BMJ Open

Needs and rights awareness of stroke survivors in urban and rural China: a cross-sectional, multiple-centre questionnaire survey

Journal:	*BMJ Open*
Manuscript ID	bmjopen-2018-021820
Article Type:	Research
Date Submitted by the Author:	22-Jan-2018
Complete List of Authors:	Xia, Xiaoshuang; The Second Hospital of Tianjin Medical University, Tianjin, China , Neurology Zhang, Tianli; The Second Hospital of Tianjin Medical University Wang, Peilu; The Second Hospital of Tianjin Medical University, Tianjin, China , Neurology Du, Yanfen; The Second Hospital of Tianjin Medical University, Tianjin, China , Neurology Wang, Chunru; Ning He Hospital of Tianjin Wei, Zhiqiang; The Second Hospital of Tianjin Medical University, Tianjin, China , Neurology Jiang, Guojing; The Bronch of Tianjin City No.3 Center Hospital Cheng, Qiong; Da Gang Hospital of Tianjin Li, Qiang; Port Hospital of Tianjin Li, Jinpeng; Binhai Hospital of Tianjin Medical University General Hospital Wang, Qingling; XiangYang Community Medical Service Center of Tianjin Binhai New Area Dong, Qi; The Second Hospital of Tianjin Medical University, Tianjin, China , Neurology Guo, Xiaobin; The Second Hospital of Tangshan Sun, Meihua; Teng Zhou Central People's Hospital Wang, Lin; The Second Hospital of Tianjin Medical University, Tianjin, China , Geratology Liu, Ming; Stroke Clinical Research Unit, Department of Neurology, West China Hospital, Sichuan University Li, Xin; The Second Hospital of Tianjin Medical University, Tianjin, China , Neurology
Keywords:	Stroke < NEUROLOGY, treatment, care, needs, rural, urban

Needs and rights awareness of stroke survivors in urban and rural China: a cross-sectional, multiple-centre questionnaire survey

Xiaoshuang Xia,[1] Tianli Zhang,[1] Peilu Wang,[1] Yanfen Du,[1] Chunru Wang,[2] Zhiqiang Wei,[1] Guojing Jiang,[3] Qiong Cheng,[4] Qiang Li,[5] Jinpeng Li,[6] Qingling Wang,[7] Qi Dong,[1] Xiaobin Guo,[8] Meihua Sun,[9] Lin Wang,[10] Ming Liu,[11] Xin Li,[1]

[1]Department of Neurology, The Second Hospital of Tianjin Medical University, Tianjin, China

[2]Department of Neurology, Ning He Hospital of Tianjin, China

[3]Department of Neurology, The Bronch of Tianjin City No.3 Center Hospital, Tianjin, China

[4]Da Gang Hospital of Tianjin, China

[5]Port Hospital of Tianjin, China

[6]Binhai Hospital of Tianjin Medical University General Hospital, Tianjin, China

[7]XiangYang Community Medical Service Center of Tianjin Binhai New Area, Tianjin, China

[8]Department of General Medicine, The Second Hospital of Tangshan, Hebei, China

[9]Teng Zhou Central People's Hospital, Shandong, China

[10]Department of Geratology, The Second Hospital of Tianjin Medical University and Tianjin Geriatric Institute, Tianjin, China

[11]Stroke Clinical Research Unit, Department of Neurology, West China Hospital, Sichuan University, Chengdu, China

Correspondence to:

Xin Li, MD, PhD, Department of Neurology, The Second Hospital of Tianjin Medical University, No 22, Pingjiang Road, Hexi District, Tianjin 300211, China, lixinsci@126.com

or Ming Liu, MD, PhD, Stroke Clinical Research Unit, Department of Neurology, West China Hospital, Sichuan University, No 37, Guo Xue Xiang, Chengdu 610041, China, wyplmh@hotmail.com

Key words: stroke, treatment, care, needs, rural, urban

Word count: 4732

ABSTRACT

Objectives: Stroke survivors require assistance and support in their daily lives. This survey aims to investigate the needs and rights awareness in Chinese stroke survivors and caregivers in rural and urban settings.

Setting: This survey was adapted from the one created by the World Stroke Organization. The questionnaire included demands for psychological support, treatment and care, social support, and information. From January 2015 to January 2016, the survey was pilot tested with urban and rural-dwelling stroke survivors and caregivers from seven hospitals. 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: One thousand, one hundred and sixty-seven stroke survivors and 1119 caregivers were enrolled.

Primary outcome measures: The needs of stroke survivors and caregivers in rural and urban areas were compared. The correlations between needs of rural and urban stroke survivors and caregivers and potential effect factors were analyzed respectively.

***Results*:** Among the cohort, 93.5% reported the need for psychological support, 88.6% for treatment and care, 84.8% for information, and 62.7% for social support. The total needs and each aspect of needs of stroke survivors in urban settings were

greater than of those in rural settings (P<0.01). In rural areas, total needs and each aspect of needs were positively correlated with education level (P<0.01).

Conclusions: Needs and rights awareness of stroke survivors should also be recognized in both urban and rural China. According to the different needs of patients and their caregivers, regional and individualized services were needed by stroke survivors and their caregivers.

Strengths and limitations of this study

- Multiple-centre study of needs and rights awareness have not been reported in China.
- Stroke survivors and their caregivers in China reported high demands for psychological support, treatment and care, social support, and information.
- The total needs and each aspect of needs of stroke survivors in urban settings were greater than of those in rural settings. In rural areas, total needs and each aspect of needs were positively correlated with education level.
- Limitations include potential bias due to the exclusion of patients with severe language or cognitive impairment. The number of participants was also limited.

INTRODUCTION

The absolute number of people who have strokes increased annually, as well as related deaths and disability-adjusted life-years lost.[1 2] Therefore, it is important to know what stroke survivors and caregivers need. Surveys of stroke survivors have reported unmet needs in several domains, such as care, communication, information provision, and managing stroke-related problems.[3 4] Less is known about the comprehensive analysis of different components and extent of patients' needs. To frame a global bill of rights for stroke patients, the World Stroke Association (WSO) has launched an online survey to determine what stroke survivors and caregivers require. (https://www.surveymonkey.com/s/WSOStrokeSurvivor-Chinese and https://www.surveymonkey.com/s/WSOStrokeCarer-Chinese).

Our previous single-center study found that the high demands were eagerly reported by most stroke survivors[5]. This multiple-centre survey aims to further investigate the needs and rights awareness in Chinese stroke survivors and caregivers in rural and urban settings, which could provide a reference for the improvement of the stroke-related health service system, providing stroke survivors with the greatest chance of a good recovery and a healthier, more productive, and independent life.

METHODS

Study population

This study was approved by our local Ethics Committee at the Second Hospital of Tianjin Medical University. Individual ethics approval was obtained from the ethics

committee responsible for each of the hospitals that participated in this survey. All the patients and caregivers gave informed consent.

From January 2015 to January 2016, the survey was pilot tested with a sample of stroke survivors and caregivers from the Stroke Clinical Registry and Follow-up Database of twelve hospitals. According to the Kendall sample size determination method of the questionnaire, at least 70-140 samples for each group were needed; therefore, we recruited more participants than the sample size determined. Eligibility criteria for stroke survivors were: (1) aged 18years or over; (2) a clinical and imaging diagnosis of stroke; (3) able to complete the survey with or without help from caregivers; (4) 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 who met the above criteria were recruited. Only caregivers who were family members of the patients were chosen. Paid caregivers were excluded.

Survey development

The questionnaire was adapted from one that was designed by the WSO. The questionnaire consisted of four general questions and 14 questions about the needs and rights awareness of stroke survivors. The general questions included age, gender, level of education, and time since the first stroke. The other 14 questions included demands of treatment, 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.

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 purpose of the survey and the procedure was explained fully to all participants.

The questionnaire which was translated into 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 0.906, 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 0.927, corrected by inter-item correlation above 0.70. The Cronbach's α values were good for all scales for the study.

Statistical Analysis

Frequencies and proportions were used to 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 between rural and urban. 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. P-value at 0.05were considered significant.

RESULTS

Study population

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

Table 1.Characteristics of stroke survivors and caregivers

		Stroke Survivors N(%)	Stroke Caregivers N(%)
Total		1167	1119
Age (y)		65.39±10.94	47.96±12.3
Gender			
	Male	721(61.8)	597(53.4)
	Female	446(38.2)	522(46.6)
Time since stroke			
	<1y	576(48.6)	452 (40.4)
	1-3y	241(20.7)	258(23.1)
	4-7y	167(14.3)	157(14.0)
	8-10y	110(9.4)	118(10.5)
	>10y	82(7.0)	134(12.0)
Education			
	<3y	117(10.0)	22(2)
	3-6y	355(30.4)	103(9.2)
	6-9y	372(31.9)	345(30.8)
	9-12y	230(19.7)	276(24.7)

	>12y	93(8.0)	373(33.3)
Type of stroke			
	Ischemic stroke	921(78.9)	892(79.7)
	Hemorrhagic stroke	246(21.1)	227(20.3)
NIHSS* Score			
	<4	530(45.4)	468(41.8)
	4-15	602(51.6)	613(54.8)
	>15	35(3.0)	38(3.4)

* NIHSS: National institutes of Health Stroke Scale

A total of 2286 stroke survivors and caregivers completed the survey, including 1167 stroke survivors and 1119 caregivers. The 1167 stroke survivors included 446 women and 721 men with a mean age of (65.39±10.94). Of these patients, 517 (44.3%) stroke survivors dwelt in urban locations, while 650 (55.7%) dwelt in rural locations. Five hundred sixty-seven (48.6%) patients experienced their first stroke within one year and 323 (27.7%) patients had more than nine years of education.

The 1119 caregivers included 522 women and 597 men, with a mean age of (47.96±12.3).The duration of care for 459 (41.0%) of the patients was less than one year, and 988 (88.3%) caregivers had more than nine years of education.

Needs of total stroke survivors and caregivers

The participants reported needs for psychological support (93.5%), treatment

and care(88.6%), information (84.8%), and social support (62.7%).Total needs and each aspect of needs were positively correlated with education level (P<0.05).

The results of the survey showed that caregivers prioritized the needs for information (94.5%), psychological support (92.3%), treatment and care(88.1%), and social support (76.2%).These were also positively correlated with levels of education(P<0.05).

Needs in urban and rural areas

Table 2 shows the characteristics of stroke survivors in urban and rural settings. The stroke survivors in urban areas were older than those in rural areas (P<0.001). Time since the first stroke in rural-dwelling stroke survivors was shorter than that in urban-dwelling stroke survivors, while education level was higher in stroke survivors in urban areas. There was no difference in the National Institutes of Health Stroke Scale score between the two groups. The total needs and each aspect of needs in stroke survivors in urban areas were greater than of those in rural areas (Table 3).

Table 2.Characteristics of stroke survivors in urban and rural settings

	Urban (n=517) N(%)	Rural (n=650) N(%)	t/χ^2	P
Age	68.18±10.39	63.17±10.87	7.977	<0.001
Gender(male)	311(60.2)	410(63.1)	1.014	0.307

Time since stroke			54.680	<0.001
<1y	190(36.8)	377(58.0)		
1-3y	123(23.8)	118(18.2)		
4-7y	92(17.8)	75(11.5)		
8-10y	66(12.8)	44(6.8)		
>10y	46(8.9)	36(5.5)		
Education			25.044	<0.001
<3y	29(5.6)	88(13.5)		
3-6y	151(29.2)	204(31.4)		
6-9y	185(35.8)	187(28.8)		
9-12y	104(20.1)	126(19.4)		
>12y	48(9.3)	45(6.9)		
NIHSS* Score			3.518	0.172
<4	245(47.4)	341(52.5)		
4-15	260(50.3)	299(46.0)		
>15	12(2.3)	10(1.5)		

* NIHSS: National institutes of Health Stroke Scale

Table 3.Needs of stroke survivors in urban and rural settings

	Total	Psychological support	Information	Treatment and care	Social support
Urban	4.7(4.2-4.9)	5.0(4.0-5.0)	5.0(4.5-5.0)	5.0(4.4-5.0)	4.6(4.0-4.8)

Rural	4.2(4.0-4.7)	4.5(4.0-5.0)	4.5(4.0-5.0)	4.4(4.0-4.8)	4.0(3.8-4.6)
Z	-8.402	-5.685	-9.899	-10.795	-9.771
P	<0.001	<0.001	<0.001	<0.001	<0.001

There was no correlation between the needs and age, gender, education level, or time since the first stroke in patients from urban areas ($P>0.05$).In rural patients, total needs and each aspect of needs were positively correlated with education level ($P<0.01$). The needs for information, social supports, and treatment and care were negatively correlated with age ($P<0.01$). Among rural patients, men had greater needs for information, social supports, and treatment and care than women (Table 4).

Table 4.Needs of rural stroke survivors by gender

	Total	Psychological support	Information	Treatment and care	Social support
Male	4.3(4.0-4.8)	4.5(4.0-5.0)	4.5(4.0-5.0)	4.6(4.0-5.0)	4.1(3.8-4.6)
Female	4.1(3.9-4.1)	4.0(4.0-5.0)	4.0(3.5-4.5)	4.2(4.0-4.8)	4.0(3.6-4.6)
Z	-3.194	-1.727	-3.275	-2.972	-2.102
P	0.001	0.084	0.001	0.003	0.036

DISCUSSION

This survey investigated the needs of Chinese stroke survivors and caregivers in rural and urban settings. Patients and their caregivers had high demands for

psychological support, treatment and care, social support, and information. Of the above, psychological support was needed the most.

Because disability remains after stroke, a significant number of stroke survivors are dependent on others to help them with activities of everyday living. Many experience limitations in activity and social participation, which may lead them to have psychological issues such as anxiety and depression.[3] Stroke survivors have reported that their quality of life (QOL) after stroke is poor.[6] The Global Stroke Bill of Rights developed by the WSO, sets out the rights of each stroke survivor to receive the best stroke care, be informed and prepared, and be supported in their recovery.[7]

Needs of stroke survivors

In our study, psychological needs had the highest support rate, suggesting that stroke survivors in China had the strongest demand for psychological support. A survey in Australia found that emotional needs were less likely to be fully met than physical needs.[3] Psychological distress after stroke is common, as a result of its sudden onset and the potential loss of physical activity.[8] Some surveys have demonstrated that emotional problems among stroke survivors would be prejudicial to the treatment and rehabilitation of these patients after stroke.[9-12] Data from the South London Stroke Register showed that the cumulative incidence of depression after stroke was 55%.[13]Only 10% of the respondents of one study who suffered from emotional problems had received support from a community psychological service.[14] The newest version of the Chinese Stroke Guidelines goes further, recommending psychological support to patients after stroke. A multi-perspective,

qualitative study suggests that psychological support, including not only formal provision, but also information, advice, and peer or social support, should be supplied to stroke survivors.[8] Just as Dr. Trudeau's epitaph famously declares, "To Cure Sometimes, To Relieve Often, To Comfort Always."

The needs for treatment and care were second only to the need for psychological support. As stroke is an emergent and disastrous disease, timely and appropriate diagnosis and therapy are vital to patient survival and recovery. Long-term individualized and optimized treatment and care are also needed to prevent recurrent stroke and improve patients' quality of life.[15]

Needs for knowledge about stroke were also reported by most stroke survivors. A previous study showed that knowledge about stroke warning signs and risk factors was very poor in stroke survivors in China, and only 9.2% reported calling for emergency services. With that knowledge, stroke survivors could better understand the disease, helping them to rehabilitate and prevent stroke recurrence.

A survey in China showed that physical and services barriers restrict stroke survivors' participation in social activity.[16] Financial support was also needed by stroke survivors to maintain their treatment, care, and activities of daily life.[14] Social security systems for stroke survivors need to be improved in developing countries such as China.

In this survey, we found that needs were positively correlated with the level of education. Patients with a higher education level showed stronger needs, which did not match the findings of a similar survey conducted in the UK.[17]

The stroke caregivers' opinions

Not consistent with the stroke survivors, caregivers were ultimately concerned with obtaining information. A longitudinal study of caregivers' perspectives found that family caregivers expected to obtain assistance and related care information.[18] It is equally important that caregivers acquire knowledge of prevention and control of disease.

Needs in urban and rural settings

The stroke survivors who lived in urban settings were older than those in rural settings; as shown in a study in China, the age at onset of stroke in patients living in urban areas was higher than that in rural areas.[19] The time since the first stroke in rural-dwelling stroke survivors was shorter than that in urban-dwelling stroke survivors. Among stroke survivors in rural settings, 55.8%experienced their first stroke within one year. There was a remarkable, decreasing trend in stroke mortality in urban areas, which is mainly observed in the elderly population, but with little change in rural areas.[20]

A survey in Korea found that QOL was significantly lower for stroke patients in rural areas compared to those in urban areas.[21] The needs and rights awareness of stroke survivors in rural settings were not as strong as for those in urban settings. Data from a sample of urban and rural community cohorts observed that a rural advantage for psychological quality of life compared to urban participants.[22] That may be part of the reason for less psychological needs in rural areas. However, a study of suicide ideation in acute ischemic stroke patients in China showed that suicide ideation was

more frequent in patients who lived in rural regions.[23] This is a reminder that the psychological needs of stroke survivors in rural populations should not be ignored.

Compared to those from urban areas, individuals from rural areas were less likely to receive stroke unit care, brain and carotid imaging, or inpatient rehabilitation.[24] Sustained use of secondary prevention medications is not ideal in individuals who live in rural areas.[25] As a study in China has shown, the prevalence of hypertension was higher, but awareness, treatment, and control were lower in rural than urban residents.[26] Future work should focus on improving stroke interventions and care in rural areas. The Rural Stroke Project in Australia, which invested in clinical coordinators who implemented organizational change, together with increased clinician resources, effectively improved care of stroke patients in rural hospitals.[27]

The knowledge of stroke among patients is unsatisfactory, particularly among those in rural areas.[28 29] A nationwide survey in China showed that individuals living in rural areas were less likely to have knowledge of transient ischemic attack.[30] A lower educational level was found in rural survivors in this study, which was consistent with the results of other studies.[22 31] In an Irish survey, those who had only a primary level of education had the least understanding of stroke.[32] Some strategies have been used to raise the knowledge of stroke in rural settings, such as educational flyers,[33] television,[34] and a community-specific public education campaign.[35]

Patients in rural area were more likely to be fully retired due to ill-health.[36] Physical/structural and services/assistance barriers were considered the dominant

barriers to activity and participation for stroke survivors in the rural areas of China.[16] Poorer QOL was associated with reduced social interaction.[37] High medical expenses and low income after stroke brought financial burden to families, especially in rural areas with a rudimentary social security system. The new rural cooperative medical system had some impact on reducing catastrophic medical payments associated with these diseases, but improvement of the reimbursement rate is necessary to further improve the system's effectiveness.[38]

Limitation

Firstly, patients who had severe language or cognitive impairment were excluded in the present study, leading to some bias against patients who could not express their views. Secondly, the number of participants was limited, and in the future, studies should have larger sample sizes.

Conclusion

Although the needs of patients in rural areas were not as strong as those in urban areas, it did not mean that all the needs of rural stroke survivors had been met, while they hadn't aware these needs they could had and could raise their quality of life. Public health organizations and decision makers should not neglect the needs of stroke survivors. Stroke services should consider each stroke survivor's needs for psychological and physical care, starting from the onset of stroke all the way through rehabilitation and reintegration into the community, which require a more concerted effort across specialists in stroke units, communities, and social supports.

Acknowledgments

The authors would like to acknowledge the World Stroke Organization (WSO), which allowed us to adapt the questionnaire about the rights of stroke survivors and caregivers. We acknowledge the multicenter groups have conducted the work.

Contributorship statement

Xiaoshuang Xia conceived the study and wrote the manuscript. Xin Li contributed significantly to 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. Tianli Zhang helped the data analyses. Peilu Wang, Yanfen Du, Chunru Wang, Zhiqiang Wei, Guojing Jiang, Qiong Cheng, Qiang Li, Jinpeng Li, Qingling Wang, Qi Dong,. Xiaobin Guo and Meihua Sun collected the data from the survey. Lin Wang helped perform the analysis with constructive discussions. All authors reviewed the manuscript.

Conflict of Interest Statement

The Authors declare that there is no conflict of interest.

Funding

This work is supported by the key project in the Science and Technology Foundation of Tianjin Health and Family Planning [15KG136], the Natural Science Foundation of Tianjin[16JCYBJC25500] and Tianjin science and technology plan projects[17KPHDSF00170].

Data sharing statement

No additional data are available.

Disclosures:

None

References

1. Feigin VL, Roth GA, Naghavi M, et al. Global burden of stroke and risk factors in 188 countries, during 1990-2013: a systematic analysis for the Global Burden of Disease Study 2013. The Lancet. Neurology 2016;**15**(9):913-24 doi: 10.1016/s1474-4422(16)30073-4[published Online First: Epub Date]|.
2. Benjamin EJ, Blaha MJ, Chiuve SE, et al. Heart Disease and Stroke Statistics—2017. Circulation 2017;**135**(10):e146-603
3. Andrew NE, Kilkenny M, Naylor R, et al. Understanding long-term unmet needs in Australian survivors of stroke. International journal of stroke : official journal of the International Stroke Society 2014;**9 Suppl A100**:106-12 doi: 10.1111/ijs.12325[published Online First: Epub Date]|.
4. Kruithof WJ, Post MW, van Mierlo ML, van den Bos GA, de Man-van Ginkel JM, Visser-Meily JM. Caregiver burden and emotional problems in partners of stroke patients at two months and one year post-stroke: Determinants and prediction. Patient education and counseling 2016 doi: 10.1016/j.pec.2016.04.007[published Online First: Epub Date]|.
5. Li X, Xia X, Wang P, Zhang S, Liu M, Wang L. Needs and rights awareness of stroke survivors and caregivers: a cross-sectional, single-centre questionnaire survey. BMJ open 2017;**7**(10)
6. De Wit L, Theuns P, Dejaeger E, et al. Long-term impact of stroke on patients' health-related quality of life. Disability and rehabilitation 2016:1-6 doi: 10.1080/09638288.2016.1200676[published Online First: Epub Date]|.
7. site. RTWsow. http://www.world-stroke.org/newsletter/latest-updates/18-news/latest-updates/261-toolkit-for-the-global-bill-of-rights: Accessed November 23, 2015.
8. Harrison M, Ryan T, Gardiner C, Jones A. Psychological and emotional needs, assessment, and support post-stroke: a multi-perspective qualitative study. Topics in stroke rehabilitation 2016:1-7 doi: 10.1080/10749357.2016.1196908[published Online First: Epub Date]|.
9. Chau JP, Thompson DR, Chang AM, et al. Depression among Chinese stroke survivors six months after discharge from a rehabilitation hospital. Journal of clinical nursing 2010;**19**(21-22):3042-50 doi: 10.1111/j.1365-2702.2010.03317.x[published Online First: Epub Date]|.
10. Ekstam L, Johansson U, 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 doi: 10.1136/bmjopen-2014-006784[published Online First: Epub Date]|.
11. Matsuzaki S, Hashimoto M, Yuki S, Koyama A, Hirata Y, Ikeda M. The relationship between

post-stroke depression and physical recovery. Journal of affective disorders 2015;**176**:56-60 doi: 10.1016/j.jad.2015.01.020[published Online First: Epub Date]|.

12. Park GY, Im S, Oh CH, Lee SJ, Pae CU. The association between the severity of poststroke depression and clinical outcomes after first-onset stroke in Korean patients. General hospital psychiatry 2015;**37**(3):245-50 doi: 10.1016/j.genhosppsych.2015.02.009[published Online First: Epub Date]|.
13. Ayerbe L, Ayis S, Crichton S, Wolfe CD, Rudd AG. The natural history of depression up to 15 years after stroke: the South London Stroke Register. Stroke; a journal of cerebral circulation 2013;**44**(4):1105-10 doi: 10.1161/strokeaha.111.679340[published Online First: Epub Date]|.
14. Walsh ME, Galvin R, 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. Disability and rehabilitation 2015;**37**(20):1834-8 doi: 10.3109/09638288.2014.981302[published Online First: Epub Date]|.
15. Miller EL, Murray L, Richards L, et al. Comprehensive overview of nursing and interdisciplinary rehabilitation care of the stroke patient: a scientific statement from the American Heart Association. Stroke; a journal of cerebral circulation 2010;**41**(10):2402-48 doi: 10.1161/STR.0b013e3181e7512b[published Online First: Epub Date]|.
16. 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 doi: 10.1016/j.apmr.2015.01.024[published Online First: Epub Date]|.
17. McKevitt C, Fudge N, Redfern J, et al. Self-reported long-term needs after stroke. Stroke; a journal of cerebral circulation 2011;**42**(5):1398-403 doi: 10.1161/strokeaha.110.598839[published Online First: Epub Date]|.
18. 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
19. Zhai Y, Wang WZ, Zhao WH, Yang XG, Kong LZ. [The prevalence and onset of age of stroke in Chinese adults]. Zhonghua yu fang yi xue za zhi [Chinese journal of preventive medicine] 2009;**43**(12):1069-72
20. Zhang XH, Guan T, Mao J, Liu L. Disparity and its time trends in stroke mortality between urban and rural populations in China 1987 to 2001: changing patterns and their implications for public health policy. Stroke; a journal of cerebral circulation 2007;**38**(12):3139-44 doi: 10.1161/strokeaha.107.494336[published Online First: Epub Date]|.
21. Jun HJ, Kim KJ, Chun IA, Moon OK. The relationship between stroke patients' socio-economic conditions and their quality of life: the 2010 Korean community health survey. Journal of physical therapy science 2015;**27**(3):781-4 doi: 10.1589/jpts.27.781[published Online First: Epub Date]|.
22. Allen J, Inder KJ, Harris ML, Lewin TJ, Attia JR, Kelly BJ. Quality of life impact of cardiovascular and affective conditions among older residents from urban and rural communities. Health and quality of life outcomes 2013;**11**:140 doi: 10.1186/1477-7525-11-140[published Online First: Epub Date]|.
23. Dou J, Tang J, Lu CH, Jiang ES, Wang PX. A study of suicidal ideation in acute ischemic stroke patients. Health and quality of life outcomes 2015;**13**:7 doi: 10.1186/s12955-014-0198-9[published Online First: Epub Date]|.
24. Koifman J, Hall R, Li S, et al. The association between rural residence and stroke care and outcomes.

Journal of the neurological sciences 2016;**363**:16-20 doi: 10.1016/j.jns.2016.02.019[published Online First: Epub Date]|.

25. Yusuf S, Islam S, Chow CK, et al. Use of secondary prevention drugs for cardiovascular disease in the community in high-income, middle-income, and low-income countries (the PURE Study): a prospective epidemiological survey. Lancet (London, England) 2011;**378**(9798):1231-43 doi: 10.1016/s0140-6736(11)61215-4[published Online First: Epub Date]|.
26. Li W, Gu H, Teo KK, et al. Hypertension prevalence, awareness, treatment, and control in 115 rural and urban communities involving 47 000 people from China. Journal of hypertension 2016;**34**(1):39-46 doi: 10.1097/hjh.0000000000000745[published Online First: Epub Date]|.
27. Cadilhac DA, Purvis T, Kilkenny MF, et al. Evaluation of rural stroke services: does implementation of coordinators and pathways improve care in rural hospitals? Stroke; a journal of cerebral circulation 2013;**44**(10):2848-53 doi: 10.1161/strokeaha.113.001258[published Online First: Epub Date]|.
28. Swanoski MT, Lutfiyya MN, Amaro ML, Akers MF, Huot KL. Knowledge of heart attack and stroke symptomology: a cross-sectional comparison of rural and non-rural US adults. BMC public health 2012;**12**:283 doi: 10.1186/1471-2458-12-283[published Online First: Epub Date]|.
29. Wiszniewska M, Gluszkiewicz M, Kobayashi A, et al. Knowledge of risk factors and stroke symptoms among nonstroke patients. European neurology 2012;**67**(4):220-5 doi: 10.1159/000335569[published Online First: Epub Date]|.
30. Wang Y, Zhao X, Jiang Y, et al. Prevalence, knowledge, and treatment of transient ischemic attacks in China. Neurology 2015;**84**(23):2354-61 doi: 10.1212/wnl.0000000000001665[published Online First: Epub Date]|.
31. Mi T, Sun S, Du Y, et al. Differences in the distribution of risk factors for stroke among the high-risk population in urban and rural areas of Eastern China. Brain and behavior 2016;**6**(5):e00461 doi: 10.1002/brb3.461[published Online First: Epub Date]|.
32. Hickey A, Holly D, 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). International journal of stroke : official journal of the International Stroke Society 2012;**7**(4):298-306 doi: 10.1111/j.1747-4949.2011.00698.x[published Online First: Epub Date]|.
33. Inoue Y, Honda S, Watanabe M, Ando Y. Educational campaigns at point of purchase in rural supermarkets improve stroke knowledge. Journal of stroke and cerebrovascular diseases : the official journal of National Stroke Association 2015;**24**(2):480-4 doi: 10.1016/j.jstrokecerebrovasdis.2014.09.022[published Online First: Epub Date]|.
34. He M, Liu N, Ji N, et al. Effects of organized education by video on knowledge of early stroke symptoms among a Chinese rural population. International journal of stroke : official journal of the International Stroke Society 2014;**9**(8):E41 doi: 10.1111/ijs.12393[published Online First: Epub Date]|.
35. He M, Wang J, Gong L, et al. Community-based stroke system of care for Chinese rural areas. Stroke; a journal of cerebral circulation 2014;**45**(8):2385-90 doi: 10.1161/strokeaha.114.006030[published Online First: Epub Date]|.
36. Pit SW, Shrestha R, Schofield D, Passey M. Partial and complete retirement due to ill-health among mature age Australians. Public health 2013;**127**(6):561-71 doi: 10.1016/j.puhe.2012.12.022[published Online First: Epub Date]|.

37. Howitt SC, Jones MP, Jusabani A, et al. A cross-sectional study of quality of life in incident stroke survivors in rural northern Tanzania. Journal of neurology 2011;**258**(8):1422-30 doi: 10.1007/s00415-011-5948-6[published Online First: Epub Date]|.

38. Wang Q, Liu H, Lu ZX, Luo Q, Liu JA. Role of the new rural cooperative medical system in alleviating catastrophic medical payments for hypertension, stroke and coronary heart disease in poor rural areas of China. BMC public health 2014;**14**:907 doi: 10.1186/1471-2458-14-907[published Online First: Epub Date]|.

BMJ Open

Needs and rights awareness of stroke survivors and caregivers in urban and rural China: a cross-sectional, multiple-centre questionnaire survey

Journal:	*BMJ Open*
Manuscript ID	bmjopen-2018-021820.R1
Article Type:	Research
Date Submitted by the Author:	07-Oct-2018
Complete List of Authors:	Xia, Xiaoshuang; The Second Hospital of Tianjin Medical University, Tianjin, China , Neurology Tian, Xiaolin; The Second Hospital of Tianjin Medical University, Tianjin, China Zhang, Tianli; The Second Hospital of Tianjin Medical University Wang, Peilu; The Second Hospital of Tianjin Medical University, Tianjin, China , Neurology Du, Yanfen; The Second Hospital of Tianjin Medical University, Tianjin, China , Neurology Wang, Chunru; Ning He Hospital of Tianjin Wei, Zhiqiang; The Second Hospital of Tianjin Medical University, Tianjin, China , Neurology Jiang, Guojing; The Bronch of Tianjin City No.3 Center Hospital Cheng, Qiong; Da Gang Hospital of Tianjin Li, Qiang; Port Hospital of Tianjin Li, Jinpeng; Binhai Hospital of Tianjin Medical University General Hospital Wang, Qingling; XiangYang Community Medical Service Center of Tianjin Binhai New Area Dong, Qi; The Second Hospital of Tianjin Medical University, Tianjin, China , Neurology Guo, Xiaobin; The Second Hospital of Tangshan Sun, Meihua; Teng Zhou Central People's Hospital Wang, Lin; The Second Hospital of Tianjin Medical University, Tianjin, China , Geratology Liu, Ming; Stroke Clinical Research Unit, Department of Neurology, West China Hospital, Sichuan University Li, Xin; The Second Hospital of Tianjin Medical University, Tianjin, China , Neurology
Primary Subject Heading:	Neurology
Secondary Subject Heading:	Public health, Rehabilitation medicine, Mental health
Keywords:	Stroke < NEUROLOGY, treatment, care, needs, rural, urban

Needs and rights awareness of stroke survivors and caregivers in urban and rural China: a cross-sectional, multiple-centre questionnaire survey

Xiaoshuang Xia,[1] Xiaolin Tian, [1] Tianli Zhang,[1] Peilu Wang,[1] Yanfen Du,[1] Chunru Wang,[2] Zhiqiang Wei,[1] Guojing Jiang,[3] Qiong Cheng,[4] Qiang Li,[5] Jinpeng Li,[6] Qingling Wang,[7] Qi Dong,[1] Xiaobin Guo,[8] Meihua Sun,[9] Lin Wang,[10] Ming Liu,[11] Xin Li,[1]

[1]Department of Neurology, The Second Hospital of Tianjin Medical University, Tianjin, China

[2]Department of Neurology, Ning He Hospital of Tianjin, China

[3]Department of Neurology, The Bronch of Tianjin City No.3 Center Hospital, Tianjin, China

[4]Da Gang Hospital of Tianjin, China

[5]Port Hospital of Tianjin, China

[6]Binhai Hospital of Tianjin Medical University General Hospital, Tianjin, China

[7]XiangYang Community Medical Service Center of Tianjin Binhai New Area, Tianjin, China

[8]Department of General Medicine, The Second Hospital of Tangshan, Hebei, China

[9]Teng Zhou Central People's Hospital, Shandong, China

[10]Department of Geratology, The Second Hospital of Tianjin Medical University and Tianjin Geriatric Institute, Tianjin, China

[11]Stroke Clinical Research Unit, Department of Neurology, West China Hospital,

Sichuan University, Chengdu, China

Xiaoshuang Xia and Xiaolin Tian are co-first authors.

Correspondence to:

Xin Li, MD, PhD, Department of Neurology, The Second Hospital of Tianjin Medical University, No 22, Pingjiang Road, Hexi District, Tianjin 300211, China, lixinsci@126.com

or Ming Liu, MD, PhD, Stroke Clinical Research Unit, Department of Neurology, West China Hospital, Sichuan University, No 37, Guo Xue Xiang, Chengdu 610041, China, wyplmh@hotmail.com

Key words: stroke, treatment, care, needs, rural, urban

Word count: 5000

ABSTRACT

Objectives: Stroke survivors require assistance and support in their daily lives. This survey aims to investigate the needs and rights awareness in Chinese stroke survivors and caregivers in rural and urban settings.

Setting: This survey was adapted from the one created by the World Stroke Organization. The questionnaire included demands for psychological support, treatment and care, social support, and information. From January 2015 to January 2016, the survey was pilot tested with urban and rural-dwelling stroke survivors and caregivers from twelve hospitals. 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: One thousand, one hundred and sixty-seven stroke survivors and 1119 caregivers were enrolled.

Primary outcome measures: The needs of stroke survivors and caregivers in rural and urban areas were compared. The correlations between needs of rural and urban stroke survivors and caregivers and potential effect factors were analyzed respectively.

***Results*:** Among the cohort, 93.5% reported the need for psychological support, 88.6% for treatment and care, 84.8% for information, and 62.7% for social support. The total needs and each aspect of needs of stroke survivors in urban settings were

greater than of those in rural settings (P<0.01). In rural areas, total needs and each aspect of needs were positively correlated with education level (P<0.01).

Conclusions: Needs and rights awareness of stroke survivors should also be recognized in both urban and rural China. According to the different needs of patients and their caregivers, regional and individualized services were needed by stroke survivors and their caregivers.

Strengths and limitations of this study

- Multiple-centre study of needs and rights awareness have not been reported in China.
- The breadth of the evidence collected including stroke survivors and their caregivers, and then the comparison is made in urban settings and rural settings.
- The needs and rights awareness of stroke survivors and their caregivers involves demands for psychological support, treatment and care, social support, and information.
- Limitations include potential bias due to the exclusion of patients with severe language or cognitive impairment. The number of participants was also limited.

INTRODUCTION

The absolute number of people who have strokes increased annually, as well as related deaths and disability-adjusted life-years lost.[1 2] Stroke survivors have reported that their quality of life (QOL) after stroke is poor.[3] Therefore, it is important to know what stroke survivors and caregivers need. Surveys of stroke survivors have reported unmet needs in several domains, such as care, communication, information provision, and managing stroke-related problems.[4 5] Less is known about the comprehensive analysis of different components and extent of patients' needs. To frame a global bill of rights for stroke patients, the World Stroke Organization (WSO) has launched an online survey to determine what stroke survivors and caregivers require in the worldwide. (https://www.surveymonkey.com/s/WSOStrokeSurvivor-Chinese and https://www.surveymonkey.com/s/WSOStrokeCarer-Chinese). On the basis of this , the Global Stroke Bill of Rights developed by the WSO, sets out the rights of each stroke survivor to receive the best stroke care, be informed and prepared, and be supported in their recovery.[6]

The opinions from China, a country with a large number of stroke patients in which the healthcare system may be different from that in Europe or Australia seems to be indispensable. The Chinese government has been taking several important steps addressing the challenges of stroke care and prevention, including conducting training and public stroke education, establishing standardized therapies and protocols, and networking with community hospitals[7]. A community-based stroke system of care

and an educational campaign, which was developed in three townships in China, was proved to be effective and practical for optimising stroke treatments and improving patient outcomes[8]. Our previous single-center study found that the high demands were eagerly reported by most stroke survivors[9]. This multiple-centre survey aims to further investigate the needs and rights awareness in Chinese stroke survivors and caregivers in rural and urban settings, which could provide a reference for the improvement of the stroke-related health service system, providing stroke survivors with the greatest chance of a good recovery and a healthier, more productive, and independent life.

METHODS

Study population

This study was approved by our local Ethics Committee at the Second Hospital of Tianjin Medical University. Individual ethics approval was obtained from the ethics committee responsible for each of the hospitals that participated in this survey. All the patients and caregivers gave informed consent.

From January 2015 to January 2016, the consecutive stroke survivors and caregivers from the Stroke Clinical Registry and Follow-up Database of twelve hospitals were invited to participate in the study when they were followed to the hospital. According to the Kendall sample size determination method of the questionnaire, at least 70-140 samples for each group were needed; therefore, we recruited more participants than the sample size determined. Eligibility criteria and

exclusion criteria for stroke survivors were the same as our previous research [9]. Caregivers who had been taking care of the stroke patients including those unable to come to the hospital in the Stroke Clinical Registry and Follow-up Database were recruited. Only caregivers who were family members of the patients were chosen. Paid caregivers were excluded.

Patient and Public Involvement

The patients in our study were not involved in the development of the research question and outcome measures, the recruitment of subjects and the undertaking of the study. Each participant received a report describing the results of our study.

Survey development

The questionnaire was adapted from the Chinese version that was designed by the WSO. The questionnaire consisted of four general questions and 14 questions about the needs and rights awareness of stroke survivors. The general questions included age, gender, level of education, and time since the first stroke. The clinical data including stoke type and NIHSS score were collected. The other 14 questions included demands for prompt and effective treatment, information about stroke, and psychological and social support. The stroke caregivers questionnaire includes 14 questions about the needs that they believe the patients had. 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.

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 purpose of the survey and the procedure was explained fully to all participants.

Statistical Analysis

Continuous variables are presented as mean±SD. Frequencies and proportions were used to summarize levels of answers. The Spearman Rank Correlation Coefficient was used to analyze the correlations between levels of needs and potential associated factors. Levels of different needs were compared between rural and urban. Categorical variables are displayed as frequencies and percentages. Continuous variables were analyzed using t-test. Categorical variables were analyzed using a chi-square (χ^2) test. Comparisons between groups were made using the Mann–Whitney *U* test. P-value at 0.05were considered significant.

RESULTS

Study population

The descriptive characteristics of stroke survivors and caregivers were summarized in Table 1 and Table 2.

Table 1.Characteristics of stroke survivors

	Total (n=1167) N(%)	Urban (n=517) N(%)	Rural (n=650) N(%)	t/χ^2	*P*
Age	65.39±10.94	68.18±10.39	63.17±10.87	7.977	<0.001
Gender					
Male	721(61.8)	311(60.2)	410(63.1)	1.014	0.307

Female	446(38.2)	206(30.8)	240(36.9)		
Time since stroke				54.680	<0.001
<1y	576(48.6)	190(36.8)	377(58.0)		
1-3y	241(20.7)	123(23.8)	118(18.2)		
4-7y	167(14.3)	92(17.8)	75(11.5)		
8-10y	110(9.4)	66(12.8)	44(6.8)		
>10y	82(7.0)	46(8.9)	36(5.5)		
Education				25.044	<0.001
<3y	117(10.0)	29(5.6)	88(13.5)		
3-6y	355(30.4)	151(29.2)	204(31.4)		
6-9y	372(31.9)	185(35.8)	187(28.8)		
9-12y	230(19.7)	104(20.1)	126(19.4)		
>12y	93(8.0)	48(9.3)	45(6.9)		
NIHSS* Score	4.38±3.42	4.21±3.29		0.801	0.423
Type of stroke					
Ischemic stroke	921(78.9)	418（80.9）	503（76.8）	2.080	0.149
Hemorrhagic stroke	246(21.1)	99（19.1）	147（23.2）		

* NIHSS: National institutes of Health Stroke Scale

t-test or χ^2 test was used to compare characteristics of stroke survivors in urban and rural settings

Table 2.Characteristics of stroke caregivers

	Total (n=1119) N(%)	Urban (n=530) N(%)	Rural (n=589) N(%)	t/χ^2	*P*
Age	47.96±12.3	50.94±11.04	45.28±12.91	7.906	<0.001
Gender					
Male	597(53.4)	281(53.0)	308(52.3)	0.808	0.811
Female	522(46.6)	249(47.0)	281(47.7)		
Time since stroke				33.021	<0.001
<1y	452 (40.4)	207(39.1)	245(41.6)		
1-3y	258(23.1)	96(18.1)	162(26.5)		
4-7y	157(14.0)	71(13.4)	86(14.6)		
8-10y	118(10.5)	75(14.2)	43(7.3)		
>10y	134(12.0)	81(15.3)	53(9.0)		
Education					
<3y	22(2)	2(0.4)	20(3.4)	36.015	<0.001
3-6y	103(9.2)	28(5.3)	75(12.7)		
6-9y	345(30.8)	186(35.1)	159(27.0)		
9-12y	276(24.7)	132(24.9)	144(24.4)		

>12y	373(33.3)	182(34.3)	191(32.4)		
NIHSS* Score	5.28±3.85	5.19±3.52	5.35±4.13	0.673	0.501
Type of stroke					
Ischemic stroke	892(79.7)	432(81.5)	460(78.1)	2.007	0.158
Hemorrhagic stroke	227(20.3)	98(18.5)	129(21.9)		

* NIHSS: National institutes of Health Stroke Scale

t-test or χ^2 test was used to compare characteristics of stroke survivors in urban and rural settings

A total of 2286 stroke survivors and caregivers completed the survey, including 1167 stroke survivors and 1119 caregivers. The 1167 stroke survivors included 446 women and 721 men with a mean age of (65.39±10.94). Of these patients, 517 (44.3%) stroke survivors dwelt in urban locations, while 650 (55.7%) dwelt in rural locations. Five hundred sixty-seven (48.6%) patients experienced their first stroke within one year and 323 (27.7%) patients had more than nine years of education.

The 1119 caregivers included 522 women and 597 men, with a mean age of (47.96±12.3).The duration of care for 452 (40.4%) of the patients was less than one year, and 649 (60.0%) caregivers had more than nine years of education.

The stroke survivors and caregivers in urban areas were older than those in rural areas (P<0.001). Time since the first stroke in rural-dwelling stroke survivors was

shorter than that in urban-dwelling stroke survivors, while education level was higher in stroke survivors and caregivers in urban areas. There was no difference in the National Institutes of Health Stroke Scale score between the two groups.

Needs of total stroke survivors and caregivers

The participants reported needs for psychological support (93.5%), treatment and care(88.6%), information (84.8%), and social support (62.7%).Total needs and each aspect of needs were positively correlated with education level (P<0.05). The results of the survey showed that caregivers prioritized the needs for information (94.5%), psychological support (92.3%), treatment and care(88.1%), and social support (76.2%).These were also positively correlated with levels of education(P<0.05). The scores of needs about that had been shown in Table 3.

Needs in urban and rural areas

The total needs and each aspect of needs in stroke survivors in urban areas were greater than of those in rural areas (Table 4, Figure 1).

Table 3.Needs of total stroke survivors and caregivers

	Stroke survivors	Stroke caregivers
Total	4.5（4.0-4.9）	4.8(4.4-5.0)
Psychological support	4.5（4.0-5.0）	5.0(4.5-5.0)
Information	4.5（4.0-5.0）	5.0(4.5-5.0)
Treatment and care	4.5（4.0-5.0）	4.8(4.4-5.0)
Social support	4.2（4.0-4.8）	4.6(4.2-5.0)

Table 4.Needs of stroke survivors in urban and rural settings

	Urban	Rural	Z	*P*
Total	4.7(4.2-4.9)	4.2(4.0-4.7)	-8.402	<0.001
Psychological support	5.0(4.0-5.0)	4.5(4.0-5.0)	-5.685	<0.001
Information	5.0(4.5-5.0)	4.5(4.0-5.0)	-9.899	<0.001
Treatment and care	5.0(4.4-5.0)	4.4(4.0-4.8)	-10.795	<0.001
Social support	4.6(4.0-4.8)	4.0(3.8-4.6)	-9.771	<0.001

There was no correlation between the needs and age, gender, education level, or time since the first stroke in patients from urban areas (P>0.05).In rural patients, total needs and each aspect of needs were positively correlated with education level (P<0.01). The needs for information, social supports, and treatment and care were negatively correlated with age (P<0.01). Among rural patients, men had greater needs for information, social supports, and treatment and care than women (Table 5).

Table 5.Needs of rural stroke survivors by gender

	Male	Female	Z	*P*
Total	4.3(4.0-4.8)	4.1(3.9-4.1)	-3.194	0.001
Psychological support	4.5(4.0-5.0)	4.0(4.0-5.0)	-1.727	0.084
Information	4.5(4.0-5.0)	4.0(3.5-4.5)	-3.275	0.001

Treatment and care	4.6(4.0-5.0)	4.2(4.0-4.8)	-2.972	0.003
Social support	4.1(3.8-4.6)	4.0(3.6-4.6)	-2.102	0.036

DISCUSSION

The questionnaire 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 0.906, 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 0.927, corrected by inter-item correlation above 0.70. The Cronbach's α values were good for all scales for the study.

This survey investigated the needs of Chinese stroke survivors and caregivers in rural and urban settings. Patients and their caregivers had high demands for psychological support, treatment and care, social support, and information. Of the above, psychological support was needed the most.

Needs of stroke survivors

In our study, stroke survivors in China had the strongest demand for psychological support. A survey in Australia found that emotional needs were less likely to be fully met than physical needs.[4] Psychological distress after stroke is common, as a result of its sudden onset and the potential loss of physical activity.[10] Some surveys have demonstrated that emotional problems among stroke survivors would be prejudicial to the treatment and rehabilitation of these patients after

stroke.[11-14] Only 10% of the respondents of one study who suffered from emotional problems had received support from a community psychological service.[15] The newest version of the Chinese Stroke Guidelines goes further, recommending psychological support to patients after stroke. A multi-perspective, qualitative study suggests that psychological support, including not only formal provision, but also information, advice, and peer or social support, should be supplied to stroke survivors.[10]

The needs for treatment and care were second only to the need for psychological support. As stroke is an emergent and disastrous disease, timely and appropriate therapy is vital to patient survival and recovery. Long-term individualized and optimized treatment and care are also needed to prevent recurrent stroke and improve patients' quality of life.[16]

Needs for knowledge about stroke were also reported by most stroke survivors. A previous study showed that knowledge about stroke warning signs and risk factors was very poor in stroke survivors in China, and only 9.2% reported calling for emergency services.[17] With that knowledge, stroke survivors could better understand the disease, helping them to rehabilitate and prevent stroke recurrence.

A survey in China showed that physical and services barriers restrict stroke survivors' participation in social activity.[18] Financial support was also needed by stroke survivors to maintain their treatment, care, and activities of daily life.[15] Social security systems for stroke survivors need to be improved in developing countries such as China.

In this survey, we found that needs were positively correlated with the level of education. The reason could be that the patients of higher education had more awareness of patients' rights.[19]

The stroke caregivers' opinions

Not consistent with the stroke survivors, caregivers were ultimately concerned with obtaining information. A longitudinal study of caregivers' perspectives found that family caregivers expected to obtain assistance and related care information.[20] It is equally important that caregivers acquire knowledge of prevention and control of disease.

Needs in urban and rural settings

The stroke survivors who lived in urban settings were older than those in rural settings; as shown in a study in China, the age at onset of stroke in patients living in urban areas was higher than that in rural areas.[21] Among stroke survivors in rural settings, 55.8%experienced their first stroke within one year. There was a remarkable, decreasing trend in stroke mortality in urban areas, which is mainly observed in the elderly population, but with little change in rural areas.[22]

A survey in Korea found that QOL was significantly lower for stroke patients in rural areas compared to those in urban areas.[23] The needs and rights awareness of stroke survivors in rural settings were not as strong as for those in urban settings. Data from a sample of urban and rural community cohorts observed that a rural advantage for psychological quality of life compared to urban participants.[24] That may be part of the reason for less psychological needs in rural areas. However, a study of suicide

ideation in acute ischemic stroke patients in China showed that suicide ideation was more frequent in patients who lived in rural regions.[25] This is a reminder that the psychological needs of stroke survivors in rural populations should not be ignored.

Compared to those from urban areas, individuals from rural areas were less likely to receive stroke unit care, brain and carotid imaging, or inpatient rehabilitation.[26] Sustained use of secondary prevention medications is low in individuals who live in rural areas.[27] As a study in China has shown, the prevalence of hypertension was higher, but awareness, treatment, and control were lower in rural than urban residents.[28] Future work should focus on improving stroke interventions and care in rural areas. The Rural Stroke Project in Australia, which invested in clinical coordinators who implemented organizational change, together with increased clinician resources, effectively improved care of stroke patients in rural hospitals.[29]

The knowledge of stroke among patients is unsatisfactory, particularly among those in rural areas.[30 31] A nationwide survey in China showed that individuals living in rural areas were less likely to have knowledge of transient ischemic attack.[32] A lower educational level was found in rural survivors in this study, which was consistent with the results of other studies.[24 33] In an Irish survey, those who had only a primary level of education had the least understanding of stroke.[34] Some strategies have been used to raise the knowledge of stroke in rural settings, such as educational flyers,[35] television,[36] and a community-specific public education campaign.[37]

Patients in rural area were more likely to be fully retired due to ill-health.[38]

Physical/structural and services/assistance barriers were considered the dominant barriers to activity and participation for stroke survivors in the rural areas of China.[18] Poorer QOL was associated with reduced social interaction.[39] The new rural cooperative medical system had some impact on reducing catastrophic medical payments associated with these diseases, but improvement of the reimbursement rate is necessary to further improve the system's effectiveness.[40]

Limitation

Patients who had severe language or cognitive impairment were excluded in the present study, leading to some bias against patients who could not express their views.

Conclusion

Needs regarding psychological support, treatment and care, social support, and information in both rural and urban stroke patients, as well as in caregivers, were strong. Public health organizations and decision makers should not neglect the needs of stroke survivors. Stroke services should consider each stroke survivor's needs for psychological and physical care, starting from the onset of stroke all the way through rehabilitation and reintegration into the community, which require a more concerted effort across specialists in stroke units, communities, and social supports.

Acknowledgments

The authors would like to acknowledge the World Stroke Organization (WSO), which allowed us to adapt the questionnaire about the rights of stroke survivors and caregivers. We acknowledge the multicenter groups have conducted the work. We thank all the patients involved in this study for their cooperation and support.

Contributorship statement

Xiaoshuang Xia conceived the study and wrote the manuscript. Xiaolin Tian helped to conceive the study. Xin Li contributed significantly to 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. Tianli Zhang helped the data analyses. Peilu Wang, Yanfen Du, Chunru Wang, Zhiqiang Wei, Guojing Jiang, Qiong Cheng, Qiang Li, Jinpeng Li, Qingling Wang, Qi Dong,. Xiaobin Guo and Meihua Sun collected the data from the survey. Lin Wang helped perform the analysis with constructive discussions. All authors reviewed the manuscript.

Conflict of Interest Statement

The Authors declare that there is no conflict of interest.

Funding

This work is supported by the key project in the Science and Technology Foundation of Tianjin Health and Family Planning [15KG136], the Natural Science Foundation of Tianjin[16JCYBJC25500] and Tianjin science and technology plan projects[17KPHDSF00170].

Data sharing statement

No additional data are available.

Disclosures:

None

References

1. Feigin VL, Roth GA, Naghavi M, et al. Global burden of stroke and risk factors in 188 countries, during 1990-2013: a systematic analysis for the Global Burden of Disease Study 2013. The Lancet. Neurology 2016;**15**(9):913-24 doi: 10.1016/s1474-4422(16)30073-4[published Online First: Epub Date]|.
2. Benjamin EJ, Blaha MJ, Chiuve SE, et al. Heart Disease and Stroke Statistics—2017. Circulation 2017;**135**(10):e146-603
3. De Wit L, Theuns P, Dejaeger E, et al. Long-term impact of stroke on patients' health-related quality of life. Disability and rehabilitation 2016:1-6 doi: 10.1080/09638288.2016.1200676[published Online First: Epub Date]|.
4. Andrew NE, Kilkenny M, Naylor R, et al. Understanding long-term unmet needs in Australian survivors of stroke. International journal of stroke : official journal of the International Stroke Society 2014;**9 Suppl A100**:106-12 doi: 10.1111/ijs.12325[published Online First: Epub Date]|.
5. Kruithof WJ, Post MW, van Mierlo ML, van den Bos GA, de Man-van Ginkel JM, Visser-Meily JM. Caregiver burden and emotional problems in partners of stroke patients at two months and one year post-stroke: Determinants and prediction. Patient education and counseling 2016 doi: 10.1016/j.pec.2016.04.007[published Online First: Epub Date]|.
6. site. RTWsow. http://www.world-stroke.org/newsletter/latest-updates/18-news/latest-updates/261-toolkit-for-the-global-bill-of-rights: Accessed November 23, 2015.
7. Liu L, Wang D, Wong KS, Wang Y. Stroke and stroke care in China: huge burden, significant workload, and a national priority. Stroke. 2011 Dec;42(12):3651-4. doi: 10.1161/STROKEAHA.111.635755. Epub 2011 Nov 3.
8. He M, Wang J, Dong Q,et al. Community-based stroke system of care improves patient outcomes in Chinese rural areas. J Epidemiol Community Health. 2018 Jul;72(7):630-635. doi: 10.1136/jech-2017-210185. Epub 2018 Mar 7.20
9. Li X, Xia X, Wang P, Zhang S, Liu M, Wang L. Needs and rights awareness of stroke survivors and caregivers: a cross-sectional, single-centre questionnaire survey. BMJ open 2017;**7**(10)
10. Harrison M, Ryan T, Gardiner C, Jones A. Psychological and emotional needs, assessment, and support post-stroke: a multi-perspective qualitative study. Topics in stroke rehabilitation 2016:1-7 doi: 10.1080/10749357.2016.1196908[published Online First: Epub Date]|.
11. Chau JP, Thompson DR, Chang AM, et al. Depression among Chinese stroke survivors six months after discharge from a rehabilitation hospital. Journal of clinical nursing 2010;**19**(21-22):3042-50 doi: 10.1111/j.1365-2702.2010.03317.x[published Online First: Epub Date]|.
12. Ekstam L, Johansson U, 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 doi: 10.1136/bmjopen-2014-006784[published Online First: Epub Date]|.
13. Matsuzaki S, Hashimoto M, Yuki S, Koyama A, Hirata Y, Ikeda M. The relationship between post-stroke depression and physical recovery. Journal of affective disorders 2015;**176**:56-60 doi: 10.1016/j.jad.2015.01.020[published Online First: Epub Date]|.

14. Park GY, Im S, Oh CH, Lee SJ, Pae CU. The association between the severity of poststroke depression and clinical outcomes after first-onset stroke in Korean patients. General hospital psychiatry 2015;**37**(3):245-50 doi: 10.1016/j.genhosppsych.2015.02.009[published Online First: Epub Date]|.

15. Walsh ME, Galvin R, 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. Disability and rehabilitation 2015;**37**(20):1834-8 doi: 10.3109/09638288.2014.981302[published Online First: Epub Date]|.

16. Miller EL, Murray L, Richards L, et al. Comprehensive overview of nursing and interdisciplinary rehabilitation care of the stroke patient: a scientific statement from the American Heart Association. Stroke; a journal of cerebral circulation 2010;**41**(10):2402-48 doi: 10.1161/STR.0b013e3181e7512b[published Online First: Epub Date]|.

17. Zeng Y1, He GP, Yi GH, et al. 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 doi: 10.1111/j.1365-2702.2012.04118.x.

18. 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 doi: 10.1016/j.apmr.2015.01.024[published Online First: Epub Date]|.17. McKevitt C, Fudge N, Redfern J, et al. Self-reported long-term needs after stroke. Stroke; a journal of cerebral circulation 2011;**42**(5):1398-403 doi: 10.1161/strokeaha.110.598839[published Online First: Epub Date]|.

19. Yaghobian M, Kaheni S, Danesh M, Rezayi Abhari F. Association between awareness of patient rights and patient's education, seeing bill, and age: a cross-sectional study. Glob J Health Sci 2014;6(3):55-64 doi: 10.5539/gjhs.v6n3p55.

20. 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

21. Zhai Y, Wang WZ, Zhao WH, Yang XG, Kong LZ. [The prevalence and onset of age of stroke in Chinese adults]. Zhonghua yu fang yi xue za zhi [Chinese journal of preventive medicine] 2009;**43**(12):1069-72

22. Zhang XH, Guan T, Mao J, Liu L. Disparity and its time trends in stroke mortality between urban and rural populations in China 1987 to 2001: changing patterns and their implications for public health policy. Stroke; a journal of cerebral circulation 2007;**38**(12):3139-44 doi: 10.1161/strokeaha.107.494336[published Online First: Epub Date]|.

23. Jun HJ, Kim KJ, Chun IA, Moon OK. The relationship between stroke patients' socio-economic conditions and their quality of life: the 2010 Korean community health survey. Journal of physical therapy science 2015;**27**(3):781-4 doi: 10.1589/jpts.27.781[published Online First: Epub Date]|.

24. Allen J, Inder KJ, Harris ML, Lewin TJ, Attia JR, Kelly BJ. Quality of life impact of cardiovascular and affective conditions among older residents from urban and rural communities. Health and quality of life outcomes 2013;**11**:140 doi: 10.1186/1477-7525-11-140[published Online First: Epub Date]|.

25. Dou J, Tang J, Lu CH, Jiang ES, Wang PX. A study of suicidal ideation in acute ischemic stroke patients. Health and quality of life outcomes 2015;**13**:7 doi: 10.1186/s12955-014-0198-9[published Online First: Epub Date]|.

26. Koifman J, Hall R, Li S, et al. The association between rural residence and stroke care and outcomes. Journal of the neurological sciences 2016;**363**:16-20 doi: 10.1016/j.jns.2016.02.019[published Online First: Epub Date]|.
27. Yusuf S, Islam S, Chow CK, et al. Use of secondary prevention drugs for cardiovascular disease in the community in high-income, middle-income, and low-income countries (the PURE Study): a prospective epidemiological survey. Lancet (London, England) 2011;**378**(9798):1231-43 doi: 10.1016/s0140-6736(11)61215-4[published Online First: Epub Date]|.
28. Li W, Gu H, Teo KK, et al. Hypertension prevalence, awareness, treatment, and control in 115 rural and urban communities involving 47 000 people from China. Journal of hypertension 2016;**34**(1):39-46 doi: 10.1097/hjh.0000000000000745[published Online First: Epub Date]|.
29. Cadilhac DA, Purvis T, Kilkenny MF, et al. Evaluation of rural stroke services: does implementation of coordinators and pathways improve care in rural hospitals? Stroke; a journal of cerebral circulation 2013;**44**(10):2848-53 doi: 10.1161/strokeaha.113.001258[published Online First: Epub Date]|.
30. Swanoski MT, Lutfiyya MN, Amaro ML, Akers MF, Huot KL. Knowledge of heart attack and stroke symptomology: a cross-sectional comparison of rural and non-rural US adults. BMC public health 2012;**12**:283 doi: 10.1186/1471-2458-12-283[published Online First: Epub Date]|.
31. Wiszniewska M, Gluszkiewicz M, Kobayashi A, et al. Knowledge of risk factors and stroke symptoms among nonstroke patients. European neurology 2012;**67**(4):220-5 doi: 10.1159/000335569[published Online First: Epub Date]|.
32. Wang Y, Zhao X, Jiang Y, et al. Prevalence, knowledge, and treatment of transient ischemic attacks in China. Neurology 2015;**84**(23):2354-61 doi: 10.1212/wnl.0000000000001665[published Online First: Epub Date]|.
33. Mi T, Sun S, Du Y, et al. Differences in the distribution of risk factors for stroke among the high-risk population in urban and rural areas of Eastern China. Brain and behavior 2016;**6**(5):e00461 doi: 10.1002/brb3.461[published Online First: Epub Date]|.
34. Hickey A, Holly D, 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). International journal of stroke : official journal of the International Stroke Society 2012;**7**(4):298-306 doi: 10.1111/j.1747-4949.2011.00698.x[published Online First: Epub Date]|.
35. Inoue Y, Honda S, Watanabe M, Ando Y. Educational campaigns at point of purchase in rural supermarkets improve stroke knowledge. Journal of stroke and cerebrovascular diseases : the official journal of National Stroke Association 2015;**24**(2):480-4 doi: 10.1016/j.jstrokecerebrovasdis.2014.09.022[published Online First: Epub Date]|.
36. He M, Liu N, Ji N, et al. Effects of organized education by video on knowledge of early stroke symptoms among a Chinese rural population. International journal of stroke : official journal of the International Stroke Society 2014;**9**(8):E41 doi: 10.1111/ijs.12393[published Online First: Epub Date]|.
37. He M, Wang J, Gong L, et al. Community-based stroke system of care for Chinese rural areas. Stroke; a journal of cerebral circulation 2014;**45**(8):2385-90 doi: 10.1161/strokeaha.114.006030[published Online First: Epub Date]|.
38. Pit SW, Shrestha R, Schofield D, Passey M. Partial and complete retirement due to ill-health among mature age Australians. Public health 2013;**127**(6):561-71 doi:

10.1016/j.puhe.2012.12.022[published Online First: Epub Date]|.

39. Howitt SC, Jones MP, Jusabani A, et al. A cross-sectional study of quality of life in incident stroke survivors in rural northern Tanzania. Journal of neurology 2011;**258**(8):1422-30 doi: 10.1007/s00415-011-5948-6[published Online First: Epub Date]|.

40. Wang Q, Liu H, Lu ZX, Luo Q, Liu JA. Role of the new rural cooperative medical system in alleviating catastrophic medical payments for hypertension, stroke and coronary heart disease in poor rural areas of China. BMC public health 2014;**14**:907 doi: 10.1186/1471-2458-14-907[published Online First: Epub Date]|.

Figure 1 The total needs and each aspect of needs in stroke survivors in urban areas were greater than of those in rural areas (P<0.001)

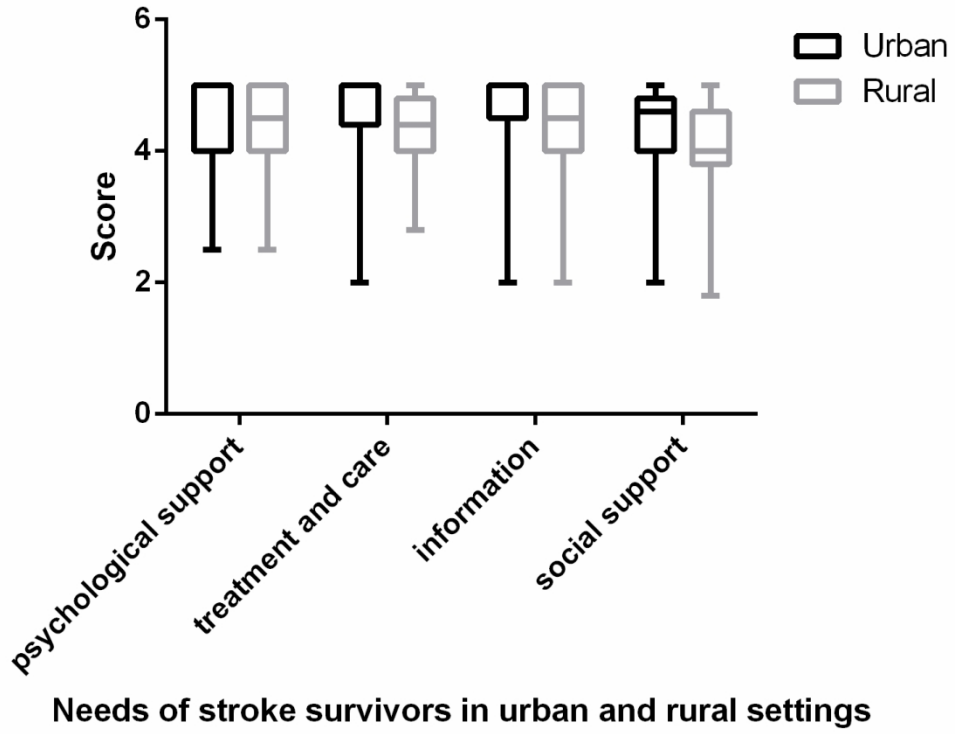

Figure 1 The total needs and each aspect of needs in stroke survivors in urban areas were greater than of those in rural areas (P<0.001)

128x102mm (300 x 300 DPI)

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 1-3
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found	page 3
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	page 5, lines 2-14
Objectives	3	State specific objectives, including any prespecified hypotheses	Page6, lines 4-9
Methods			
Study design	4	Present key elements of study design early in the paper	Page 7, lines 11-21
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	page 6, lines 17-20
Participants	6	(*a*) Give the eligibility criteria, and the sources and methods of selection of participants	page 6, lines 21-22 page 7, lines 1-5
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	page 7, lines 13-17
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 7, lines22, page 8, line 1
Study size	10	Explain how the study size was arrived at	page 6, lines20-22
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	Page7, lines 19-21
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding	page 8, lines3-10
		(*b*) Describe any methods used to examine subgroups and interactions	page 8, lines6-10
		(*c*) Explain how missing data were addressed	NA
		(*d*) If applicable, describe analytical methods taking account of sampling strategy	NA
		(*e*) Describe any sensitivity analyses	page 8, lines10
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 11, lines5-7
		(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	Table 1 and Table 2

		(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	Table 3
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	NA
		(*b*) Report category boundaries when continuous variables were categorized	NA
		(*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 13, lines3-8
Discussion			
Key results	18	Summarise key results with reference to study objectives	page 14-18
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 18, lines8-9
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	page 18, lines19-20
Generalisability	21	Discuss the generalisability (external validity) of the study results	page 18, lines16-17
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 19, lines12-16

*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.

BMJ Open

Needs and rights awareness of stroke survivors and caregivers in urban and rural China: a cross-sectional, multiple-centre questionnaire survey

Journal:	*BMJ Open*
Manuscript ID	bmjopen-2018-021820.R2
Article Type:	Research
Date Submitted by the Author:	09-Feb-2019
Complete List of Authors:	Xia, Xiaoshuang; The Second Hospital of Tianjin Medical University, Tianjin, China , Neurology Tian, Xiaolin; The Second Hospital of Tianjin Medical University, Tianjin, China Zhang, Tianli; The Second Hospital of Tianjin Medical University Wang, Peilu; The Second Hospital of Tianjin Medical University, Tianjin, China , Neurology Du, Yanfen; The Second Hospital of Tianjin Medical University, Tianjin, China , Neurology Wang, Chunru; Ning He Hospital of Tianjin Wei, Zhiqiang; The Second Hospital of Tianjin Medical University, Tianjin, China , Neurology Jiang, Guojing; The Bronch of Tianjin City No.3 Center Hospital Cheng, Qiong; Da Gang Hospital of Tianjin Li, Qiang; Port Hospital of Tianjin Li, Jinpeng; Binhai Hospital of Tianjin Medical University General Hospital Wang, Qingling; XiangYang Community Medical Service Center of Tianjin Binhai New Area Dong, Qi; The Second Hospital of Tianjin Medical University, Tianjin, China , Neurology Guo, Xiaobin; The Second Hospital of Tangshan Sun, Meihua; Teng Zhou Central People's Hospital Wang, Lin; The Second Hospital of Tianjin Medical University, Tianjin, China , Geratology Liu, Ming; Stroke Clinical Research Unit, Department of Neurology, West China Hospital, Sichuan University Li, Xin; The Second Hospital of Tianjin Medical University, Tianjin, China , Neurology
Primary Subject Heading:	Neurology
Secondary Subject Heading:	Public health, Rehabilitation medicine, Mental health
Keywords:	Stroke < NEUROLOGY, treatment, care, needs, rural, urban

Needs and rights awareness of stroke survivors and caregivers in urban and rural China: a cross-sectional, multiple-centre questionnaire survey

Xiaoshuang Xia,[1] Xiaolin Tian, [1] Tianli Zhang,[1] Peilu Wang,[1] Yanfen Du,[1] Chunru Wang,[2] Zhiqiang Wei,[1] Guojing Jiang,[3] Qiong Cheng,[4] Qiang Li,[5] Jinpeng Li,[6] Qingling Wang,[7] Qi Dong,[1] Xiaobin Guo,[8] Meihua Sun,[9] Lin Wang,[10] Ming Liu,[11] Xin Li,[1]

[1]Department of Neurology, The Second Hospital of Tianjin Medical University, Tianjin, China

[2]Department of Neurology, Ning He Hospital of Tianjin, China

[3]Department of Neurology, The Bronch of Tianjin City No.3 Center Hospital, Tianjin, China

[4]Da Gang Hospital of Tianjin, China

[5]Port Hospital of Tianjin, China

[6]Binhai Hospital of Tianjin Medical University General Hospital, Tianjin, China

[7]XiangYang Community Medical Service Center of Tianjin Binhai New Area, Tianjin, China

[8]Department of General Medicine, The Second Hospital of Tangshan, Hebei, China

[9]Teng Zhou Central People's Hospital, Shandong, China

[10]Department of Geratology, The Second Hospital of Tianjin Medical University and Tianjin Geriatric Institute, Tianjin, China

[11]Stroke Clinical Research Unit, Department of Neurology, West China Hospital,

Sichuan University, Chengdu, China

Xiaoshuang Xia and Xiaolin Tian are co-first authors.

Correspondence to:

Xin Li, MD, PhD, Department of Neurology, The Second Hospital of Tianjin Medical University, No 22, Pingjiang Road, Hexi District, Tianjin 300211, China, lixinsci@126.com

or Ming Liu, MD, PhD, Stroke Clinical Research Unit, Department of Neurology, West China Hospital, Sichuan University, No 37, Guo Xue Xiang, Chengdu 610041, China, wyplmh@hotmail.com

Key words: stroke, treatment, care, needs, rural, urban

Word count: 5040

ABSTRACT

Objectives: Stroke survivors require assistance and support in their daily lives. This survey aims to investigate the needs and rights awareness in Chinese stroke survivors and caregivers in rural and urban settings.

Setting: This survey was adapted from the one created by the World Stroke Organization. The questionnaire included demands for psychological support, treatment and care, social support, and information. From January 2015 to January 2016, the survey was pilot tested with urban and rural-dwelling stroke survivors and caregivers from twelve hospitals. 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: One thousand, one hundred and sixty-seven stroke survivors and 1119 caregivers were enrolled.

Primary outcome measures: The needs of stroke survivors and caregivers in rural and urban areas were compared. The correlations between needs of rural and urban stroke survivors and caregivers and potential effect factors were analyzed respectively.

***Results*:** Among the cohort, 93.5% reported the need for psychological support, 88.6% for treatment and care, 84.8% for information, and 62.7% for social support. The total needs and each aspect of needs of stroke survivors in urban settings were

greater than of those in rural settings (P<0.01). In rural areas, total needs and each aspect of needs were positively correlated with education level (P<0.01).

Conclusions: Needs and rights awareness of stroke survivors should also be recognized in both urban and rural China. According to the different needs of patients and their caregivers, regional and individualized services were needed by stroke survivors and their caregivers.

Strengths and limitations of this study

- Multiple-centre study of needs and rights awareness have not been reported in China.
- The breadth of the evidence collected including stroke survivors and their caregivers, and then the comparison is made in urban settings and rural settings.
- The needs and rights awareness of stroke survivors and their caregivers involves demands for psychological support, treatment and care, social support, and information.
- Limitations include potential bias due to the exclusion of patients with severe language or cognitive impairment. The number of participants was also limited.

INTRODUCTION

The absolute number of people who have strokes increased annually, as well as related deaths and disability-adjusted life-years lost.[1 2] Stroke survivors have reported that their quality of life (QOL) after stroke is poor.[3] Therefore, it is important to know what stroke survivors and caregivers need. Surveys of stroke survivors have reported unmet needs in several domains, such as care, communication, information provision, and managing stroke-related problems.[4 5] Less is known about the comprehensive analysis of different components and extent of patients' needs. To frame a global bill of rights for stroke patients, the World Stroke Organization (WSO) has launched an online survey to determine what stroke survivors and caregivers require in the worldwide. (https://www.surveymonkey.com/s/WSOStrokeSurvivor-Chinese and https://www.surveymonkey.com/s/WSOStrokeCarer-Chinese). On the basis of this , the Global Stroke Bill of Rights developed by the WSO, sets out the rights of each stroke survivor to receive the best stroke care, be informed and prepared, and be supported in their recovery.[6]

The opinions from China, a country with a large number of stroke patients in which the healthcare system may be different from that in Europe or Australia seems to be indispensable. The Chinese government has been taking several important steps addressing the challenges of stroke care and prevention, including conducting training and public stroke education, establishing standardized therapies and protocols, and networking with community hospitals[7]. A community-based stroke system of care and an educational campaign, which was developed in three townships in China, was

proved to be effective and practical for optimising stroke treatments and improving patient outcomes[8]. Our previous single-center study found that the high demands were eagerly reported by most stroke survivors[9]. This multiple-centre survey aims to further investigate the needs and rights awareness in Chinese stroke survivors and caregivers in rural and urban settings, which could provide a reference for the improvement of the stroke-related health service system, providing stroke survivors with the greatest chance of a good recovery and a healthier, more productive, and independent life.

METHODS

Study population

This study was approved by our local Ethics Committee at the Second Hospital of Tianjin Medical University. Individual ethics approval was obtained from the ethics committee responsible for each of the hospitals that participated in this survey. All the patients and caregivers gave informed consent.

From January 2015 to January 2016, the consecutive stroke survivors and caregivers from the Stroke Clinical Registry and Follow-up Database of twelve hospitals were invited to participate in the study when they were followed to the hospital. According to the Kendall sample size determination method of the questionnaire, at least 70-140 samples for each group were needed; therefore, we recruited more participants than the sample size determined. Eligibility criteria for stroke survivors were: (1) aged 18years or over; (2) a clinical and imaging diagnosis of

stroke; (3) able to complete the survey with or without help from caregivers; (4) 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 including those unable to come to the hospital in the Stroke Clinical Registry and Follow-up Database were recruited. Only caregivers who were family members of the patients were chosen. Paid caregivers were excluded.

Patient and Public Involvement

The patients in our study were not involved in the development of the research question and outcome measures, the recruitment of subjects and the undertaking of the study. Each participant received a report describing the results of our study.

Survey development

The questionnaire was adapted from the Chinese version that was designed by the WSO. The questionnaire consisted of four general questions and 14 questions about the needs and rights awareness of stroke survivors. The general questions included age, gender, level of education, and time since the first stroke. The clinical data including stoke type and NIHSS score were collected. The other 14 questions included demands for prompt and effective treatment, information about stroke, and psychological and social support. The stroke caregivers questionnaire includes 14 questions about the needs that they believe the patients had. 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.

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 purpose of the survey and the procedure was explained fully to all participants.

Statistical Analysis

Continuous variables are presented as mean±SD. Frequencies and proportions were used to summarize levels of answers. The Spearman Rank Correlation Coefficient was used to analyze the correlations between levels of needs and potential associated factors. Levels of different needs were compared between rural and urban. Categorical variables are displayed as frequencies and percentages. Continuous variables were analyzed using t-test. Categorical variables were analyzed using a chi-square (χ^2) test. Comparisons between groups were made using the Mann–Whitney *U* test. P-value at 0.05were considered significant.

RESULTS

Study population

The descriptive characteristics of stroke survivors and caregivers were summarized in Table 1 and Table 2.

Table 1.Characteristics of stroke survivors

	Total (n=1167) N(%)	Urban (n=517) N(%)	Rural (n=650) N(%)	t/χ^2	*P*
Age	65.39±10.94	68.18±10.39	63.17±10.87	7.977	<0.001

Gender					
Male	721(61.8)	311(60.2)	410(63.1)	1.014	0.307
Female	446(38.2)	206(30.8)	240(36.9)		
Time since stroke				54.680	<0.001
<1y	576(48.6)	190(36.8)	377(58.0)		
1-3y	241(20.7)	123(23.8)	118(18.2)		
4-7y	167(14.3)	92(17.8)	75(11.5)		
8-10y	110(9.4)	66(12.8)	44(6.8)		
>10y	82(7.0)	46(8.9)	36(5.5)		
Education				25.044	<0.001
<3y	117(10.0)	29(5.6)	88(13.5)		
3-6y	355(30.4)	151(29.2)	204(31.4)		
6-9y	372(31.9)	185(35.8)	187(28.8)		
9-12y	230(19.7)	104(20.1)	126(19.4)		
>12y	93(8.0)	48(9.3)	45(6.9)		
NIHSS* Score	4.38±3.42	4.21±3.29		0.801	0.423
Type of stroke					
Ischemic stroke	921(78.9)	418（80.9）	503（76.8）	2.080	0.149
Hemorrhagic stroke	246(21.1)	99（19.1）	147（23.2）		

* NIHSS: National institutes of Health Stroke Scale

t-test or χ^2 test was used to compare characteristics of stroke survivors in urban and rural settings

Table 2.Characteristics of stroke caregivers

	Total (n=1119) N(%)	Urban (n=530) N(%)	Rural (n=589) N(%)	t/χ^2	*P*
Age	47.96±12.3	50.94±11.04	45.28±12.91	7.906	<0.001
Gender					
Male	597(53.4)	281(53.0)	308(52.3)	0.808	0.811
Female	522(46.6)	249(47.0)	281(47.7)		
Time since stroke				33.021	<0.001
<1y	452 (40.4)	207(39.1)	245(41.6)		
1-3y	258(23.1)	96(18.1)	162(26.5)		
4-7y	157(14.0)	71(13.4)	86(14.6)		
8-10y	118(10.5)	75(14.2)	43(7.3)		
>10y	134(12.0)	81(15.3)	53(9.0)		
Education					
<3y	22(2)	2(0.4)	20(3.4)	36.015	<0.001
3-6y	103(9.2)	28(5.3)	75(12.7)		
6-9y	345(30.8)	186(35.1)	159(27.0)		

9-12y	276(24.7)	132(24.9)	144(24.4)		
>12y	373(33.3)	182(34.3)	191(32.4)		
NIHSS* Score	5.28±3.85	5.19±3.52	5.35±4.13	0.673	0.501
Type of stroke					
Ischemic stroke	892(79.7)	432(81.5)	460(78.1)	2.007	0.158
Hemorrhagic stroke	227(20.3)	98(18.5)	129(21.9)		

* NIHSS: National institutes of Health Stroke Scale

t-test or χ^2 test was used to compare characteristics of stroke survivors in urban and rural settings

A total of 2286 stroke survivors and caregivers completed the survey, including 1167 stroke survivors and 1119 caregivers. The 1167 stroke survivors included 446 women and 721 men with a mean age of (65.39±10.94). Of these patients, 517 (44.3%) stroke survivors dwelt in urban locations, while 650 (55.7%) dwelt in rural locations. Five hundred sixty-seven (48.6%) patients experienced their first stroke within one year and 323 (27.7%) patients had more than nine years of education.

The 1119 caregivers included 522 women and 597 men, with a mean age of (47.96±12.3).The duration of care for 452 (40.4%) of the patients was less than one year, and 649 (60.0%) caregivers had more than nine years of education.

The stroke survivors and caregivers in urban areas were older than those in rural

areas (P<0.001). Time since the first stroke in rural-dwelling stroke survivors was shorter than that in urban-dwelling stroke survivors, while education level was higher in stroke survivors and caregivers in urban areas. There was no difference in the National Institutes of Health Stroke Scale score between the two groups.

Needs of total stroke survivors and caregivers

The participants reported needs for psychological support (93.5%), treatment and care(88.6%), information (84.8%), and social support (62.7%).Total needs and each aspect of needs were positively correlated with education level (P<0.05). The results of the survey showed that caregivers prioritized the needs for information (94.5%), psychological support (92.3%), treatment and care(88.1%), and social support (76.2%).These were also positively correlated with levels of education(P<0.05). The scores of needs about that had been shown in Table 3.

Needs in urban and rural areas

The total needs and each aspect of needs in stroke survivors in urban areas were greater than of those in rural areas (Table 4, Figure 1).

Table 3.Needs of total stroke survivors and caregivers

	Stroke survivors	Stroke caregivers
Total	4.5（4.0-4.9）	4.8(4.4-5.0)
Psychological support	4.5（4.0-5.0）	5.0(4.5-5.0)
Information	4.5（4.0-5.0）	5.0(4.5-5.0)
Treatment and care	4.5（4.0-5.0）	4.8(4.4-5.0)
Social support	4.2（4.0-4.8）	4.6(4.2-5.0)

Table 4.Needs of stroke survivors in urban and rural settings

	Urban	Rural	Z	*P*
Total	4.7(4.2-4.9)	4.2(4.0-4.7)	-8.402	<0.001
Psychological support	5.0(4.0-5.0)	4.5(4.0-5.0)	-5.685	<0.001
Information	5.0(4.5-5.0)	4.5(4.0-5.0)	-9.899	<0.001
Treatment and care	5.0(4.4-5.0)	4.4(4.0-4.8)	-10.795	<0.001
Social support	4.6(4.0-4.8)	4.0(3.8-4.6)	-9.771	<0.001

There was no correlation between the needs and age, gender, education level, or time since the first stroke in patients from urban areas (P>0.05).In rural patients, total needs and each aspect of needs were positively correlated with education level (P<0.01). The needs for information, social supports, and treatment and care were negatively correlated with age (P<0.01). Among rural patients, men had greater needs for information, social supports, and treatment and care than women (Table 5).

Table 5.Needs of rural stroke survivors by gender

	Male	Female	Z	*P*
Total	4.3(4.0-4.8)	4.1(3.9-4.1)	-3.194	0.001
Psychological support	4.5(4.0-5.0)	4.0(4.0-5.0)	-1.727	0.084

Information	4.5(4.0-5.0)	4.0(3.5-4.5)	-3.275	0.001
Treatment and care	4.6(4.0-5.0)	4.2(4.0-4.8)	-2.972	0.003
Social support	4.1(3.8-4.6)	4.0(3.6-4.6)	-2.102	0.036

DISCUSSION

The questionnaire 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 0.906, 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 0.927, corrected by inter-item correlation above 0.70. The Cronbach's α values were good for all scales for the study.

This survey investigated the needs of Chinese stroke survivors and caregivers in rural and urban settings. Patients and their caregivers had high demands for psychological support, treatment and care, social support, and information. Of the above, psychological support was needed the most.

Needs of stroke survivors

In our study, stroke survivors in China had the strongest demand for psychological support. A survey in Australia found that emotional needs were less likely to be fully met than physical needs.[4] Psychological distress after stroke is common, as a result of its sudden onset and the potential loss of physical activity.[10] Some surveys have demonstrated that emotional problems among stroke survivors would be prejudicial to

the treatment and rehabilitation of these patients after stroke.[11-14] Only 10% of the respondents of one study who suffered from emotional problems had received support from a community psychological service.[15] The newest version of the Chinese Stroke Guidelines goes further, recommending psychological support to patients after stroke. A multi-perspective, qualitative study suggests that psychological support, including not only formal provision, but also information, advice, and peer or social support, should be supplied to stroke survivors.[10]

The needs for treatment and care were second only to the need for psychological support. As stroke is an emergent and disastrous disease, timely and appropriate therapy is vital to patient survival and recovery. Long-term individualized and optimized treatment and care are also needed to prevent recurrent stroke and improve patients' quality of life.[16]

Needs for knowledge about stroke were also reported by most stroke survivors. A previous study showed that knowledge about stroke warning signs and risk factors was very poor in stroke survivors in China, and only 9.2% reported calling for emergency services.[17] With that knowledge, stroke survivors could better understand the disease, helping them to rehabilitate and prevent stroke recurrence.

A survey in China showed that physical and services barriers restrict stroke survivors' participation in social activity.[18] Financial support was also needed by stroke survivors to maintain their treatment, care, and activities of daily life.[15] Social security systems for stroke survivors need to be improved in developing countries such as China.

In this survey, we found that needs were positively correlated with the level of education. The reason could be that the patients of higher education had more awareness of patients' rights.[19]

The stroke caregivers' opinions

Not consistent with the stroke survivors, caregivers were ultimately concerned with obtaining information. A longitudinal study of caregivers' perspectives found that family caregivers expected to obtain assistance and related care information.[20] It is equally important that caregivers acquire knowledge of prevention and control of disease.

Needs in urban and rural settings

The stroke survivors who lived in urban settings were older than those in rural settings; as shown in a study in China, the age at onset of stroke in patients living in urban areas was higher than that in rural areas.[21] Among stroke survivors in rural settings, 55.8%experienced their first stroke within one year. There was a remarkable, decreasing trend in stroke mortality in urban areas, which is mainly observed in the elderly population, but with little change in rural areas.[22]

A survey in Korea found that QOL was significantly lower for stroke patients in rural areas compared to those in urban areas.[23] The needs and rights awareness of stroke survivors in rural settings were not as strong as for those in urban settings. Data from a sample of urban and rural community cohorts observed that a rural advantage for psychological quality of life compared to urban participants.[24] That may be part of the reason for less psychological needs in rural areas. However, a study of suicide

ideation in acute ischemic stroke patients in China showed that suicide ideation was more frequent in patients who lived in rural regions.[25] This is a reminder that the psychological needs of stroke survivors in rural populations should not be ignored.

Compared to those from urban areas, individuals from rural areas were less likely to receive stroke unit care, brain and carotid imaging, or inpatient rehabilitation.[26] Sustained use of secondary prevention medications is low in individuals who live in rural areas.[27] As a study in China has shown, the prevalence of hypertension was higher, but awareness, treatment, and control were lower in rural than urban residents.[28] Future work should focus on improving stroke interventions and care in rural areas. The Rural Stroke Project in Australia, which invested in clinical coordinators who implemented organizational change, together with increased clinician resources, effectively improved care of stroke patients in rural hospitals.[29]

The knowledge of stroke among patients is unsatisfactory, particularly among those in rural areas.[30 31] A nationwide survey in China showed that individuals living in rural areas were less likely to have knowledge of transient ischemic attack.[32] A lower educational level was found in rural survivors in this study, which was consistent with the results of other studies.[24 33] In an Irish survey, those who had only a primary level of education had the least understanding of stroke.[34] Some strategies have been used to raise the knowledge of stroke in rural settings, such as educational flyers,[35] television,[36] and a community-specific public education campaign.[37]

Patients in rural area were more likely to be fully retired due to ill-health.[38] Physical/structural and services/assistance barriers were considered the dominant

barriers to activity and participation for stroke survivors in the rural areas of China.[18] Poorer QOL was associated with reduced social interaction.[39] The new rural cooperative medical system had some impact on reducing catastrophic medical payments associated with these diseases, but improvement of the reimbursement rate is necessary to further improve the system's effectiveness.[40]

Limitation

Patients who had severe language or cognitive impairment were excluded in the present study, leading to some bias against patients who could not express their views.

Conclusion

Needs regarding psychological support, treatment and care, social support, and information in both rural and urban stroke patients, as well as in caregivers, were strong. Public health organizations and decision makers should not neglect the needs of stroke survivors. Stroke services should consider each stroke survivor's needs for psychological and physical care, starting from the onset of stroke all the way through rehabilitation and reintegration into the community, which require a more concerted effort across specialists in stroke units, communities, and social supports.

Acknowledgments

The authors would like to acknowledge the World Stroke Organization (WSO), which allowed us to adapt the questionnaire about the rights of stroke survivors and caregivers. We acknowledge the multicenter groups have conducted the work. We thank all the patients involved in this study for their cooperation and support.

Contributorship statement

Xiaoshuang Xia conceived the study and wrote the manuscript. Xiaolin Tian helped to conceive the study. Xin Li contributed significantly to 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. Tianli Zhang helped the data analyses. Peilu Wang, Yanfen Du, Chunru Wang, Zhiqiang Wei, Guojing Jiang, Qiong Cheng, Qiang Li, Jinpeng Li, Qingling Wang, Qi Dong,. Xiaobin Guo and Meihua Sun collected the data from the survey. Lin Wang helped perform the analysis with constructive discussions. All authors reviewed the manuscript.

Conflict of Interest Statement

The Authors declare that there is no conflict of interest.

Funding

This work is supported by the key project in the Science and Technology Foundation of Tianjin Health and Family Planning [15KG136], the Natural Science Foundation of Tianjin[16JCYBJC25500] and Tianjin science and technology plan projects[17KPHDSF00170].

Data sharing statement

No additional data are available.

Disclosures:

None

References

1. Feigin VL, Roth GA, Naghavi M, et al. Global burden of stroke and risk factors in 188 countries, during 1990-2013: a systematic analysis for the Global Burden of Disease Study 2013. The Lancet. Neurology 2016;**15**(9):913-24 doi: 10.1016/s1474-4422(16)30073-4[published Online First: Epub Date]|.
2. Benjamin EJ, Blaha MJ, Chiuve SE, et al. Heart Disease and Stroke Statistics—2017. Circulation 2017;**135**(10):e146-603
3. De Wit L, Theuns P, Dejaeger E, et al. Long-term impact of stroke on patients' health-related quality of life. Disability and rehabilitation 2016:1-6 doi: 10.1080/09638288.2016.1200676[published Online First: Epub Date]|.
4. Andrew NE, Kilkenny M, Naylor R, et al. Understanding long-term unmet needs in Australian survivors of stroke. International journal of stroke : official journal of the International Stroke Society 2014;**9 Suppl A100**:106-12 doi: 10.1111/ijs.12325[published Online First: Epub Date]|.
5. Kruithof WJ, Post MW, van Mierlo ML, van den Bos GA, de Man-van Ginkel JM, Visser-Meily JM. Caregiver burden and emotional problems in partners of stroke patients at two months and one year post-stroke: Determinants and prediction. Patient education and counseling 2016 doi: 10.1016/j.pec.2016.04.007[published Online First: Epub Date]|.
6. site. RTWsow. http://www.world-stroke.org/newsletter/latest-updates/18-news/latest-updates/261-toolkit-for-the-global-bill-of-rights: Accessed November 23, 2015.
7. Liu L, Wang D, Wong KS, Wang Y. Stroke and stroke care in China: huge burden, significant workload, and a national priority. Stroke. 2011 Dec;42(12):3651-4. doi: 10.1161/STROKEAHA.111.635755. Epub 2011 Nov 3.
8. He M, Wang J, Dong Q,et al. Community-based stroke system of care improves patient outcomes in Chinese rural areas. J Epidemiol Community Health. 2018 Jul;72(7):630-635. doi: 10.1136/jech-2017-210185. Epub 2018 Mar 7.20
9. Li X, Xia X, Wang P, Zhang S, Liu M, Wang L. Needs and rights awareness of stroke survivors and caregivers: a cross-sectional, single-centre questionnaire survey. BMJ open 2017;**7**(10)
10. Harrison M, Ryan T, Gardiner C, Jones A. Psychological and emotional needs, assessment, and support post-stroke: a multi-perspective qualitative study. Topics in stroke rehabilitation 2016:1-7 doi: 10.1080/10749357.2016.1196908[published Online First: Epub Date]|.
11. Chau JP, Thompson DR, Chang AM, et al. Depression among Chinese stroke survivors six months after discharge from a rehabilitation hospital. Journal of clinical nursing 2010;**19**(21-22):3042-50 doi: 10.1111/j.1365-2702.2010.03317.x[published Online First: Epub Date]|.
12. Ekstam L, Johansson U, 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 doi: 10.1136/bmjopen-2014-006784[published Online First: Epub Date]|.
13. Matsuzaki S, Hashimoto M, Yuki S, Koyama A, Hirata Y, Ikeda M. The relationship between post-stroke depression and physical recovery. Journal of affective disorders 2015;**176**:56-60 doi: 10.1016/j.jad.2015.01.020[published Online First: Epub Date]|.
14. Park GY, Im S, Oh CH, Lee SJ, Pae CU. The association between the severity of poststroke depression and clinical outcomes after first-onset stroke in Korean patients. General hospital psychiatry 2015;**37**(3):245-50 doi: 10.1016/j.genhosppsych.2015.02.009[published Online First: Epub Date]|.
15. Walsh ME, Galvin R, 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. Disability and rehabilitation 2015;**37**(20):1834-8 doi: 10.3109/09638288.2014.981302[published Online First: Epub Date]|.

16. Miller EL, Murray L, Richards L, et al. Comprehensive overview of nursing and interdisciplinary rehabilitation care of the stroke patient: a scientific statement from the American Heart Association. Stroke; a journal of cerebral circulation 2010;**41**(10):2402-48 doi: 10.1161/STR.0b013e3181e7512b[published Online First: Epub Date]|.
17. Zeng Y1, He GP, Yi GH, et al. 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 doi: 10.1111/j.1365-2702.2012.04118.x.
18. 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 doi: 10.1016/j.apmr.2015.01.024[published Online First: Epub Date]|.17. McKevitt C, Fudge N, Redfern J, et al. Self-reported long-term needs after stroke. Stroke; a journal of cerebral circulation 2011;**42**(5):1398-403 doi: 10.1161/strokeaha.110.598839[published Online First: Epub Date]|.
19. Yaghobian M, Kaheni S, Danesh M, Rezayi Abhari F. Association between awareness of patient rights and patient's education, seeing bill, and age: a cross-sectional study. Glob J Health Sci 2014;6(3):55-64 doi: 10.5539/gjhs.v6n3p55.
20. 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
21. Zhai Y, Wang WZ, Zhao WH, Yang XG, Kong LZ. [The prevalence and onset of age of stroke in Chinese adults]. Zhonghua yu fang yi xue za zhi [Chinese journal of preventive medicine] 2009;**43**(12):1069-72
22. Zhang XH, Guan T, Mao J, Liu L. Disparity and its time trends in stroke mortality between urban and rural populations in China 1987 to 2001: changing patterns and their implications for public health policy. Stroke; a journal of cerebral circulation 2007;**38**(12):3139-44 doi: 10.1161/strokeaha.107.494336[published Online First: Epub Date]|.
23. Jun HJ, Kim KJ, Chun IA, Moon OK. The relationship between stroke patients' socio-economic conditions and their quality of life: the 2010 Korean community health survey. Journal of physical therapy science 2015;**27**(3):781-4 doi: 10.1589/jpts.27.781[published Online First: Epub Date]|.
24. Allen J, Inder KJ, Harris ML, Lewin TJ, Attia JR, Kelly BJ. Quality of life impact of cardiovascular and affective conditions among older residents from urban and rural communities. Health and quality of life outcomes 2013;**11**:140 doi: 10.1186/1477-7525-11-140[published Online First: Epub Date]|.
25. Dou J, Tang J, Lu CH, Jiang ES, Wang PX. A study of suicidal ideation in acute ischemic stroke patients. Health and quality of life outcomes 2015;**13**:7 doi: 10.1186/s12955-014-0198-9[published Online First: Epub Date]|.
26. Koifman J, Hall R, Li S, et al. The association between rural residence and stroke care and outcomes. Journal of the neurological sciences 2016;**363**:16-20 doi: 10.1016/j.jns.2016.02.019[published Online First: Epub Date]|.
27. Yusuf S, Islam S, Chow CK, et al. Use of secondary prevention drugs for cardiovascular disease in the community in high-income, middle-income, and low-income countries (the PURE Study): a

prospective epidemiological survey. Lancet (London, England) 2011;**378**(9798):1231-43 doi: 10.1016/s0140-6736(11)61215-4[published Online First: Epub Date]|.

28. Li W, Gu H, Teo KK, et al. Hypertension prevalence, awareness, treatment, and control in 115 rural and urban communities involving 47 000 people from China. Journal of hypertension 2016;**34**(1):39-46 doi: 10.1097/hjh.0000000000000745[published Online First: Epub Date]|.
29. Cadilhac DA, Purvis T, Kilkenny MF, et al. Evaluation of rural stroke services: does implementation of coordinators and pathways improve care in rural hospitals? Stroke; a journal of cerebral circulation 2013;**44**(10):2848-53 doi: 10.1161/strokeaha.113.001258[published Online First: Epub Date]|.
30. Swanoski MT, Lutfiyya MN, Amaro ML, Akers MF, Huot KL. Knowledge of heart attack and stroke symptomology: a cross-sectional comparison of rural and non-rural US adults. BMC public health 2012;**12**:283 doi: 10.1186/1471-2458-12-283[published Online First: Epub Date]|.
31. Wiszniewska M, Gluszkiewicz M, Kobayashi A, et al. Knowledge of risk factors and stroke symptoms among nonstroke patients. European neurology 2012;**67**(4):220-5 doi: 10.1159/000335569[published Online First: Epub Date]|.
32. Wang Y, Zhao X, Jiang Y, et al. Prevalence, knowledge, and treatment of transient ischemic attacks in China. Neurology 2015;**84**(23):2354-61 doi: 10.1212/wnl.0000000000001665[published Online First: Epub Date]|.
33. Mi T, Sun S, Du Y, et al. Differences in the distribution of risk factors for stroke among the high-risk population in urban and rural areas of Eastern China. Brain and behavior 2016;**6**(5):e00461 doi: 10.1002/brb3.461[published Online First: Epub Date]|.
34. Hickey A, Holly D, 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). International journal of stroke : official journal of the International Stroke Society 2012;**7**(4):298-306 doi: 10.1111/j.1747-4949.2011.00698.x[published Online First: Epub Date]|.
35. Inoue Y, Honda S, Watanabe M, Ando Y. Educational campaigns at point of purchase in rural supermarkets improve stroke knowledge. Journal of stroke and cerebrovascular diseases : the official journal of National Stroke Association 2015;**24**(2):480-4 doi: 10.1016/j.jstrokecerebrovasdis.2014.09.022[published Online First: Epub Date]|.
36. He M, Liu N, Ji N, et al. Effects of organized education by video on knowledge of early stroke symptoms among a Chinese rural population. International journal of stroke : official journal of the International Stroke Society 2014;**9**(8):E41 doi: 10.1111/ijs.12393[published Online First: Epub Date]|.
37. He M, Wang J, Gong L, et al. Community-based stroke system of care for Chinese rural areas. Stroke; a journal of cerebral circulation 2014;**45**(8):2385-90 doi: 10.1161/strokeaha.114.006030[published Online First: Epub Date]|.
38. Pit SW, Shrestha R, Schofield D, Passey M. Partial and complete retirement due to ill-health among mature age Australians. Public health 2013;**127**(6):561-71 doi: 10.1016/j.puhe.2012.12.022[published Online First: Epub Date]|.
39. Howitt SC, Jones MP, Jusabani A, et al. A cross-sectional study of quality of life in incident stroke survivors in rural northern Tanzania. Journal of neurology 2011;**258**(8):1422-30 doi: 10.1007/s00415-011-5948-6[published Online First: Epub Date]|.
40. Wang Q, Liu H, Lu ZX, Luo Q, Liu JA. Role of the new rural cooperative medical system in alleviating

1 catastrophic medical payments for hypertension, stroke and coronary heart disease in poor
2 rural areas of China. BMC public health 2014;**14**:907 doi: 10.1186/1471-2458-14-
3 907[published Online First: Epub Date]|.
4
5

Figure 1 The total needs and each aspect of needs in stroke survivors in urban areas were greater than of those in rural areas ($P<0.001$)

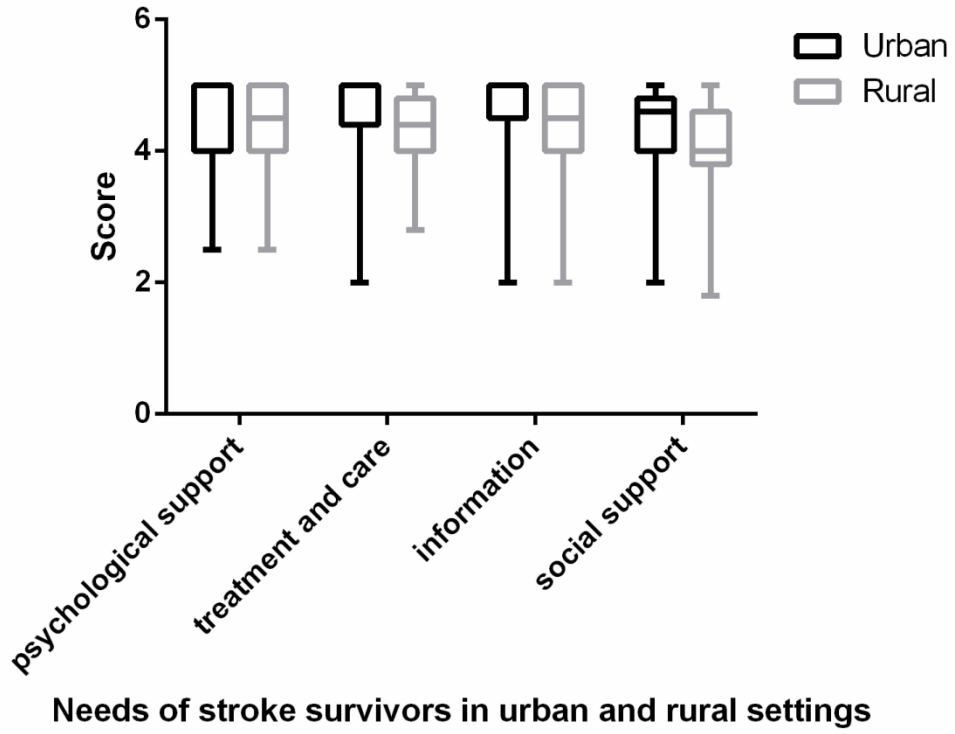

Figure 1 The total needs and each aspect of needs in stroke survivors in urban areas were greater than of those in rural areas (P<0.001)

128x102mm (300 x 300 DPI)

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 1-3
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found	page 3
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	page 5, lines 2-14
Objectives	3	State specific objectives, including any prespecified hypotheses	Page6, lines 4-9
Methods			
Study design	4	Present key elements of study design early in the paper	Page 7, lines 11-21
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	page 6, lines 17-20
Participants	6	(*a*) Give the eligibility criteria, and the sources and methods of selection of participants	page 6, lines 21-22 page 7, lines 1-5
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	page 7, lines 13-17
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 8, line 1-3
Study size	10	Explain how the study size was arrived at	page 6, lines19-21
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	Page7, lines 19-23
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding	page 8, lines5-12
		(*b*) Describe any methods used to examine subgroups and interactions	page 8, lines8-12
		(*c*) Explain how missing data were addressed	NA
		(*d*) If applicable, describe analytical methods taking account of sampling strategy	NA
		(*e*) Describe any sensitivity analyses	page 8, lines12
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 11, lines5-7
		(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	Table 1 and Table 2
		(b) Indicate number of participants with missing data for each	NA

		variable of interest	
Outcome data	15*	Report numbers of outcome events or summary measures	Table 3
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	NA
		(*b*) Report category boundaries when continuous variables were categorized	NA
		(*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 13, lines4-9
Discussion			
Key results	18	Summarise key results with reference to study objectives	page 14-18
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 18, lines7-8
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	page 18, lines10-16
Generalisability	21	Discuss the generalisability (external validity) of the study results	page 17, lines13-20
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 19, lines11-15

*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.