

## Preplanned Studies

## Assessment of the Health-Related Quality of Life in Neurocysticercosis Patients in Hot Spot Areas — China, 2017–2018

Yingjun Qian<sup>1</sup>; Xinzhong Zang<sup>2</sup>; Huanzhang Li<sup>3</sup>; Zhaoyu Guo<sup>1</sup>; Changhai Zhou<sup>1</sup>; Menbao Qian<sup>1</sup>; Yingdan Chen<sup>1</sup>; Hongkun Liu<sup>4</sup>; Yuhua Liu<sup>4</sup>; Shizhu Li<sup>1,†</sup>

### Summary

#### What is already known about this topic?

Neurocysticercosis is the most severe form of infection caused by ingesting cysticerci, the larval cysts of the pork tapeworm, *Taenia solium*. Approximately 50 million people worldwide have neurocysticercosis, which is the leading cause of acquired epilepsy in many endemic countries.

#### What is added by this report?

The health of neurocysticercosis patients can be seriously impaired, including through loss of mobility, inability to do self-care, impairment of usual activities, pain/discomfort, anxiety/depression, and impaired cognition. Cognitive impairment is the major consequence of neurocysticercosis and significant contributor to decreased health-related quality of life. Our study made the first estimate of disability weight from neurocysticercosis as a key parameter for disease burden assessment in China.

#### What are the implications for public health practice?

To prevent severe health outcomes from neurocysticercosis in China, it is necessary to improve public awareness of neurocysticercosis and relevant health behaviors.

Cysticercosis is considered by the World Health Organization (WHO) to be a neglected tropical disease. It is a parasitic tissue infection caused by cysticerci, the larval cysts of the pork tapeworm *Taenia solium* in an intermediate host. Humans are the definitive hosts of *T. solium*, which is acquired via ingestion of cysticerci in undercooked pork. Human cysticercosis is only acquired from ingestion of *T. solium* eggs through fecal-oral transmission: either autoinfection or swallowing eggs from carriers. When

cysticerci encyst in the central nervous system, neurocysticercosis (NCC) can occur (1). WHO estimated that in 2015 there were 2.5–8.3 million NCC cases resulting in a loss of 2.8 million disability-adjusted life years (DALY) (1). NCC is endemic in southeast China; Dali Prefecture in Yunnan Province is a hot spot (2–3). However, there are few domestic studies of NCC patients' quality of life and burden of disease. To fill this knowledge gap, our study assessed health outcomes and estimated disability weight (DW) in NCC inpatients through a hospital-based survey in Dali that was conducted in 2017–2018. The study showed that human health was seriously damaged in six dimensions, among which cognitive impairment was the most serious. We estimated DW to illustrate the urgency of increasing public awareness of NCC and improving relevant health behaviors.

From September 2017 to September 2018, inpatients in the affiliated hospital of Dali Prefectural Institute of Research and Control on Schistosomiasis, Dali City, Yunnan Province, were enrolled into the study if they met inclusion criteria and had no exclusions. Confirmed NCC cases were included if they met national cysticercosis diagnostic criteria (WS 381-2012), but patients with combined cysticercosis or who were below 5 years of age were excluded. Participants were categorized into two groups — a first-visit group and a follow-up group. The first-visit group was patients who received standard, hospital-based anti-cysticercosis treatment for the first time. The follow-up group was patients who received standard in-hospital treatment for their second-or-more time.

Health-related quality of life (HRQoL) was assessed in face-to-face interviews. We obtained demographic, diagnostic, and treatment data and administered the EQ-5D+C\* survey. EQ-5D is a standardized measure

\* EQ-5D+C is the abbreviation of European Quality of Life Scale (EQ) consisting of five dimensions (5D) with the additional dimension cognition (+C), which are rated with three levels (3L): no health problems, moderate health problems and extreme health problems. The 5D are: mobility, self-care, usual activities, pain/discomfort and anxiety/depression.

of health status developed by the EuroQol Group. This instrument provides a simple, generic measure of health for clinical and economic appraisals and for population surveys. It has 5 dimensions: mobility, self-care, usual activities, pain/discomfort, and anxiety/depression. Each dimension has 3 levels: no problems, some problems, and extreme problems (4). EQ-5D+C was developed from EQ-5D and is used in disease burden research to assess cognitive impairment (5). We included cognitive impairment assessment as the 6th health dimension because cognitive loss is commonly seen with NCC (6). DW was calculated with the formula,  $DW = 1 - EQ-VAS^{\dagger}/100$ . EQ-VAS uses the EuroQol Visual Analogue Scale and records the respondent's self-rated health on a vertical, visual analogue scale where 100 is "the best imaginable health state" and 0 is "the worst imaginable health state." We used EpiData (version 3.1, The EpiData Association, Odense, Denmark) to correct logic errors. Statistical analyses were performed with SPSS (version 19, IBM, Armonk, NY, USA).

Our study enrolled 210 participants. The average age was  $38.9 \pm 15.5$  years; 32.9% (69/210) of participants were 30–44 years of age. Eighty-four subjects were in the first-visit group and 126 were in the follow-up group. The most prominent clinical manifestations were headache (68.10%), memory impairment (61.43%), and epilepsy (37.1%). Epilepsy was more prominent in the first-visit group than in the follow-up group (54.76% *vs.* 25.40%;  $\chi^2 = 18.52$ ,  $P < 0.001$ ). Headache was reported by 76.19% in the first-visit group and 62.70% in the follow-up group

( $\chi^2 = 8.76$ ,  $P < 0.05$ ). Memory impairment was reported by 52.38% in the first-visit group and 67.46% in the follow-up ( $\chi^2 = 8.76$ ,  $P < 0.05$ ) (Supplemental Table S1, available in <http://weekly.chinacdc.cn>).

Table 1 shows EQ-5D+C survey results; 93.33% patients (196/210) had at least one health problem; 83.33% (175/210) had moderate health problems; and 10.0% (21/210) had extreme health problems. Cognitive impairment was the most frequently reported health problem (71.9%, 151/210). Of the six health indicator dimensions, pain/discomfort ranked the highest (77.38%) in the first-visit group followed by cognitive impairment (67.86%) while cognitive impairment was highest in the follow-up group (74.60%). No statistically significant differences were seen between the two groups in the six health dimensions. Logistic regression analysis showed statistically significant differences by age group. Compared to the 5–14 year old group, the risk of cognitive impairment was 16.33 times greater among 45–59 year old group (Supplementary Table S2, available in <http://weekly.chinacdc.cn>).

The median EQ-VAS score was 70 (interquartile interval: 60–80; range: 20–96). Multiple linear regression showed that EQ-VAS was negatively correlated with problems with usual activities, pain/discomfort, anxiety/depression, and cognitive impairment. Standardized regression coefficients showed that the greatest impact on EQ-VAS was cognitive impairment (−0.32), followed by problems with usual activities (−0.27), and pain/discomfort (−0.25) (Table 2). Multi-factor analysis showed that

TABLE 1. NCC patients' 6 health dimensions of health problems.

Dimension	No. having health problems			Participants with health problems (%) <sup>*</sup>	Having health problems <sup>*</sup>		$\chi^2$	P
	None (%)	Moderate (%)	Extreme (%)		First-visit group (N <sup>†</sup> =84) n <sup>§</sup> (%)	Follow-up group (N <sup>†</sup> =126) n <sup>§</sup> (%)		
Mobility <sup>¶</sup>	201(95.71)	9(4.29)	0(0.00)	9(4.29)	5(5.95)	4(3.17)		>0.05
Self-care <sup>¶</sup>	204(97.14)	6(2.86)	0(0.00)	6(2.86)	2(2.38)	4(3.17)		>0.05
Daily activities	124(59.05)	83(39.52)	3(1.43)	86(40.95)	38(45.24)	48(38.10)	1.06	>0.05
Pain/discomfort	61(29.05)	147(70.00)	2(0.95)	149(70.95)	65(77.38)	84(66.67)	2.81	>0.05
Anxiety/depression	80(38.09)	118(56.19)	12(5.71)	130(61.90)	53(63.10)	77(61.11)	0.03	>0.05
Cognitive impairment	59(28.1)	144(68.57)	7(3.33)	151(71.90)	57(67.86)	94(74.60)	1.14	>0.05
Any dimension <sup>¶</sup>	14(6.67)	175(83.33)	21(10.00)	196(93.33)	80(95.24)	116(92.06)		>0.05

Abbreviation: NCC=neur ocysticercosis.

<sup>\*</sup> health problems=having moderate and extreme health problems.

<sup>†</sup> N=No. of participants in the first-visit group and follow-up group.

<sup>§</sup> n=No. of participants having health problems in first-visit group and follow-up group.

<sup>¶</sup> Fisher exact probability test was used.

<sup>†</sup> EQ-VAS means European quality of life visual analogue scale.

the regression model was statistically significant overall ( $F=16.99$ ,  $P<0.001$ ).  $R^2$  was equal to 0.46, indicating that the included variables could account for 46% of the total variation in EQ-VAS scores. The first-ever assessment in China of the overall NCC DW was 0.3 (0.2–0.4), with no statistically significant differences between gender ( $Z=-0.15$ ,  $P>0.05$ ) or group ( $Z=0.62$ ,  $P>0.05$ ).

## DISCUSSION

NCC is the most severe form of cysticercosis and is often characterized by headaches and epileptic seizures. We found that the most prominent clinical manifestations in NCC patients were headache, impaired memory, and epilepsy. Comparison of first-visit and follow-up groups showed that the proportion of NCC patients with epilepsy in the follow-up group was significantly lower than the proportion with epilepsy in the first-visit group, suggesting that standardized treatment was helpful to decrease this major health outcome for NCC patients. Over 60% (129/210) of NCC patients reported impaired memory. Although little attention was attached to memory impairment, it is common in cysticercosis, and long-term memory impairment causes great psychological pressure and seriously affects quality of life (7–8). The average EQ-VAS was 70, which is lower than the 80.91 score found in the National Health Service survey (9), indicating that HRQoL is heavily degraded in NCC patients.

Of the six dimensions of health, we found that the top-reported problem in NCC patients was cognitive impairment, showing that cognitive impairment is a prominent health problem for both first-visit and follow-up groups and implying that more attention should be paid to cognition problems in NCC. The risk of impaired cognitive ability increased with age. Risk of impaired cognitive ability was 16.33 times higher in the 45–59 age group compared to the 5–14 age group. Therefore, more attention should be paid to cognitive impairment in this age group, considering that cognition is a mainstay of productivity.

Disability weight is a critical parameter for estimating disease burden. Our study estimated DW at 0.3 in NCC patients through an assessment of quality of life, highlighting significant health loss in this population. Impaired memory is a cause of cognitive disorders (7), and we found significantly more memory impairment in the follow-up group than in the first-visit group. Since memory impairment is a key contributor to DW, this finding suggests that follow-up treatment did not improve the overall health status of NCC patients. Health education has been proved a robust intervention tool leading to knowledge improvement and improvement in community hygiene practices (10). Our study showed a poor quality of life in terms of six health dimensions measured in the standard EQ-5D assessment tool. Cognitive impairment was responsible for most health loss among NCC patients, calling for consistent health education in this population.

The study was subject to at least two limitations.

TABLE 2. Linear regression analysis of factors influencing EQ-VAS score.

Influencing factors	Partial regression coefficient	SE	<i>t</i>	<i>P</i>	Standardized coefficients
Intercept	87.44	2.94	29.72	<0.0001	
Age group (years)					
15–29	–1.39	3.47	–0.40	>0.05	–0.05
30–44	–0.33	3.43	–0.10	>0.05	–0.01
45–59	–0.09	3.48	–0.03	>0.05	0.00
≥60	–3.20	3.90	–0.82	>0.05	–0.07
Occupation	2.62	1.56	1.68	>0.05	0.10
Mobility	–0.38	3.43	–0.11	>0.05	–0.01
Self-care	–6.19	4.16	–1.49	>0.05	–0.08
Usual activity	–7.13	1.46	–4.88	<0.001	–0.27
Pain/discomfort	–6.97	1.50	–4.66	<0.001	–0.25
Anxiety/depression	–5.42	1.52	–3.56	<0.001	–0.20
Cognitive impairment	–9.12	1.65	–5.52	<0.001	–0.32

Abbreviations: EQ-VAS=European quality of life visual analogue scale; SE=standard error.

First, it was a retrospective study. There may have been recall bias in this face-to-face survey. Second, EQ-VAS records respondents' self-assessment of health status and may not be representative of the general population. Participants were recruited in Dali, which may not be representative of the entire NCC population. A large-scale study is needed to fully assess the NCC disease burden in China.

In conclusion, our study documented great health losses in NCC patients, with cognitive impairment being the most serious health outcome. Standardized treatment was not associated with improvement in cognitive impairment. Patients 45–59 years of age are at the highest risk of cognitive impairment. Strengthening health education targeted populations with a custom of eating raw pork may reduce the health impact of NCC in China.

**Funding:** Supported by the National Natural Science Foundation of China (No.32161143036), the Fifth Round of Three-Year Public Health Action Plan of Shanghai (No. GWV-10.1-XK13), and the National Special Science and Technology Project for Major Infectious Diseases of China (Grant No. 2016ZX10004222-004).

doi: 10.46234/ccdcw2022.134

# Corresponding author: Shizhu Li, lysz@chinacdc.cn.

<sup>1</sup> National Institute of Parasitic Diseases, Chinese Center for Disease Control and Prevention (Chinese Center for Tropical Diseases Research); NHC Key Laboratory of Parasite and Vector Biology; WHO Collaborating Centre for Tropical Diseases, Shanghai, China; <sup>2</sup> Qilu Hospital, Cheeloo College of Medicine, Shandong University, Qingdao City, Shandong Province, China; <sup>3</sup> Dandong City Center for Disease Control and Prevention, Dandong City, Liaoning Province, China; <sup>4</sup> Dali Prefectural Institute of Research and Control on Schistosomiasis, Dali City, Yunnan Province, China.

Submitted: January 17, 2022; Accepted: July 10, 2022

## REFERENCES

1. World Health Organization. Taeniasis/cysticercosis. 2021. <https://www.who.int/news-room/fact-sheets/detail/taeniasis-cysticercosis>. [2022-1-17].
2. Guo ZY, Liu JF, Zhou CH, Qian MB, Chen YD, Zhou XN, et al. Current status and challenges for taeniasis and cysticercosis control in China. *Chin J Schisto Control* 2021;33(6):563–9. <https://kns.cnki.net/kcms/detail/32.1374.R.20211213.1713.006.html>. (In Chinese).
3. Zang XZ, Li HZ, Liu HK, Liu YH, Zhou CH, Chen YD, et al. Epidemiological analysis of new cases of cysticercosis in Dali Prefecture, Yunnan province from 2014 to 2017. *Chin J Schisto Control* 2019;31(2):143–7. <http://www.zgxfz.com/CN/abstract/abstract10891.shtml>. (In Chinese).
4. EQ-5D. 2021. <http://www.euroqol.org>. [2022-1-17].
5. Jia TW, Utzinger J, Deng Y, Yang K, Li YY, Zhu JH, et al. Quantifying quality of life and disability of patients with advanced schistosomiasis japonica. *PLoS Negl Trop Dis* 2011;5(2):e966. <https://pubmed.ncbi.nlm.nih.gov/21358814/>.
6. Li HZ. Temporal and spatial distribution characteristics based on cysticercosis inpatients [dissertation]. Beijing: Chinese Center for Disease Control and Prevention; 2018. [https://kns.cnki.net/kcms/detail/detail.aspx?dbcode=CMFD&dbname=CMFD201901&filename=1018308979.nh&uniplatform=NZKPT&v=127qiU1vPdn77Twr64WFM19rDcpkQKZsnz0OOAANZtNZn70ByVpLe\\_5NgDZzUXe1](https://kns.cnki.net/kcms/detail/detail.aspx?dbcode=CMFD&dbname=CMFD201901&filename=1018308979.nh&uniplatform=NZKPT&v=127qiU1vPdn77Twr64WFM19rDcpkQKZsnz0OOAANZtNZn70ByVpLe_5NgDZzUXe1). (In Chinese).
7. Liu QY, Ge LY, Ruan XY, Ji F, Wang HQ, Liu YL. Study on the impact of neurocysticercosis on memory. *Chin J Parasit Dis Control* 1994;7(4):292–3. <https://kns.cnki.net/KCMS/detail/detail.aspx?dbcode=CJFD&filename=ZISC404.022>. (In Chinese).
8. Wallin MT, Pretell EJ, Bustos JA, Caballero M, Alfaro M, Kane R, et al. Cognitive changes and quality of life in neurocysticercosis: a longitudinal study. *PLoS Negl Trop Dis* 2012;6(1):e1493. <http://dx.doi.org/10.1371/journal.pntd.0001493>.
9. Jia XX, Hu HY, Wang XX, Zhuo L, Xu L, Zhang YG, et al. Analysis on self-rated health status and its influencing factors among Chinese residents aged 15 and above. *Chin J Health Policy* 2016;9(6):62–7. <http://www.cnki.com.cn/Article/CJFDTOTAL-ZGWZ201606012.htm>. (In Chinese).
10. Lauridsen S, Braae UC, Ngowi HA, Johansen MV. Impacts of using the electronic-health education program 'The Vicious Worm' for prevention of *Taenia solium*. *Acta Trop* 2019;193:18–22. <http://dx.doi.org/10.1016/j.actatropica.2019.02.018>.

SUPPLEMENTARY TABLE S1. Clinical manifestations in NCC patients between first-visit group and follow-up group.

Group	No. of NCC patients	Epilepsy (%) <sup>*</sup>	Headache (%) <sup>†</sup>	Impaired memory (%) <sup>†</sup>	Muscle paresthesia (%) <sup>§</sup>	Eye discomfort (%) <sup>§</sup>
First-visit	84	46(54.76)	64(76.19)	44(52.38)	26(30.95)	12(14.29)
Follow-up	126	32(25.40)	79(62.70)	85(67.46)	37(29.37)	11(8.73)
Total	210	78(37.14)	143(68.10)	129(61.43)	63(30.00)	23(10.95)

Abbreviation: NCC=neurocysticercosis.

<sup>\*</sup>  $P<0.001$ .<sup>†</sup>  $P<0.05$ .<sup>§</sup>  $P>0.05$ .

SUPPLEMENTARY TABLE S2. Cognitive impairment in NCC patients among different age groups.

Age group (years)	n	No. with cognitive impairment (%)	$\beta$	$P$	OR
5–14	10	2(20.00)			
15–29	51	34(66.67)	2.08	<0.05	8.00
30–44	69	51(73.91)	2.43	<0.01	11.33
45–59	61	49(80.32)	2.27	<0.01	16.33
≥60	19	15(78.94)	2.71	<0.01	15.00

Abbreviation: NCC=neurocysticercosis.