published Online First: Epub Date]|.
9. Rights TftGBo. World stroke organization web site. http://www.world-stroke.org/newsletter/latest-updates/18-news/latest-updates/261-toolkit-for-the-global-bill-of-rights:Accessed November 23, 2015.
10. McKevitt C FN, Redfern J, Sheldenkar A, Crichton S, Rudd AR, Forster A, Young J, Nazareth I, Silver LE, Rothwell PM, Wolfe CD. Self-reported long-term needs after stroke. Stroke 2011;**42**(5):1398-403
11. Walsh ME GR, Loughnane C, Macey C, Horgan NF. Community re-integration and long-term need in the first five years after stroke: results from a national survey. Disabil Rehabil 2014;**13**:1-5
12. Chau JP TD, Chang AM, Woo J, Twinn S, Cheung SK, Kwok T. Depression among Chinese stroke survivors six months after discharge from a rehabilitation hospital. J Clin Nurs 2010;**19**(21-22):3042-50
13. Ekstam L JU, Guidetti S, Eriksson G, Ytterberg C. The combined perceptions of people with stroke and their carers regarding rehabilitation needs 1 year after stroke: a mixed methods study. BMJ Open 2015;**5**(2):e006784
14. Matsuzaki S HM, Yuki S, Koyama A, Hirata Y, Ikeda M. The relationship between post-stroke depression and physical recovery. J Affect Disord 2015;**176**:56-60
15. Park GY IS, Oh CH, Lee SJ, Pae CU. The association between the severity of poststroke depression and clinical outcomes after first-onset stroke in Korean patients. Gen Hosp Psychiatry 2015;**37**(3):245-50
16. Broomfield NM QT, Abdul-Rahim AH, Walters MR, Evans JJ. Depression and anxiety symptoms post-stroke/TIA: prevalence and associations in cross-sectional data from a regional stroke registry. BMC Neurol 2014;**14**:198
17. Kernan WN OB, Black HR, Bravata DM, Chimowitz MI, Ezekowitz MD, Fang MC, Fisher M, Furie KL, Heck DV, Johnston SC, Kasner SE, Kittner SJ, Mitchell PH, Rich MW, Richardson D, Schwamm LH, Wilson JA;

American Heart Association Stroke Council, Council on Cardiovascular and Stroke Nursing, Council on Clinical Cardiology, and Council on Peripheral Vascular Disease. Guidelines for the prevention of stroke in patients with stroke and transient ischemic attack: a guideline for healthcare professionals from the American Heart Association/American Stroke Association. Stroke 2014;**45**(7):2160-236

18. Lip GY LD. Stroke prevention in atrial fibrillation: a systematic review. JAMA 2015;**313**(19):1950-62
19. Niu JW YJ, Gao S, Xu WH. Low awareness of stroke guidelines and preference for Chinese herbs in community physicians: a national survey in China. Ann Transl Med 2014;**2**(8):76
20. Lindsay P, Furie KL, Davis SM, Donnan GA, Norrving B. World Stroke Organization global stroke services guidelines and action plan. Int J Stroke 2014;**9 Suppl A100**:4-13
21. Skolarus LE BJ, Brown DL, Freedman VA. Understanding Stroke Survivorship: Expanding the concept of post-stroke disability. Stroke 2014;**45**(1):224-30
22. Zhang L, Yan T, You L, Li K. Barriers to activity and participation for stroke survivors in rural China. Archives of physical medicine and rehabilitation 2015;**96**(7):1222-8
23. Feigin VL FM, Krishnamurthi R, Mensah GA, Connor M, Bennett DA, Moran AE, Sacco RL, Anderson L, Truelsen T, O'Donnell M, Venketasubramanian N, Barker-Collo S, Lawes CM, Wang W, Shinohara Y, Witt E, Ezzati M, Naghavi M, Murray C; Global Burden of Diseases, Injuries, and Risk Factors Study 2010 (GBD 2010) and the GBD Stroke Experts Group. Global and regional burden of stroke during 1990–2010: findings from the Global Burden of Disease Study 2010. Lancet 2014;**383**(9913):245-54
24. Hachinski V, Donnan GA, Gorelick PB, et al. Stroke: working toward a prioritized world agenda. Stroke 2010;**41**(6):1084-99
25. Nakibuuka J SM, Katabira E, Ddumba E, Byakika-Tusiime J, Furlan AJ. Knowledge and Perception of Stroke: A Population-Based Survey in Uganda. ISRN Stroke 2014;**2014**
26. Hickey A OHA, McGee H, Donnellan C, Shelley E, Horgan F, O'Neill D. Stroke awareness in the general population: knowledge of stroke risk factors and warning signs in older adults. BMC Geriatr 2009;**9**:35
27. Akiyama H HY. Knowledge of transient ischemic attack among the Japanese. J Stroke Cerebrovasc Dis 2013;**22**(4):457-64
28. Zeng Y HG, Yi GH, Huang YJ, Zhang QH, He LL. Knowledge of stroke warning signs and risk factors among patients with previous stroke or TIA in China. J Clin Nurs 2012;**21**(19-20):2886-95
29. Hickey A HD, McGee H, Conroy R, Shelley E. Knowledge of stroke risk factors and warning signs in Ireland: development and application of the Stroke Awareness Questionnaire (SAQ). Int J Stroke 2012;**7**(4):298-306
30. Hachinski V. World Stroke Day Proclamation. stroke 2008;**39**:2409-20
31. Tsai PC YP, Tai JJ, Lou MF. Needs of family caregivers of stroke patients: a longitudinal study of caregivers' perspectives. Patient Prefer Adherence 2015;**9**:449-57

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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 (WSO) 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 over 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 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 under 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.

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.

INTRODUCTION

Stroke is a 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 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% to 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 cancer[5] 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 stroke patients[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 and caregivers require, the WSO has launched an online survey.

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 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 over 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 stroke patients 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 5-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 inter-item correlation above 0.70. The scales

reliability of the stroke caregivers' questionnaire was assessed with a total Cronbach's α of 0.817, corrected by inter-item correlation f above 0.70. The Cronbach's α values were good for all scales for the study.

Statistical Analysis

Frequencies and proportions were used to summarize levels of answers. The Spearman Rank Relational Coefficient was used to analyze 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 analyzed using a chi-square (χ^2) test. Comparisons between groups were made using the Mann–Whitney *U* test. Statistical tests were performed at the 95% confidence 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, with a mean age of 69.5. The 212 caregivers included 117 women and 95 men between the ages of 20 and 88, with a mean age of 52.6. Stroke survivors they cared for were aged between 45 and 92 years, with a mean age of 72.2.

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			
	<1y	170(68.5%)	132 (62.3%)
	1-3y	41(16.5%)	37(17.5%)
	4-7y	13(5.2%)	22(10.4%)
	8-10y	6(2.4%)	8(3.8%)
	>10y	18(7.3%)	13(6.1%)
Education			
	<3y	19(7.7%)	2(0.9%)
	3-6y	44(17.7%)	13(6.1%)
	6-9y	70(28.2%)	56(26.4%)
	9-12y	88(35.5%)	93(43.9%)
	>12y	27(10.9%)	48(22.6%)
Type of stroke			
	Ischemic stroke	192(77.4%)	170(80.2%)
	Hemorrhagic 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

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 was 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 correlations between levels of needs and potential effect factors

	Total		Psychological support		Information		Treatment and care		Social support	
	rho	P	Rho	P	Rho	P	rho	P	Rho	P
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

The total needs and every aspect of the needs of patients under 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) (Table 3 and Table 4).

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

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

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 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 under 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 over 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 stroke patients, 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, post-stroke depression was a common complication which seriously impairs quality of life[16 17]. Psychological expertise and formal psychological support were needed by stoke 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 oral 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 post-discharge 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- 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 under the age of 66 obtained a full- 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 developing countries such as China.

Information needs

In the present 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 ischemic 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, not only to meet the needs of patients, but also 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 counseling 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 the present study. The results could not reflect their needs, which may lead to some bias. Secondly, nearly 70% of stroke survivors who participated in this survey experienced their stroke less than one 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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Contributorship statement

Xin Li contributed conceived and designed the study and revised the manuscript. Ming Liu conceived of the study and revised the manuscript. Xin Li and Ming Liu are co-correspondence authors. Xiaoshuang Xia analysed the data and wrote the manuscript. Peilu Wang collected the data from the survey. Shuting Zhang helped collect the data. Lin Wang helped perform the analysis with constructive discussions.

Competing interests

None declared.

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Data sharing statement

No additional data are available.

Disclosures:

None

References

1. Bo Norrving BK. The global burden of stroke and need for a continuum of care. Neurology 2013;**80**(Suppl 2):S5-S12
2. JS K. Stroke in Asia: a global disaster. International Journal of Stroke 2014;**9**(7):856-57
3. Qian Jia L-PL, Yong-Jun Wang. Stroke in China. Clinical and Experimental Pharmacology and Physiology 2010;**37**:259-64
4. Miller EL ML, Richards L, Zorowitz RD, Bakas T, Clark P & Billinger SA. Comprehensive overview of nursing and interdisciplinary rehabilitation care of the stroke patient: a scientific statement from the American Heart Association. Stroke 2010;**41**:2402-48
5. Lawler M LCT, Banks I, Conte P, De Lorenzo F, Meunier F, Pinedo HM, Selby P, Murphy MJ, Johnston PG; European Cancer Concord (ECC). A Bill of Rights for patients with cancer in Europe. Lancet Oncol 2014;**15**(3):258-60
6. L. N. A Bill of "Rights" for patients with COPD: the "right" therapy for the "right" patient at the "right" time. Thorax 2010;**65**(1):2-3
7. Damrow J, Gaarder K, Chopra S, et al. Global stroke bill of rights. Int J Stroke 2014;**9**(8):964 doi: 10.1111/ijs.12399[published Online First: Epub Date]|.
8. Davis S, Norrving B. World Stroke Day: one world voice for stroke. Int J Stroke 2013;**8 Suppl A100**:2-3 doi: 10.1111/ijs.12185[published Online First: Epub Date]|.
9. Rights TftGBo. World stroke organization web site. http://www.world-stroke.org/newsletter/latest-updates/18-news/latest-updates/261-toolkit-for-the-global-bill-of-rights:Accessed November 23, 2015.
10. McKevitt C FN, Redfern J, Sheldenkar A, Crichton S, Rudd AR, Forster A, Young J, Nazareth I, Silver LE, Rothwell PM, Wolfe CD. Self-reported long-term needs after stroke. Stroke 2011;**42**(5):1398-403
11. Wu X, Min L, Cong L, Jia Y, Liu C, Zhao H, Liu P, Luo Y. Sex differences in health-related quality of life among adult stroke patients in Northeastern China. J Clin Neurosci 2014; **21**(6):957-61
12. Walsh ME GR, Loughnane C, Macey C, Horgan NF. Community re-integration and long-term need in the first five years after stroke: results from a national survey. Disabil Rehabil 2014;**13**:1-5
13. Chau JP TD, Chang AM, Woo J, Twinn S, Cheung SK, Kwok T. Depression among Chinese stroke survivors six months after discharge from a rehabilitation hospital. J Clin Nurs 2010;**19**(21-22):3042-50
14. Ekstam L JU, Guidetti S, Eriksson G, Ytterberg C. The combined perceptions of people with stroke and their carers regarding rehabilitation needs 1 year after stroke: a mixed methods study. BMJ Open 2015;**5**(2):e006784
15. Matsuzaki S HM, Yuki S, Koyama A, Hirata Y, Ikeda M. The relationship between post-stroke depression and physical recovery. J Affect Disord 2015;**176**:56-60
16. Park GY IS, Oh CH, Lee SJ, Pae CU. The association between the severity of poststroke depression and

clinical outcomes after first-onset stroke in Korean patients. Gen Hosp Psychiatry 2015;**37**(3):245-50

17. Broomfield NM QT, Abdul-Rahim AH, Walters MR, Evans JJ. Depression and anxiety symptoms post-stroke/TIA: prevalence and associations in cross-sectional data from a regional stroke registry. BMC Neurol 2014;**14**:198
18. Harrison M, Ryan T, Gardiner C, Jones A. Psychological and emotional needs, assessment, and support post-stroke: a multi-perspective qualitative study. Top Stroke Rehabil 2016;**16**:1-7
19. Kernan WN OB, Black HR, Bravata DM, Chimowitz MI, Ezekowitz MD, Fang MC, Fisher M, Furie KL, Heck DV, Johnston SC, Kasner SE, Kittner SJ, Mitchell PH, Rich MW, Richardson D, Schwamm LH, Wilson JA; American Heart Association Stroke Council, Council on Cardiovascular and Stroke Nursing, Council on Clinical Cardiology, and Council on Peripheral Vascular Disease. Guidelines for the prevention of stroke in patients with stroke and transient ischemic attack: a guideline for healthcare professionals from the American Heart Association/American Stroke Association. Stroke 2014;**45**(7):2160-236
20. Lip GY LD. Stroke prevention in atrial fibrillation: a systematic review. JAMA 2015;**313**(19):1950-62
21. Chen L, Xiao LD, De Bellis A. First-time stroke survivors and caregivers' perceptions of being engaged in rehabilitation. J Adv Nurs 2016;72(1):73-84
22. Kamalakannan S, Gudlavalleti Venkata M, Prost A, Natarajan S, Pant H, Chitalurri N, Goenka S, Kuper H. Rehabilitation Needs of Stroke Survivors After Discharge From Hospital in India. Arch Phys Med Rehabil 2016;97(9):1526-1532.e9
23. Niu JW YJ, Gao S, Xu WH. Low awareness of stroke guidelines and preference for Chinese herbs in community physicians: a national survey in China. Ann Transl Med 2014;**2**(8):76
24. Lindsay P, Furie KL, Davis SM, Donnan GA, Norrving B. World Stroke Organization global stroke services guidelines and action plan. Int J Stroke 2014;**9 Suppl A100**:4-13
25. Skolarus LE BJ, Brown DL, Freedman VA. Understanding Stroke Survivorship: Expanding the concept of post-stroke disability. Stroke 2014;**45**(1):224-30
26. Zhang L, Yan T, You L, Li K. Barriers to activity and participation for stroke survivors in rural China. Archives of physical medicine and rehabilitation 2015;**96**(7):1222-8
27. Feigin VL FM, Krishnamurthi R, Mensah GA, Connor M, Bennett DA, Moran AE, Sacco RL, Anderson L, Truelsen T, O'Donnell M, Venketasubramanian N, Barker-Collo S, Lawes CM, Wang W, Shinohara Y, Witt E, Ezzati M, Naghavi M, Murray C; Global Burden of Diseases, Injuries, and Risk Factors Study 2010 (GBD 2010) and the GBD Stroke Experts Group. Global and regional burden of stroke during 1990–2010: findings from the Global Burden of Disease Study 2010. Lancet 2014;**383**(9913):245-54
28. Hachinski V, Donnan GA, Gorelick PB, et al. Stroke: working toward a prioritized world agenda. Stroke 2010;**41**(6):1084-99
29. Nakibuuka J SM, Katabira E, Ddumba E, Byakika-Tusiime J, Furlan AJ. Knowledge and Perception of Stroke: A Population-Based Survey in Uganda. ISRN Stroke 2014;**2014**
30. Hickey A OHA, McGee H, Donnellan C, Shelley E, Horgan F, O'Neill D. Stroke awareness in the general population: knowledge of stroke risk factors and warning signs in older adults. BMC Geriatr 2009;**9**:35
31. Akiyama H HY. Knowledge of transient ischemic attack among the Japanese. J Stroke Cerebrovasc Dis 2013;**22**(4):457-64
32. Zeng Y HG, Yi GH, Huang YJ, Zhang QH, He LL. Knowledge of stroke warning signs and risk factors among patients with previous stroke or TIA in China. J Clin Nurs 2012;**21**(19-20):2886-95
33. Hickey A HD, McGee H, Conroy R, Shelley E. Knowledge of stroke risk factors and warning signs in Ireland: development and application of the Stroke Awareness Questionnaire (SAQ). Int J Stroke 2012;**7**(4):298-306

34. Hachinski V. World Stroke Day Proclamation. stroke 2008;**39**:2409-20

35. Tsai PC YP, Tai JJ, Lou MF. Needs of family caregivers of stroke patients: a longitudinal study of caregivers' perspectives. Patient Prefer Adherence 2015;**9**:449-57

AGE: EDUCATION:

ID: DIAGNOSIS: NIHSS SCORE:

The World Stroke Organization is making a Bill of Rights for stroke patients. It will help The Bill of Rights forms the basis to ensure that every patient has access to all elements of appropriate stroke care, to optimize their best chance of survival and recovery. The Stroke Bill of Rights was developed by a group of stroke survivors and caregivers from each region of the world. They need help to find out what are the most important things in their recovery. They will be very appreciated if you take 5-10 minutes to answer this survey. You need to finish all the 17 questions.This is for the patients, and the other is for the carers.

1. What is your age?

☐ 18 - 29 ☐ 50 - 59 ☐ 80-89
☐ 30 - 39 ☐ 60 - 69 ☐ 90-99
☐ 40 - 49 ☐ 70 - 79 ☐ above 100

2.What is your sex?

☐ male ☐ female

3.How long has it been since you had your first stroke?

☐ Within3 year ☐ 3-6 years ☐ 6-9years ☐ 9-12yesrs ☐ above12 years

4.I need for information about the signs of stroke.

☐ very agree ☐ agree ☐ neutral ☐ disagree ☐ very disagree

5.I need for a rapid diagnosis so I can be treated quickly.

☐ very agree ☐ agree ☐ neutral ☐ disagree ☐ very disagree

6.I need for treatment by a specialized team at all atages of my journey(in hospital an during rehabilitation)

☐ very agree ☐ agree ☐ neutral ☐ disagree ☐ very disagree

7. I need for informations about what has happened to me and about living with stroke fo as long as I require it.

☐very agree ☐agree ☐neutral ☐disagree ☐very disagree

8. I have the right to be induced in all aspects of society regardless of any disability I may have.

☐very agree ☐agree ☐neutral ☐disagree ☐very disagree

9. I need for psychological supports to provide hope for the best possible recovery I can make now and into the future.

☐very agree ☐agree ☐neutral ☐disagree ☐very disagree

10. I need for considerate care.

☐very agree ☐agree ☐neutral ☐disagree ☐very disagree

11. I need for Communications with other stroke suvivors and caregivers so I may gain and provide support in my recovery from stroke.

☐very agree ☐agree ☐neutral ☐disagree ☐very disagree

12. I have the right receive psychological and emotional support in a form that best meets my needs.

☐very agree ☐agree ☐neutral ☐disagree ☐very disagree

13. I need for treatment that is right for me as an individual considering my age, gender, culture, goals and my changing needs over time.

☐very agree ☐agree ☐neutral ☐disagree ☐very disagree

14. I need for support(financial or otherwise) to ensure I am cared for in the longer term.

☐very agree ☐agree ☐neutral ☐disagree ☐very disagree

15. I need for support to return to work and/or to other activities I may choose to participate in after my stroke.

☐ very agree ☐ agree ☐ neutral ☐ disagree ☐ very disagree

16. I need for treatment regardless of financial situation, gender, culture or place that I live.

☐ very agree ☐ agree ☐ neutral ☐ disagree ☐ very disagree

17. I need for formal and informal advocacy to assist me with access to the services I need.

☐ very agree ☐ agree ☐ neutral ☐ disagree ☐ very disagree

STROBE Statement—Checklist of items that should be included in reports of ***cross-sectional studies***

	Item No	Recommendation	
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract	✓
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found	✓
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	✓
Objectives	3	State specific objectives, including any prespecified hypotheses	✓
Methods			
Study design	4	Present key elements of study design early in the paper	✓
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	✓
Participants	6	(*a*) Give the eligibility criteria, and the sources and methods of selection of participants	✓
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	✓
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	*NA*
Bias	9	Describe any efforts to address potential sources of bias	✓
Study size	10	Explain how the study size was arrived at	✓
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	✓
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding	✓
		(*b*) Describe any methods used to examine subgroups and interactions	✓
		(*c*) Explain how missing data were addressed	NA
		(*d*) If applicable, describe analytical methods taking account of sampling strategy	✓
		(*e*) Describe any sensitivity analyses	✓
Results			
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	✓
		(b) Give reasons for non-participation at each stage	NA
		(c) Consider use of a flow diagram	NA
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	✓
		(b) Indicate number of participants with missing data for each variable of interest	NA
Outcome data	15*	Report numbers of outcome events or summary measures	✓
Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	✓
		(*b*) Report category boundaries when continuous variables were categorized	✓
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for	✓

		a meaningful time period	
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	✓
Discussion			
Key results	18	Summarise key results with reference to study objectives	✓
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	✓
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	✓
Generalisability	21	Discuss the generalisability (external validity) of the study results	✓
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	✓

*Give information separately for exposed and unexposed groups.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.

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

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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 (WSO) 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 over 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 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 under 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.

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.

INTRODUCTION

Stroke is a 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 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% to 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 cancer[5] 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 stroke patients[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 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).

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 over 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 stroke patients 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 5-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 inter-item correlation above 0.70. The scales reliability of the stroke caregivers' questionnaire was assessed with a total Cronbach's α of 0.817, corrected by inter-item correlation f above 0.70. The Cronbach's α values were good for all scales for the study.

Statistical Analysis

Frequencies and proportions were used to summarize levels of answers. The Spearman Rank Relational Coefficient was used to analyze 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 analyzed using a chi-square (χ^2) test. Comparisons between groups were made using the Mann–Whitney *U* test. Statistical tests were performed at the 95% confidence 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, with a mean age of 69.5. The 212 caregivers included 117 women and 95 men between the ages of 20 and 88, with a mean age of 52.6. Stroke survivors they cared for were aged

between 45 and 92 years, with a mean age of 72.2.

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			
	<1y	170(68.5%)	132 (62.3%)
	1-3y	41(16.5%)	37(17.5%)
	4-7y	13(5.2%)	22(10.4%)
	8-10y	6(2.4%)	8(3.8%)
	>10y	18(7.3%)	13(6.1%)
Education			
	<3y	19(7.7%)	2(0.9%)
	3-6y	44(17.7%)	13(6.1%)
	6-9y	70(28.2%)	56(26.4%)
	9-12y	88(35.5%)	93(43.9%)
	>12y	27(10.9%)	48(22.6%)
Type of stroke			
	Ischemic stroke	192(77.4%)	170(80.2%)

	Hemorrhagic 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

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 was 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)

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

	Total		Psychological support		Information		Treatment and care		Social support	
	rho	P	Rho	P	Rho	P	rho	P	Rho	P
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

The total needs and every aspect of the needs of patients under 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) (Table 3 and Table 4).

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

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

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 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 under 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 over 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 stroke patients, 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, post-stroke depression was a common complication which seriously impairs quality of life[16 17].

Psychological expertise and formal psychological support were needed by stoke 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 oral 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 post-discharge 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- 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 under the age of 66 obtained a full- 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 developing countries such as China.

Information needs

In the present 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 ischemic 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, not only to meet the needs of patients, but also 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 counseling 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 the present study. The results could not reflect their needs, which may lead to some bias. Secondly, nearly 70% of stroke survivors who participated in this survey experienced their stroke less than one 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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Contributorship statement

Xin Li contributed conceived and designed the study and revised the manuscript. Ming Liu conceived of the study and revised the manuscript. Xin Li and Ming Liu are co-correspondence authors. Xiaoshuang Xia analysed the data and wrote the manuscript. Peilu Wang collected the data from the survey. Shuting Zhang helped collect the data. Lin Wang helped perform the analysis with constructive discussions.

Competing interests

None declared.

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Data sharing statement

No additional data are available.

Disclosures:

None

References

1. Bo Norrving BK. The global burden of stroke and need for a continuum of care. Neurology 2013;**80**(Suppl 2):S5-S12
2. JS K. Stroke in Asia: a global disaster. International Journal of Stroke 2014;**9**(7):856-57
3. Qian Jia L-PL, Yong-Jun Wang. Stroke in China. Clinical and Experimental Pharmacology and Physiology 2010;**37**:259-64
4. Miller EL ML, Richards L, Zorowitz RD, Bakas T, Clark P & Billinger SA. Comprehensive overview of nursing and interdisciplinary rehabilitation care of the stroke patient: a scientific statement from the American Heart Association. Stroke 2010;**41**:2402-48
5. Lawler M LCT, Banks I, Conte P, De Lorenzo F, Meunier F, Pinedo HM, Selby P, Murphy MJ, Johnston PG; European Cancer Concord (ECC). A Bill of Rights for patients with cancer in Europe. Lancet Oncol 2014;**15**(3):258-60
6. L. N. A Bill of "Rights" for patients with COPD: the "right" therapy for the "right" patient at the "right" time. Thorax 2010;**65**(1):2-3
7. Damrow J, Gaarder K, Chopra S, et al. Global stroke bill of rights. Int J Stroke 2014;**9**(8):964 doi: 10.1111/ijs.12399[published Online First: Epub Date]|.
8. Davis S, Norrving B. World Stroke Day: one world voice for stroke. Int J Stroke 2013;**8 Suppl A100**:2-3 doi: 10.1111/ijs.12185[published Online First: Epub Date]|.
9. Rights TftGBo. World stroke organization web site. http://www.world-stroke.org/newsletter/latest-updates/18-news/latest-updates/261-toolkit-for-the-global-bill-of-rights:Accessed November 23, 2015.
10. McKevitt C FN, Redfern J, Sheldenkar A, Crichton S, Rudd AR, Forster A, Young J, Nazareth I, Silver LE, Rothwell PM, Wolfe CD. Self-reported long-term needs after stroke. Stroke 2011;**42**(5):1398-403
11. Wu X, Min L, Cong L, Jia Y, Liu C, Zhao H, Liu P, Luo Y. Sex differences in health-related quality of life among adult stroke patients in Northeastern China. J Clin Neurosci 2014; **21**(6):957-61
12. Walsh ME GR, Loughnane C, Macey C, Horgan NF. Community re-integration and long-term need in the first five years after stroke: results from a national survey. Disabil Rehabil 2014;**13**:1-5
13. Chau JP TD, Chang AM, Woo J, Twinn S, Cheung SK, Kwok T. Depression among Chinese stroke survivors six months after discharge from a rehabilitation hospital. J Clin Nurs 2010;**19**(21-22):3042-50

14. Ekstam L JU, Guidetti S, Eriksson G, Ytterberg C. The combined perceptions of people with stroke and their carers regarding rehabilitation needs 1 year after stroke: a mixed methods study. BMJ Open 2015;**5**(2):e006784
15. Matsuzaki S HM, Yuki S, Koyama A, Hirata Y, Ikeda M. The relationship between post-stroke depression and physical recovery. J Affect Disord 2015;**176**:56-60
16. Park GY IS, Oh CH, Lee SJ, Pae CU. The association between the severity of poststroke depression and clinical outcomes after first-onset stroke in Korean patients. Gen Hosp Psychiatry 2015;**37**(3):245-50
17. Broomfield NM QT, Abdul-Rahim AH, Walters MR, Evans JJ. Depression and anxiety symptoms post-stroke/TIA: prevalence and associations in cross-sectional data from a regional stroke registry. BMC Neurol 2014;**14**:198
18. Harrison M, Ryan T, Gardiner C, Jones A. Psychological and emotional needs, assessment, and support post-stroke: a multi-perspective qualitative study. Top Stroke Rehabil 2016;**16**:1-7
19. Kernan WN OB, Black HR, Bravata DM, Chimowitz MI, Ezekowitz MD, Fang MC, Fisher M, Furie KL, Heck DV, Johnston SC, Kasner SE, Kittner SJ, Mitchell PH, Rich MW, Richardson D, Schwamm LH, Wilson JA; American Heart Association Stroke Council, Council on Cardiovascular and Stroke Nursing, Council on Clinical Cardiology, and Council on Peripheral Vascular Disease. Guidelines for the prevention of stroke in patients with stroke and transient ischemic attack: a guideline for healthcare professionals from the American Heart Association/American Stroke Association. Stroke 2014;**45**(7):2160-236
20. Lip GY LD. Stroke prevention in atrial fibrillation: a systematic review. JAMA 2015;**313**(19):1950-62
21. Chen L, Xiao LD, De Bellis A. First-time stroke survivors and caregivers' perceptions of being engaged in rehabilitation. J Adv Nurs 2016;72(1):73-84
22. Kamalakannan S, Gudlavalleti Venkata M, Prost A, Natarajan S, Pant H, Chitalurri N, Goenka S, Kuper H. Rehabilitation Needs of Stroke Survivors After Discharge From Hospital in India. Arch Phys Med Rehabil 2016;97(9):1526-1532.e9
23. Niu JW YJ, Gao S, Xu WH. Low awareness of stroke guidelines and preference for Chinese herbs in community physicians: a national survey in China. Ann Transl Med 2014;**2**(8):76
24. Lindsay P, Furie KL, Davis SM, Donnan GA, Norrving B. World Stroke Organization global stroke services guidelines and action plan. Int J Stroke 2014;**9 Suppl A100**:4-13
25. Skolarus LE BJ, Brown DL, Freedman VA. Understanding Stroke Survivorship: Expanding the concept of post-stroke disability. Stroke 2014;**45**(1):224-30
26. Zhang L, Yan T, You L, Li K. Barriers to activity and participation for stroke survivors in rural China. Archives of physical medicine and rehabilitation 2015;**96**(7):1222-8
27. Feigin VL FM, Krishnamurthi R, Mensah GA, Connor M, Bennett DA, Moran AE, Sacco RL, Anderson L, Truelsen T, O'Donnell M, Venketasubramanian N, Barker-Collo S, Lawes CM, Wang W, Shinohara Y, Witt E, Ezzati M, Naghavi M, Murray C; Global Burden of Diseases, Injuries, and Risk Factors Study 2010 (GBD 2010) and the GBD Stroke Experts Group. Global and regional burden of stroke during 1990–2010: findings from the Global Burden of Disease Study 2010. Lancet 2014;**383**(9913):245-54
28. Hachinski V, Donnan GA, Gorelick PB, et al. Stroke: working toward a prioritized world agenda. Stroke 2010;**41**(6):1084-99
29. Nakibuuka J SM, Katabira E, Ddumba E, Byakika-Tusiime J, Furlan AJ. Knowledge and Perception of Stroke: A Population-Based Survey in Uganda. ISRN Stroke 2014;**2014**
30. Hickey A OHA, McGee H, Donnellan C, Shelley E, Horgan F, O'Neill D. Stroke awareness in the general population: knowledge of stroke risk factors and warning signs in older adults. BMC Geriatr 2009;**9**:35
31. Akiyama H HY. Knowledge of transient ischemic attack among the Japanese. J Stroke Cerebrovasc Dis

2013;**22**(4):457-64
32. Zeng Y HG, Yi GH, Huang YJ, Zhang QH, He LL. Knowledge of stroke warning signs and risk factors among patients with previous stroke or TIA in China. J Clin Nurs 2012;**21**(19-20):2886-95
33. Hickey A HD, McGee H, Conroy R, Shelley E. Knowledge of stroke risk factors and warning signs in Ireland: development and application of the Stroke Awareness Questionnaire (SAQ). Int J Stroke 2012;**7**(4):298-306
34. Hachinski V. World Stroke Day Proclamation. stroke 2008;**39**:2409-20
35. Tsai PC YP, Tai JJ, Lou MF. Needs of family caregivers of stroke patients: a longitudinal study of caregivers' perspectives. Patient Prefer Adherence 2015;**9**:449-57

AGE: EDUCATION:

ID: DIAGNOSIS: NIHSS SCORE:

The World Stroke Organization is making a Bill of Rights for stroke patients. It will help The Bill of Rights forms the basis to ensure that every patient has access to all elements of appropriate stroke care, to optimize their best chance of survival and recovery. The Stroke Bill of Rights was developed by a group of stroke survivors and caregivers from each region of the world. They need help to find out what are the most important things in their recovery. They will be very appreciated if you take 5-10 minutes to answer this survey. You need to finish all the 17 questions.This is for the patients, and the other is for the carers.

1. What is your age?

☐ 18 - 29 ☐ 50 - 59 ☐ 80-89
☐ 30 - 39 ☐ 60 - 69 ☐ 90-99
☐ 40 - 49 ☐ 70 - 79 ☐ above 100

2.What is your sex?

☐ male ☐ female

3.How long has it been since you had your first stroke?

☐ Within3 year ☐ 3-6 years ☐ 6-9years ☐ 9-12yesrs ☐ above12 years

4.I need for information about the signs of stroke.

☐ very agree ☐ agree ☐ neutral ☐ disagree ☐ very disagree

5.I need for a rapid diagnosis so I can be treated quickly.

☐ very agree ☐ agree ☐ neutral ☐ disagree ☐ very disagree

6.I need for treatment by a specialized team at all atages of my journey(in hospital an during rehabilitation)

☐ very agree ☐ agree ☐ neutral ☐ disagree ☐ very disagree

7. I need for informations about what has happened to me and about living with stroke fo as long as I require it.

☐very agree ☐agree ☐neutral ☐disagree ☐very disagree

8. I have the right to be induced in all aspects of society regardless of any disability I may have.

☐very agree ☐agree ☐neutral ☐disagree ☐very disagree

9. I need for psychological supports to provide hope for the best possible recovery I can make now and into the future.

☐very agree ☐agree ☐neutral ☐disagree ☐very disagree

10. I need for considerate care.

☐very agree ☐agree ☐neutral ☐disagree ☐very disagree

11. I need for Communications with other stroke suvivors and caregivers so I may gain and provide support in my recovery from stroke.

☐very agree ☐agree ☐neutral ☐disagree ☐very disagree

12. I have the right receive psychological and emotional support in a form that best meets my needs.

☐very agree ☐agree ☐neutral ☐disagree ☐very disagree

13. I need for treatment that is right for me as an individual considering my age, gender, culture, goals and my changing needs over time.

☐very agree ☐agree ☐neutral ☐disagree ☐very disagree

14. I need for support(financial or otherwise) to ensure I am cared for in the longer term.

☐very agree ☐agree ☐neutral ☐disagree ☐very disagree

15. I need for support to return to work and/or to other activities I may choose to participate in after my stroke.

☐ very agree ☐ agree ☐ neutral ☐ disagree ☐ very disagree

16. I need for treatment regardless of financial situation, gender, culture or place that I live.

☐ very agree ☐ agree ☐ neutral ☐ disagree ☐ very disagree

17. I need for formal and informal advocacy to assist me with access to the services I need.

☐ very agree ☐ agree ☐ neutral ☐ disagree ☐ very disagree

STROBE Statement—Checklist of items that should be included in reports of ***cross-sectional studies***

	Item No	Recommendation	
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract	page 1, lines 2–3
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found	page 2
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	page 4, lines 1–10
Objectives	3	State specific objectives, including any prespecified hypotheses	page 4, lines 13–16
Methods			
Study design	4	Present key elements of study design early in the paper	page 5, lines 13–15
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	page 4, lines 22 page 5, lines1–2
Participants	6	(*a*) Give the eligibility criteria, and the sources and methods of selection of participants	page 5, lines 4–11
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	page 5, lines 16–22
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	*NA*
Bias	9	Describe any efforts to address potential sources of bias	page 5, lines10–11 page 5, lines13–15
Study size	10	Explain how the study size was arrived at	page 5, lines 2–4
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	page 6, lines 1–6
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding	page 6, lines9–14
		(*b*) Describe any methods used to examine subgroups and interactions	page 6, lines11–13
		(*c*) Explain how missing data were addressed	NA
		(*d*) If applicable, describe analytical methods taking account of sampling strategy	page 6, lines12
		(*e*) Describe any sensitivity analyses	page 6, lines14
Results			
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	page 6, lines20–21
		(b) Give reasons for non-participation at each stage	NA
		(c) Consider use of a flow diagram	NA
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	page 6, lines18–22 page 7, lines 1 Table 1

		(b) Indicate number of participants with missing data for each variable of interest	NA
Outcome data	15*	Report numbers of outcome events or summary measures	page 8, lines3–6
Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	page 8, lines9
		(*b*) Report category boundaries when continuous variables were categorized	page 8, lines11 page 9, lines 1
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	NA
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	page 9, lines2–4
Discussion			
Key results	18	Summarise key results with reference to study objectives	page 10, lines13–22 page 11–14 page 15, lines1–11
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	page 15, lines13–21
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	page 16, lines1–6
Generalisability	21	Discuss the generalisability (external validity) of the study results	page 16, lines6–8
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	page 17, lines1–3

*Give information separately for exposed and unexposed groups.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.