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Infectious disease-specific health literacy in Tibet, China

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Summary

This study was aimed to develop an instrument to assess infectious disease-specific health literacy (IDSHL) in the general population of Tibet, China and identify the association between IDSHL and reported infectious disease-related symptoms. A survey using a standardized questionnaire, which included 25 questions on knowledge, behaviors and skills regarding infectious diseases, was conducted in the general population of Tibet, China between September 2011 and November 2011. The 25 questions formed the index system of the instrument assessing IDSHL (total scores: 25 scores). Factors associated with index scores of IDSHL were identified by general linear model. The association between the index score of IDSHL and the occurrence of the five selected infectious disease symptoms (fever, diarrhea, rash, jaundice or conjunctivitis) were investigated using multivariate unconditional logistic regression. Among 5717 eligible participants in the survey, 4631 participants completed all of the 25 questions in the instrument. The instrument was reliable and valid as measured by the Cronbach's alpha coefficient and split-half coefficient, and the confirmatory factor analysis. Only 1.0% (48/4631) answered ≥80% of the 25 questions correctly (score ≥20). Significant factors associated with lower health literacy score included female gender, older age, Tibetan group, lower education level, underlying diseases and more undeveloped area. For each increasing score of IDSHL, reports of fever, diarrhea or jaundice in the prior year were significantly decreased by 3% ($p = 0.015$), 4% ($p = 0.004$) and 16% ($p < 0.001$), respectively. Accurately measuring IDSHL could help identify those individuals with poor IDSHL, who could be targeted with specific interventions to improve health.

Keywords

health literacy; infectious disease; Tibet

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INTRODUCTION

Health literacy has been defined as ‘the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health’. by World Health Organization (WHO, 1998). To date measurement of health literacy has focused mainly on the abilities of reading comprehension and numeracy, usually assessed by three commonly used instruments, including the Rapid Estimate of Adult Literacy in Medicine (REALM), the Test of Functional Health Literacy in Adults (TOFHLA) and the short TOFHLA (S-TOFHLA) (Davis *et al.*, 1993; Parker *et al.*, 1995; Baker *et al.*, 1999).

Some studies have been conducted on the relationship between health literacy (as measured by REALM, TOFHLA or S-TOFHLA) to disease-related outcomes and health care utilization. These studies have demonstrated that people with lower health literacy were more likely to be hospitalized or use emergency care (Baker *et al.*, 2004; Howard *et al.*, 2005), and that among the elderly, lower health literacy was associated with a higher risk of mortality (Sudore *et al.*, 2006; Baker *et al.*, 2007). However, studies have difficulties identifying a relationship between health literacy and specific diseases, such as diabetes (Morris *et al.*, 2006; Powell *et al.*, 2007; Mancuso, 2010), hypertension (Morris *et al.*, 2006; Pandit *et al.*, 2009). This may be because the instruments assessing health literacy used have focused on the abilities of reading comprehension and numeracy. Whereas, health literacy is more than the ability to read pamphlets and make appointments, but is the achievement of knowledge, skills and confidence to improve personal and community health by changing personal lifestyles and living conditions (WHO, 1998). Therefore those studies may not accurately measure health literacy and lead to considerable variation in the associations found between health literacy and specific diseases. In order to solve this problem, health literacy should be measured by an instrument aimed at examining direct and specific factors that influence outcomes of diseases.

In recent years, infectious diseases, such as severe acute respiratory syndrome, acquired immune deficiency syndrome (AIDS), avian influenza, tuberculosis, pandemic (H1N1) 2009 influenza and Ebola virus disease have threatened global health. Yet very few studies have explored the association of health literacy with infectious diseases. Since infectious disease-specific health literacy (IDSHL) may have direct impact on occurrences and outcomes of infectious diseases, increased IDSHL may help persons prevent and promptly seek care for infectious diseases. Therefore, continuous evaluation of IDSHL would benefit the prevention and control of infectious diseases, and the development of an instrument to assess IDSHL is currently warranted.

Tibet, China is located in Qinghai-Tibetan Plateau at an average altitude >4000 m above sea level and ~95% of its population is of Tibetan ethnicity. In past decades, the central government of China has invested considerably in the construction of a system of public health services in Tibet, leading to big improvements in the prevention and control of infectious diseases; for example, the coverage rate of oral polio vaccine in children of Tibet has exceeded 90% (Bian *et al.*, 2005). However, it should be noted that some infectious diseases, such as tuberculosis, measles, hepatitis, dysentery, plague and brucellosis, are

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highly prevalent in Tibet, and Tibet is an important natural focus of plague (Gong, 2005). Threats from these long-standing diseases and emerging infectious diseases continue to exist.

In this study, we developed an instrument to assess IDSHL, and used this instrument to measure the IDSHL of the general population of Tibet, China, and the factors associated with the level of IDSHL as well as the association of IDSHL with occurrence of five typical symptoms of infectious diseases.

METHODS

Participants and survey design

Between September 2011 and November 2011, we conducted a cross-sectional survey in Tibet, China using multiple-stage stratified random sampling technique. Eligibility criteria included: (i) age ≥18 years; (ii) uninterrupted residence in Tibet for ≥6 months; (iii) informed consent. At the first stage, counties in Tibet were categorized into four strata (urban area, farming area, semi-farming/semi-pasturing area, and pasturing area). Two counties were randomly selected from each group. At the second stage, two towns/streets were randomly selected from all candidate towns/streets of each selected county. At the third stage, 360 eligible people were randomly selected from each selected town/street. The final sample size was 5760 participants whom we aimed to enroll in this survey.

Survey content and development of instrument assessing IDSHL

A standardized questionnaire was administered face to face to all participants by trained study staff who were able to speak both Mandarin and Tibetan language fluently. For the participants who were unable to speak Mandarin, the study staff spoke Tibetan language to communicate with them. The questionnaire consisted of demographic characteristics (sex, age, ethnic group, residence area and educational level), symptoms of fever, diarrhea, rash, jaundice or conjunctivitis in the year prior to the interview, and 25 questions on three aspects of infectious diseases—knowledge, behaviors and skills.

The 25 questions were selected based on literature review and expert consultation, and formed the index system of the instrument assessing IDSHL in Tibet, China (Table 1). The process of identifying the 25 questions was described as follows: Fifty candidate questions were produced by us based on referring to textbooks of infectious diseases (Yang et al., 2008), guidelines on infectious diseases (Siegel et al., 2007), the National Health Literacy Survey in China (Chinese Ministry of Health, 2008), and articles on prevention and control of infectious diseases, e.g. studies that examined the knowledge, attitude and practices about infectious diseases in China, those exploring factors related to prevention and control of infectious diseases, and those addressing the infectious diseases in Tibet, China (Gong, 2005, Prosser *et al.*, 2011). The 50 candidate questions were subsequently discussed and assessed by 5 experts, consisting of an infectious disease clinician, 3 infectious disease epidemiologists and a health education specialist. After the in-depth discussion and the strict evaluation on each question, a total of 25 questions considered to be important for prevention and control of infectious diseases in Tibet, China were finally selected to form

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the index system of the instrument assessing IDSHL. The index system was pretested in 30 residents in Tibet, China and minor revisions were made on some questions to make participants understand more easily.

An index score of health literacy was calculated as follows: one point for a correct answer and zero for an incorrect answer for a maximum total index score of 25 points.

The study was approved by the Institutional Review Board and the Human Research Ethics Committee of Beijing Center for Disease Prevention and Control.

Statistical analysis

Data were entered in duplicate using EpiData Software. To assess the degree to which our index system measured the intended construct of IDSHL, consisting of knowledge, behaviors and skills, we evaluated construct validity of the index system by confirmatory factor analysis using the indicators as follows: root mean square error of approximation (RMSEA), comparative fit index (CFI), standard root mean-square residual (SRMR), goodness-of-fit index (GFI), adjusted goodness-of-fit index (AGFI) by AMOS 7.0 and other analyses were conducted using the SPSS 16.0 statistical package. Means and standard deviations (SD) were calculated for continuous variables, and percentages were calculated for categorical variables. Reliability of the index system was evaluated using Cronbach's alpha coefficient and split-half coefficient (Parker *et al.*, 1995). Factors associated with index scores of IDSHL in participants were identified by general linear model. The association between the index score of IDSHL and the occurrence of the five selected infectious disease symptoms in participants were investigated using multivariate unconditional logistic regression analysis controlling for sex, age, ethnic group, living area, education background and underlying disease. All the tests were two-sided, and statistical significance was defined as $p < 0.05$. We defined adequate IDSHL as a score ≥20 (80% of the 25 IDSHL questions answered correctly similar as in TOFHLA) (Parker *et al.*, 1995).

RESULTS

Characteristics of participants

A total of 5760 eligible participants were visited, and 5717 agreed to participate in the survey, among which 4631 (81.0%) completed all of the 25 questions that assessed IDSHL and were finally included in the analysis. The proportion of females was 54.5% (2516/4620) and the mean age of the participants was 44.0 years (SD: 1.5 years); 35.7% (1652/4627) were ≥50 years. Of all participants, 96.7% (4311/4456) were Tibetan. At least 20% of participants resided in each of the four areas. Of 4608 participants, 3895 (84.5%) participants did not receive education above primary school; and of 4531 participants, 1127 (24.9%) reported underlying diseases (Table 2).

Reliability and validity of the index system of the instrument assessing IDSHL—The index score system had a satisfactory internal consistency reliability as measured by Cronbach's alpha coefficient and split-half coefficient (0.700 and 0.621, respectively) (Bland and Altman, 1997). In addition, the confirmatory factor analysis showed a good construct

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validity (RMSEA = 0.053, CFI = 0.834, SRMR = 0.049, GFI = 0.939, AGFI = 0.927) (Browne and Cudeck, 1993; Joreskog and Sorbom, 1996; Hu and Bentler, 1999).

IDSHL and associated factors—The mean score of IDSHL of the 4631 participants who responded to all 25 questions was 10.3 (SD = 3.6). Only 1.0% (48/4631) answered ≥80% of the 25 questions correctly (score ≥20).

After multivariate analysis, independent factors associated with a lower health literacy score included female sex (β, −0.20, $p = 0.025$), older age (reference: 18–29 years; 30–49 years: β, −0.01, $p = 0.931$; ≥50 years: β, −0.79, $p < 0.001$), Tibetan group (reference: non-Tibetan group; β, −1.46, $p < 0.001$), undeveloped area (reference: urban area; farming area: β, −0.60, $p < 0.001$; semi-farming/semi-pasturing area: β, −2.39, $p < 0.001$; pasturing area: β, −1.63, $p < 0.001$), lower education level (reference: ≥college/university; senior high school: β, −1.48, $p < 0.001$; junior high school: β, −3.07, $p < 0.001$; ≤primary school: β, −6.01, $p < 0.001$), and underlying diseases (β, −0.34, $p = 0.001$) (Table 2).

Association between IDSHL and typical symptoms of infectious diseases—About 17.6% (810/4604), 21.3% (981/4604), 4.6% (212/4604), 1.7% (78/4604), 5.3% (243/4604) of the participants reported having fever, diarrhea, rash, jaundice, conjunctivitis in the year prior to the interview, respectively. Multivariate analysis found that the IDSHL index score was independently associated with prior year illness. For each increased point on the IDSHL index score, the probability of reported fever, diarrhea, or jaundice significantly decreased by 3% ($p = 0.015$), 4% ($p = 0.004$) and 16% ($p < 0.001$), respectively (Table 3).

DISCUSSION

In this study, we developed an instrument to assess IDSHL and employed it to evaluate the association of IDSHL with five symptoms of infectious disease in the general population of Tibet, China. With this instrument we were able to show that higher IDSHL scores were associated with a reduced likelihood of reporting of these five symptoms of infectious diseases in the prior year. Several factors, including female sex, older age, Tibetan group, undeveloped area, lower education and presence of underlying diseases, were associated with lower scores of the IDSHL.

The most commonly used instruments for evaluating health literacy, such REALM and TOFHLA, focus on the abilities of reading comprehension and numeracy. REALM is designed to examine an adult's capability to recognize or pronounce common medical terms, but is not designed to investigate the ability to comprehend (Davis *et al.*, 1993). TOFHLA consists of two sections testing reading comprehension and numeracy. The reading comprehension section is presented in a cloze pattern based on hospital documents, and the numeracy section relies on actual hospital forms and labeled prescription vials to test numeracy skills and the ability to take medical activities correctly (Parker *et al.*, 1995). Although lower health literacy based on these instruments was clearly associated with outcomes such as more frequent hospitalizations, increased emergency utilization and higher risk of mortality (Baker *et al.*, 2004; Howard *et al.*, 2005; Sudore *et al.*, 2006; Baker *et al.*, 2007), evidence of a correlation between lower health literacy and specific diseases has been

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lacking (Morris *et al.*, 2006; Powell *et al.*, 2007; Pandit *et al.*, 2009; Mancuso, 2010;). Therefore, these traditional instruments for health literacy assessment may be limited, and new instruments toward direct and specific factors related to specific diseases (knowledge, behaviors, and skills), which could increase the efficacy for predicting the specific diseases, should be developed. At the present, some instruments targeting broader dimensions of health literacy have been developed, such as the Health Literacy Management Scale (HeLMS) (Jordan *et al.*, 2013), the Health Literacy Questionnaire (Osborne *et al.*, 2013) and the European Health Literacy Survey Questionnaire (Sorensen *et al.*, 2013). The domains of these instruments measuring health literacy generally covered accessing health information, understanding health information, appraising health information, communication with health professionals and using health information.

In this study, an instrument of health literacy based specifically on knowledge, behaviors and skills covering multiple infectious diseases, including respiratory, enteric and zoonotic diseases, was developed. A previous study used an instrument to evaluate health literacy related to respiratory infectious diseases (Sun *et al.*, 2013a). Although the contents of this instrument were more specific and comprehensive than the traditional instruments (REALM, TOFHLA or S-TOFHLA), it still did not evaluate the status of using information, such as behaviors and skills, and only focused on the ability of gaining access to and understanding information, which may explain why no association was found between health literacy assessed by this instrument and health status (Sun *et al.*, 2013b). In contrast, the level of the IDSHL evaluated by our instrument was significantly associated with the occurrences of typical symptoms of infectious diseases, including fever, diarrhea and jaundice.

It was found that only 1.0% of the participants answered 80% or more items correctly using our developed instrument. Some previous studies on health literacy also showed that the levels of health literacy in the ethnic minority populations were lower (Parker *et al.*, 1995; U.S. Department of Education, 2006). In addition, due to generally lower socio-economic status among ethnic minorities compared with others, health outcomes after infectious diseases are also relatively more severe. For example, ethnic minorities and indigenous groups are known to experience worse outcomes of influenza infection (Centers for Disease Control and Prevention, 2009).

We found that old adult participants and participants with lower educational background had less favorable IDSHL. Health literacy has been associated with age and education background in previous studies also (U.S. Department of Education, 2006; van der Heide et al., 2013). Although females were more likely to have lower health literacy compared with males, the difference seemed minimal in our study. In comparison with the general population in other areas, those in the urban area had the best IDSHL, which indicated that the economic level might feature in the establishment and the improvement of health literacy. HeLMS comprised a domain regarding economic factor (Jordan *et al.*, 2013). However, one of the limitations of HeLMS was that a scale within this instrument related to economic factor had the greatest variance. Economic factor should be better regarded as a contextual factor rather than a health literacy scale (Osborne *et al.*, 2013). In recent years, great social-economic developments have been achieved in Tibet. In 2011, the average annual income per capita of Tibet was close to that of most provinces in China and even

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exceeded that of some provinces (National Bureau of Statistics of China, 2011). In 2007, the policy of Residents Basic Medical Insurance started to be implemented in Tibet, which brought the coverage of medical insurance to all the population in Tibet (The State Council Information Office of the People' Republic of China, 2011). In 2011, internet and roads had covered all the towns of Tibet (The Central People's Government of the People' Republic of China, 2010; Lasa Municipal Goverment, 2011). At the present, the people in Tibet usually live in fixed houses, including those in pasturing areas where herders have their own rangelands allocated by the government to graze livestock. They do not need to migrate for grazing, and they live in fixed villages (Hao, 2007). A couple of items regarding behaviors in our IDSHL instrument seem to be influenced by economic factors, but in the current socio-economic context of Tibet, these behaviors are modifiable for the people from various areas of Tibet as long as they realize the importance of these behaviors. Therefore, these items regarding behaviors are able to reflect health literacy. In addition, it should be noted that economic level can have impact on contracting an infectious disease by the mediation of influence on health literacy as well as change the risk of getting an infectious disease directly.

It was noteworthy that the general population with underlying diseases had lower IDSHL than those without underlying conditions even when adjusted for age and other confounders. This finding addressed that the IDSHL could become an indicator predicting the risk of having underlying disease, and this risk might be directly or indirectly influenced by the IDSHL assessed by our instrument.

Our study had several limitations. First, we only analysed a limited number of factors which might be correlated with IDSHL and factors associated with it could be more complicated, such as other socio-economic status factors including income, employment, type of dwelling, nutrition, substance abuse, preventive care etc, which were not collected in this study. As the information on the socio-economic status factors of the participants was not available in this study, we had difficulty performing further statistical analysis on whether persons in similar socio-economic conditions but at different levels of health literacy would have different prevalences of infectious diseases. Second, we used five typical symptoms to be representative of infectious diseases, but it is possible that these symptoms were caused by non-infectious diseases in some cases. Third, reporting bias is inevitable in this study as the incidences of these symptoms were based on retrospective self-reported information.

In conclusion, IDSHL in the general population of Tibet, China was low, and increasing health literacy was associated with fewer reported illness. Accurately measuring IDSHL could help identify those individuals with poor IDSHL, who could be targeted with specific IDSHL interventions to improve health.

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Table 1

Index system of the instrument assessing IDSHL in Tibet, China

Number	Category	Item of index system	Correct answer
1	Knowledge	What is the most efficient measure for preventing measles?	Vaccination
2	Knowledge	What is the most efficient measure for preventing influenza?	Vaccination
3	Knowledge	What are the main transmission routes of hepatitis A?	Eat contaminated food or drink contaminated water.
4	Knowledge	What are the main transmission routes of AIDS?	Transfusion, sexual transmission, maternal-neonatal transmission or needle sharing.
5	Knowledge	What are the main transmission routes of plague?	Bite of infected flea, contact with infected animals or infected human
6	Behavior	Do you spit on the ground in public places?	No
7	Behavior	Do you cover your mouth when coughing or sneezing in public places?	Yes
8	Behavior	Do you wear masks when visiting hospitals for influenza-like illness (ILI) symptoms?	Yes
9	Behavior	Do you have the intention to reduce contact with persons who have ILI symptoms?	Yes
10	Behavior	Do you wash hands before eating?	Yes
11	Behavior	Do you use separate chopping boards and knives for raw meat and cooked food?	Yes
12	Behavior	Is the water you drink usually boiled?	Yes
13	Behavior	Is there a toilet which can be used by your household?	Yes
14	Behavior	Where is the household garbage of your home disposed?	Dustbin or fixed place around the home
15	Behavior	Do you process or eat sick or dead domestic animals?	No
16	Behavior	Do you hunt, process or eat wild animals?	No
17	Behavior	Do you share tooth brush with other persons?	No
18	Behavior	Do you choose certificated dental clinic to receive therapy?	Yes
19	Behavior	Do you go to receive rabies vaccine if bitten by a dog?	Yes
20	Behavior	In how many days per week do you engage in exercise for over 30 minutes per day?	≥3 days
21	Skill	Can you usually obtain knowledge about infectious diseases you need by some ways, such as newspapers, books, internet, etc.?	Yes
22	Skill	Can you usually understand the drug instruction?	Yes
23	Skill	Can you usually understand the publicity materials about infectious diseases?	Yes
24	Skill	Read the results of the routine blood test the investigator presents to you, and point out which items are abnormal.	The participant can point out the abnormal items correctly.
25	Skill	Use the thermometer the investigator gives you to measure your temperature.	The participant can measure his/her temperature correctly using the thermometer correctly.

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Table 2

Multivariate analysis[a] for factors associated with scores of IDSHL in the general population of Tibet, China

Characteristic	Proportion (%)	Scores (Mean, SD)	β (95% CI)
Sex			
Male	2104//4620 (45.5)	10.4 (3.7)	Reference
Female	2516/4620 (54.5)	10.1 (3.5)	−0.20 (−0.38 to −0.03)
Age group-years			
18–29	942/4627 (20.4)	11.8 (3.8)	Reference
30–49	2033/4627 (43.9)	10.4 (3.5)	−0.01 (−0.26 to 0.23)
≥50	1652/4627 (35.7)	9.2 (3.2)	−0.79 (−1.06 to −0.53)
Ethnic group			
Other groups	145/4456 (3.3)	14.5 (3.5)	Reference
Tibetan group	4311/4456 (96.7)	10.1 (3.5)	−1.46 (−1.96 to −0.95)
Living area			
Urban area	1123/4631 (24.2)	12.0 (3.6)	Reference
Farming area	1202/4631 (26.0)	10.7 (3.4)	−0.60 (−0.85 to −0.36)
Semi-farming/semi-pasturing area	1279/4631 (27.6)	9.1 (3.6)	−2.39 (−2.64 to −2.14)
Pasturing area	1027/4631 (22.2)	9.3 (2.9)	−1.63 (−1.89 to −1.37)
Education background			
≥College/University	221/4608 (4.8)	15.8 (2.8)	Reference
Senior high school	163/4608 (3.5)	15.2 (2.9)	−1.48 (−2.09 to −0.88)
Junior high school	329/4608 (7.1)	13.2 (3.4)	−3.07 (−3.58 to −2.55)
≤Primary school	3895/4608 (84.5)	9.5 (3.1)	−6.01 (−6.44 to −5.57)
Underlying diseases			
No	3404/4531 (75.1)	10.7 (3.6)	Reference
Yes	1127/4531 (24.9)	9.2 (3.2)	−0.34 (−0.55 to −0.13)

NOTE: Due to a small number with missing values, not all column categories sum to the total number of the participants included in this study (n = 4631). SD, standard deviation; OR, odd ratio; CI, confidence interval.

[a]General linear model was employed. $B > 0$ indicates the variable increases health literacy score and $\beta < 0$ indicates the variable reduces health literacy score.

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Table 3

Association between IDSHL score and typical symptoms of infectious diseases in the general population of Tibet, China

Statistics for IDSHL score	Symptom[a]				
	Fever	**Diarrhea**	**Rash**	**Jaundice**	**Conjunctivitis**
Adjusted OR (95% CI)[b]	0.97 (0.94–0.99)	0.96 (0.94–0.99)	0.95 (0.91–1.00)	0.84 (0.77–0.92)	0.96 (0.91–1.00)
(1 − adjusted OR) × 100%	3%	4%	5%	16%	4%
p-value	0.015	0.004	0.062	<0.001	0.063

[a]Symptom which occurred in the year prior to interview.

[b]OR was obtained for each increased point in IDSHL by multivariate unconditional logistic regression analysis controlling sex, age, ethnic group, living area, education background and underlying disease.