Measuring disability in an urban slum community in India using the Washington Group questionnaire

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A B S T R A C T

Background  
The UN recommends that the ‘Washington Group questionnaire (WGQ) on functioning’ is used for data collection on disability. There are few studies on the WGQ from India.

Objective  
To evaluate the prevalence of disability in a community-health project, using this tool: to examine if the use of the WGQ identifies more people with disability than the tools used previously.

Method  
We performed a systematic sample survey using the WGQ in the community-health project covering a population of 50,000 residents. The questionnaire was administered to 2203 individuals.

Results  
The age and sex distribution of the sample studied matched the National Census data 2011. The study identified 41 individuals with a disability. The prevalence of disability in our sample was 1.86% (95% CI 1.3%–2.43%) compared to 2.21% in India-Census-2011. Receiver operating characteristic (ROC) curve showed that disability was more prevalent after the age of 44 years (p-value <0.0001 and AUC 0.806). The odds ratio of disability was 10.1 above this age compared with those below that age (95% CI: 5.1 to 20).

Conclusion  
Use of the WQG did not yield better data on disability prevalence than that identified by the Census. Another study, this one in Telangana, south India, by the London School of Hygiene & Tropical Medicine found that self-reporting identifies only a third of the cases of disability. More direct and leading questions are needed to empower the disabled in developing countries to identify barriers which prevent their full participation in society.

Introduction

Disability is an umbrella term covering impairments (of body function), activity limitations (difficulties in carrying out a task), and participation restrictions which curtail a person’s involvement in society.  

Üstün and colleagues characterize disability as the health experience that results from the interactions of a health conditions (diseases, disorders and injuries) with contextual factors (the physical, social and attitudinal environment). Impairment data by itself is not an adequate proxy for disability because it is aggravated by the attitudes of others and the physical environment.  

In the Indian context, neither the Central nor the State Governments have reliable data on people with disabilities.  

The WHO estimates that around 1 billion people live with disabilities - 15% of the world’s population.  

The Government of India’s ‘Planning Commission’ document, ‘Vision 2020’, estimates that 5% of the population is disabled. However, according to data from the Census of India (2011) the prevalence of disability in India is 2.1%. The prevalence was 2.13% in the 2001 Census.  

The Census in India is taken every 10 years. Local enumerators (often schoolteachers) are trained to administer the Census questionnaire in the local language. The head of the household or another knowledgeable person in the household provides the data.  

The question related to disability used in the 2011 Census is shown in Fig. 1. According to the World Bank, Census methods underestimate the incidence of disability internationally. They suggest that activity-based questions identify more people with disability. It is important to identify these people as they experience multiple disadvantages and forms of exclusion.  

Stigma associated with disability make families reluctant to acknowledge people with disability. This makes the work of counting people with disability difficult. Also ‘age-related activity limitation’ is often not acknowledged as disability. All these factors lead to an underreporting of disability.

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The prevalence of disability was 12.2% (95% CI 10.6–14.1) in a study of 4080 people in a district in Telangana, India. Authors from the London School of Hygiene and Tropical Medicine (LSHTM) reported that children with disabilities were less likely to go to school than children without disabilities (51% vs. 91%) and 6 times more likely to have to repeat a grade. Adults with disabilities were less likely to be working (44.4% vs. 80.1%) and they were more likely to have experienced a serious health condition in the previous 12 months. Adults with disabilities aged 18–49 were nearly 3 times more likely to be in the poorest quarter compared with adults without a disability. Awareness of and access to rehabilitation and assistive devices among people with disabilities was low. 7.7% were provided with an assistive device and only 12.4% received any form of rehabilitative service.10

In 2001 the United Nations' highlighted the need to make Census and survey measures of disability comparable internationally [8]. Following this the Washington Group (WG) on Disability Measurement developed the WG questionnaire (WGQ). The WGQ relies on self-reporting rather than clinical assessment. Respondents are not required to label themselves or others as disabled.11 Participation-restrictions due to problems with seeing, hearing, locomotion, mental function, self-care and communication (See Fig. 2) are sought.11 In 2016 the group on ‘Sustainable Development Goals’ (SDG), civil society actors and other experts suggested that WGQ should be the preferred method to count the world's population of the disabled.12

India has signed up to the SDGs. To achieve the SDG’s goal to ‘leave no one behind’ there is a need for accurate, reliable and comparable data from India on disability. The WGQ has not been evaluated widely in India.13 India does not use WGQ in its Census. The WGQ is not available, officially, in local languages.

We undertook this study to estimate the prevalence of disability using the WGQ in North India.

Fig. 1. Census of India 2011: Question on disability.

Fig. 2. Census questions on disability endorsed by the Washington group.
cities of many developing countries, Delhi attracts migrant workers from surrounding villages. They come and live in urban slum clusters around construction sites. Periodically the government moves the slum dwellers to the outskirts of the city. The relocation settlement at Sundar Nagar started 37 years ago. Most of the residents were from the surrounding states of Uttar Pradesh, Uttarakhand, Haryana, Rajasthan, Madhya Pradesh, Punjab and Bihar. The St Stephens Hospital Community Health Project has worked at this location for 35 years and caters to a population of about 56,000 local residents. The project of St Stephens Hospital has a well kept computerized management-information-system (MIS). Health workers collect health status related data of individuals from each household. Disability reported to the health worker is recorded but there is no training imparted to these workers to identify people with disability. The MIS data shows a disability prevalence of 1%.

The study area was selected as it provided several conveniences. On the one hand it provided a rich mix of people from different states in North India. On the other hand the rapport between the project workers and the community facilitated data collection. The project area was considered suitable to examine data from North India. The Telangana study provided data, for comparison, from a South India population.

### Sampling size calculation

The LSHTM study found self-reported activity-limitation was 3.8% (95% CI 2.9–4.9). Assuming a similar prevalence in our study, we calculated we would need to study a sample of 1734 for 90% precision at the 5% level of significance. This was rounded-off to 2000.

### Sampling method

The survey was conducted over 6 months between January 2017 and June 2017. To survey 2000 people in a population of 50,000, sys-
ask individuals about activity and function restrictions Parents provided data on children under 5.

**Inclusion/exclusion**

All individuals older than 6 months were included in the study and there were no exclusions. The community included people from different states, speaking different languages and dialects. The WGQ can be administered by health workers. A qualified medical doctor administered the questionnaire. The researcher was trained ask questions to identify activity restrictions without referring to disability, impairments, or medical conditions as prescribed by Daniel Mont administration of the questionnaire in countries where multiple languages are used.\(^{15}\)

**Statistical methods**

Data entered on to an Excel spreadsheet was analyzed using the Statistical Package for Social Sciences (SPSS) version 21.0. The prevalence was calculated for each decade of life. Prevalence is reported as percentages with the 95\% confidence intervals (CI). A p value of <0.05 was considered statistically significant.

Receiver operating characteristics (ROC) curve were used to find the age above which disability prevalence increased. The odds of disability and the area under the curve (AUC) with its and specificity and sensitivity are reported.

The hospital research ethics committee approved the study.

**Results**

All the selected households agreed to participate. Two thousand two hundred and three individuals were studied. One thousand one fifty one of them were males. The age ranged from 0.5 years to 80 years and the mean age was 28.14±17.62 years.

Table 1 shows the age and sex distribution of the study population compared with that in the community health project area. The sample surveyed was representative of the population of Sunder Nagari as a whole. Table 2 shows the distribution by age and sex in the study data against that in the national Census data. The age distribution is similar to the India population as a whole.

Fig. 3 shows the age distribution of disability. Disability is highest in the age group 71–80 (16.13\%). In the age group 11–20 years it was the lowest (0.17\%).

Table 3 tabulates individual types of disability against age. The pattern is similar – disability prevalence increased with age. Fig. 4 shows the overall prevalence of the different disabilities. Visual im-

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**Table 4**

**ROC findings for disability domains.**

<table>
<thead>
<tr>
<th>Disability Type</th>
<th>AUC(95% CI) (p-value)</th>
<th>Age Criterion</th>
<th>Odd of disability above Age criterion (95% CI)</th>
<th>Sensitivity</th>
<th>Specificity</th>
</tr>
</thead>
<tbody>
<tr>
<td>All Disability</td>
<td>0.806(0.789–0.823)</td>
<td>&gt;44</td>
<td>10.11 (CI 5.12 to 19.99)</td>
<td>70.73%</td>
<td>80.71%</td>
</tr>
<tr>
<td>Visual</td>
<td>0.854(0.839–0.869)</td>
<td>&gt;54</td>
<td>26.03 (CI 9.52–71.15)</td>
<td>77.27%</td>
<td>88.45%</td>
</tr>
<tr>
<td>Hearing</td>
<td>0.773(0.755–0.790)</td>
<td>&gt;51</td>
<td>11.88 (3.95–35.70)</td>
<td>64.29%</td>
<td>86.84%</td>
</tr>
<tr>
<td>Communicating</td>
<td>0.531(0.510–0.552)</td>
<td>&lt;=25</td>
<td>4.41 (1.21–92.06)</td>
<td>100%</td>
<td>46.89%</td>
</tr>
<tr>
<td>Remembering or concentrating</td>
<td>0.645(0.625–0.665)</td>
<td>&gt;20</td>
<td>4.87 (2.25–94.49)</td>
<td>100%</td>
<td>41.05%</td>
</tr>
<tr>
<td>Walking or climbing</td>
<td>0.882(0.868–0.896)</td>
<td>&gt;37</td>
<td>36.75 (4.80–281.56)</td>
<td>92.86%</td>
<td>73.87%</td>
</tr>
<tr>
<td>Washing all over or dressing</td>
<td>0.938(0.928–0.948)</td>
<td>&gt;44</td>
<td>51.87 (2.92–922.49)</td>
<td>100%</td>
<td>79.97%</td>
</tr>
</tbody>
</table>
painment was the most common disability. For ‘all disability’, age $>44$ provided the best discrimination (p-value <0.0001 and AUC 0.806). The odds ratio of disability was 10.1 above this age (95% CI 5.1 to 20). The ROC is shown in Fig. 5. We also looked at ROC for different types of disability Table 4).

Discussion

MIS data has recorded 1% prevalence of disability (CI 0.92%–1.08%). Using the WQG, we found the prevalence was 1.86% (95% CI 1.3%–2.43%). There was no significant difference in the rates between the sexes (men 2% and women 1.76%). Visual disability was the most common disability. The prevalence of disability was highest in the older age groups. We studied an area in which people from a number of North Indian states stayed. This could reflect disability patterns in a number of North Indian states but cannot be an accurate reflection of the prevalence of disability.

Our finding on the prevalence of disability is comparable to the Indian census data which has reported disability at 2.21%. These estimates are much lower than the WHO estimates which suggest that 15% of the world population are disabled. We had assumed that using the WQG, we would collect data on participation restrictions besides impairments and activity limitations and that our study would show up more disability than the Census data.

The findings suggest that respondents in the study described activity limitation caused by their physical impairments. People with disabilities appeared unaware of the barriers imposed by their surroundings and society which prevent their full participation.

Expectations of people in developing countries are limited by their lack of experience of better facilities available in more developed countries. For example non-availability of auditory cues for the visually impaired at pedestrian crossings lead them to accept that they cannot move without assistance. Daniel Mont has suggested that people often consider disability as stigma (often seen as divine punishment for past sins) and so they do not report disability if asked. Finally, although disability increases with age, older individuals may not report it as a problem because, for them, it’s an expected age-related change.

The WQG was developed to get internationally comparable data. Mont has described the difficulty in developing a questionnaire to elicit internationally comparable data. “For example, ‘dressing oneself’ can take on very different connotations in a society where one ordinarily slips into pants and a loose-fitting shirt compared to dressing in something as complicated as a sari…. ‘Bathing oneself’ is very different for someone who can turn on a spigot as opposed to needing to travel to a community water source” he has observed.

There are few studies using the WQG in India. Our study was from North India. A study done in Telangana in South India employing the WQG found self-reported activity-limited was 3.8% (CI 2.9–4.9). The Telangana study found the when clinical assessments were performed the prevalence of clinical impairments was 12.2% (CI 10.6–14.1). 41% of those with clinical impairments did not self-identify as having activity limitations. The Telangana group asked an additional question “Do you consider yourself [your child] to have a disability?” Only 30% of those who were identified to have a disability answered “yes”. This highlights the drawback of direct questioning approaches.

We found significantly more disability among the aged similar to the findings from Telangana. This is because of ageing related impairments. However age related impairments such as visual impairment due to cataract and age-related hearing disability are both prevented or treated. Community-level education about causes, prevention and treatment of these problems can reduce their prevalence.

This was not a multi-center study and this limits the generalisability of the prevalence data. However, both the Telangana study and our study point to difficulties in getting accurate prevalence data using the WQG.

Use of ROC

ROC curve was used to determine the age-threshold above which the odds of disability was higher. This is an innovative approach. Most studies like the Telangana study and the studies in Cameroon and Guatemala use an arbitrary cut off and examine disability above and below that age. The ROC helps to pinpoint the threshold. It identifies the optimal age for the screening of the population to achieve the best sensitivity and specificity. The sample size calculations were done bearing the incidence of ‘all disability’. Larger samples will be needed to study the ROC for individual domains of disability.

Internationally there is a momentum to use WQG in the Census. About 69 countries are using WQG for their Census. However, our study and the Tenangana study demonstrate that the WQG results in under-reporting of disability. More comprehensive methods to assess the prevalence of disability are needed.

Strengths of the study

In this study, we have used systematic random sampling techniques to survey disability in the population. Data collection was by a professional doctor in the door-to-door survey which we thought would be more reliable than data collected by less educated nonprofessional survey officers. ROC curve was used to determine the age-threshold above which the odds of disability was higher and this can provide information about the optimal age for screening.

Weaknesses of study

The single center nature of the study makes generalizability of the findings difficult. Another limitation of the study was that the sample size was calculated estimating the prevalence of ‘all disability’ and it was not adequate for examining individual domains of disability. A much bigger sample needs to be studied to look at the ROC for individual disabilities. Finally, the absence of official translations of the WQG in various Indian languages and dialects makes reproducibility difficult. These limitations must be taken into account when interpreting and extrapolating the findings of the study.

Areas for further research

There is no official translation of the WQG in Hindi or the other vernacular languages in India. A validated translation using back translation needs to be developed for the various languages and dialects.

More research is needed into how the WQG can be modified, to collect data on persons with participation-restriction.

Conclusions

The use of the WQG in this study did not identify a higher prevalence of disability that the 2011 Census of India questions. This find-
ing needs to be confirmed in larger studies. These findings need to be confirmed in larger studies.

Disclosures

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The authors have no conflicts of interest to declare.

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Uncited reference

3.

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