MEASURING DISABILITY IN AN URBAN SLUM COMMUNITY IN INDIA USING THE WASHINGTON GROUP QUESTIONNAIRE

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Abstract - The Washington Group questionnaire (WGQ) on functioning was developed for national censuses. It is recommended by the UN but there are few studies employing the WGQ in India. Objective: To estimate the prevalence of disability using this tool: to examine if it identifies disability better than the census. Method: We performed a systematic sample survey using the WGQ in the community health project area covering a population of 50,000 residents. 2203 individuals were administered the questionnaire. Results: The age and sex distribution of the sample studied matched the national census data 2011. 41 individuals with a disability were identified. 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 of prevalence at different ages showed that age >44 years provided the best discrimination in identifying disability. (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: The WGS did not elicit better data on disability prevalence than that acquired by the Census. Another study from India by London School of Hygiene & Tropical Medicine found that self-reporting identifies only a third of the cases of disability. More direct and leading questions may be needed to allow the disabled in developing countries to feel empowered to point to barriers which prevent their full participation in society.

Key Words - Activity limitation, participation restriction, International Classification of Functioning, Sustainable Development Goals.

I. INTRODUCTION

Disability is an umbrella term covering impairments (of body function or structure), activity limitations (difficulties in executing a task or action), and participation restrictions (which curtail a person's involvement in life situations) (1). According to Üstün and colleagues disability is the health experience resulting from the interactions between health conditions (diseases, disorders and injuries) and contextual factors (the physical, social and attitudinal environment) (2). The International Classification of Functioning, Disability and Health (ICF) recognizes the impact of the attitudinal and physical environment on persons with disability and they assert that impairment data by itself, is not an adequate proxy for disability (1).

The Disability Rights Promotion International (DRPI) observed in 2009 that neither the Central nor the State Governments in India have the proper statistics about how many people with disabilities live in the country (2). The WHO estimates that around 15% of the world's population - an estimated 1 billion people live with disabilities (1). However according to data from the census of India (2011) the prevalence of disability in India is 2.1 % (4). These figures are not very different from that of the 2001 census figure of 2.13%. The Government of India, Planning Commission, document, 'Vision 2020', estimates that 5% of the population is disabled (5).

The census in India is taken every 10 years. Local enumerator (often school teachers) are trained to administer the census questionnaire in the local language. The enumerator records the answer on the schedules from the head of the household or other knowledgeable persons in the household (6). The question related to disability used in the 2011 census is shown in Figure 1.

Census of India 2011

Q 9. Disability

9 a) Is this person mentally/physically disabled? Yes/No

Disability	Code
In seeing	1
Inhearing	2
In speech	3
In movement	4
Mental retardation	5
Mental illness	6
Any other	7

9 b) If 'Yes' give disability code in the box from the list below

Figure 1 Disability Question in Census 2011

A World Bank Report suggests that the methods used by the census tend to generate the lowest disability estimates worldwide and that activity-based questioning identifies more people with disability (7). It is important to identify these people as they are subjected to multiple disadvantages and forms of exclusion (8)

Identifying persons with disability is sometimes not easy because disability is a stigmatizing disorder in certain communities and consequently, it may not be

acknowledged by the family (9). Also, many senior citizens who have age-related activity limitation may not know that these fall within the classification of disability (9).

A study done by London School of Hygiene & Tropical Medicine (LSHTM) in Telangana, India, combining self-reported functional limitation with clinical evaluation, found that the overall prevalence of disability was 12.2% (95% CI 10.6-14.1). They found the prevalence increases strongly with age from 3.6% in children under 18, to 8.1% in adults 18 to 49 and 38.3% in adults older than 50 (10). They reported that children with disabilities are 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 are less likely to be working (44.4% vs 80.1%) and more likely to have experienced a serious health condition in the previous 12 months than adults without a disability. Adults with disabilities aged 18-49 are nearly 3 times more likely to be in the poorest quarter compared to adults without a disability. Awareness of and access to rehabilitation and assistive devices amongst people with disabilities was low with only 12.4% receiving any rehabilitation and 7.7% being provided with an assistive device (10).

Introductory phrase: The next questions ask about difficulties you may have doing certain activities because of a HEALTH PROBLEM.

1.Do you have difficulty seeing, even if wearing glasses? a. No - no difficulty b. Yes – some difficulty c. Yes – a lot of difficulty d. Cannot do at all

2.Do you have difficulty hearing, even if using a hearing aid? a. No- no difficulty b. Yes – some difficulty c. Yes – a lot of difficulty d. Cannot do at all

3. Do you have difficulty walking or climbing steps? a. No- no difficulty b. Yes – some difficulty c. Yes – a lot of difficulty d. Cannot do at all

4. Do you have difficulty remembering or concentrating? a. No – no difficulty b. Yes – some difficulty c. Yes – a lot of difficulty d. Cannot do at all

5. Do you have difficulty (with self-care such as) washing all over or dressing? a. No – no difficulty b. Yes – some difficulty c. Yes – a lot of difficulty d. Cannot do at all

6. Using your usual (customary) language, do you have difficulty communicating, for example understanding or being understood? a. No – no difficulty b. Yes – some difficulty c. Yes – a lot of difficulty d. Cannot do at all

Figure 2 Census Questions on Disability Endorsed by the Washington Group

The United Nations international seminar on the measurement of disability in New York on June 4, 2001, emphasized the need to improve international comparability of census and survey measures of disability [8]. The Washington Group (WG) on Disability Measurement was formed as an outcome and they developed the WG questionnaire (WGQ). The WGQ relies on self-reporting rather than clinical assessment. The questions are designed to overcome the usual drawback of disability-related questions by not necessitating respondents to label themselves or others as disabled (11) . It enquires about six functional domains mainly seeing, hearing, locomotion, mental function, self-care and communication (See Figure 2) to identify people with participation-restrictions in society (11). In 2016 the group on Sustainable Development Goals (SDG) civil society actors and other experts suggested that the 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. WGQ has not been evaluated widely in India (13). Also, India is not among countries using WGQ in its census and it is not available, officially, in local languages.
We undertook this study to estimate the prevalence of disability using the WGQ, to examine if the WGQ can better elicit data on disability in India. As this was a test situation we deployed a qualified medical professional to administer the questionnaire, to ensure enumeration was complete and accurate.

III. DETAILS EXPERIMENTAL

Study site and Population

The study was undertaken in the community health project area of St Stephens Hospital. The community health project is based in SundarNagari - an urban slum resettlement in Delhi. Like the capital cities of many developing countries, Delhi attracts migrant workers from surrounding villages. They come to live in urban slum clusters around construction sites. Periodically the government relocates the slum dwellers to an area in the outskirts of the city. The government instigated the relocation here and provided the families with 25 sq. ft plots of land on which they could build their houses (14). The relocation settlement at SundarNagari started 37 years ago. Most of the resident in this area had come to Delhi 35 to 40 years ago from the surrounding states of Uttar Pradesh, Uttaranchal, Haryana, Rajasthan and Madhya Pradesh and Punjab and Bihar. St Stephens Hospital has a community health project in this area running for nearly 35 years. The community project caters to a population of about 56,000 local residents. The project of St Stephens Hospital has a well maintained computerized management-

information-system (MIS) with a record of persons with disability. This MIS data shows disability prevalence of 1% in the area. This area was selected for study because it provided a rich mix of people from different states and the area and population was well mapped out within the community project's MIS

Samples Size Calculation

The LSHTM study found self-reported activity-limitation was 3.8 % (95% CI 2.9-4.9) [7]. 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 a period of 6 months between January 2017 and June 2017. To be able to survey 2000 persons in a population of approximately 50,000, we used systematic random sampling techniques and every 25th household was surveyed. The selected house was visited by the researcher accompanied by the local health worker from the Community Health Project. Repeat visits were performed if any house was found locked. It was planned to exclude households that did not consent to participate but collect data from the household next-door to the right instead. Every individual in the household was asked about restrictions of activity and functioning using the WGS. Data on children under the age of 5 was obtained from the parents of the child.

Inclusion/exclusion criteria

Individuals older than 6 months from the selected households were included. No one was excluded.

As this community was made up of people from different states speaking different languages and dialects, we used the WGQ procedure suggested for countries where multiple languages are used. The interviewer a medical doctor was trained to interpret the questions in a way that identifies difficulties in doing the activities without referring to disability, impairments, or medical conditions. The procedure is documented by Daniel Mont (15).

Statistical Methods

Data was entered on to an Excel spread sheet and analysis were done using the Statistical Package for Social Sciences (SPSS) version 21.0. Analysis of data on prevalence was performed in age clusters of 10 years. Mean values of continuous variables and standard deviation are reported. 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 was studied to examine the age above which specificity and sensitivity for a diagnosis of disability was best. The area under the curve (AUC) and specificity and sensitivity are reported. The odds of disability above and below that cut-off with its 95% CI was calculated. This was done collectively for all disability and then individually, for each of the 6 domains of disability.

The study was approved by the hospital research ethics committee.

RESULTS

None of the households selected, withheld consent to participate. A total of 2203 individuals of either sex were surveyed. 1151 were males and 1052 females. The age ranged from 0.5 years to 80 years and the mean age was 28.14 ± 17.62 years.

Table 1 shows age and sex distribution of the study population compared to that in the community health project area. It can be seen that the sample surveyed was representative of population of Sunder Nagari, as a whole.

Table 1Study population: Comparison with population in the community health project area

Age groups		Study Population			Community Data		
		Male	Female	Total	Male	Female	Total
0-10		163 (15.49%)	162 (14.1%)	325 (14.7%)	4226 (15.15 %)	4197 (14.74 %)	8423 (14.94 %)
11-20		287 (27.28%)	291 (25.3%)	578 (26.2%)	5593 (20.05 %)	5801 (20.38 %)	11394 (20.22 %)
21-30		240 (22.81%)	264 (22.9%)	504 (22.9%)	7866 (28.20%)	6718 (23.60 %)	14584 (25.88 %)
31-40		139 (13.21%)	173 (15.0%)	312 (14.2%)	4236 (15.19 %)	4822 (16.94 %)	9058 (16.07 %)
41-50		90 (8.55%)	90 (7.8%)	180 (8.27%)	2702 (9.68 %)	2969 (10.43 %)	5671 (10.06 %)
51-60		93 (8.84%)	96 (8.3%)	189 (8.6%)	1771 (6.35 %)	2159 (7.58%)	3930 (6.97 %)

61-70		28 (2.66%)	56 (4.9%)	84 (3.8%)	892 (3.20 %)	1127 (3.97 %)	2019 (3.58%)
71-80		12 (1.14%)	19 (1.6%)	31 (1.4%)	467 (1.67 %)	499 (1.75 %)	966 (1.71 %)
Total		**1151 (52.25%)**	**1052 (47.7%)**	**2203 (100.00%)**	**27885 (49.48 %)**	**28464 (50.52%)**	**56349 (100 %)**

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.

Age group	Males		Females		Total	
	Census	**Study sample**	**Census**	**Study sample**	**Census**	**Study sample**
0-9	19.3 %	15.49 %	18.5 %	14.07 %	17.1 %	14.75 %
10-59	73 %	80.69 %	73.1 %	79.39%	72.6 %	80 %
60 +	7.1 %	3.8 %	8 %	6.51%	8 %	5.21 %
Total	100 %	100 %	100 %	100 %	100 %	100 %

Table 2 Distribution of different age groups by sex in study population and in the Indian census 2011

Table 3Age and type of disability in the population

Age group	**Visual (%)**	**Hearing (%)**	**Locomotor (%)**	**Mental (%)**	**Self care (%)**	**Communicating (%)**	**Disabled (%)**	**Total (%)**
0-10	1 (0.31)	1 (0.31)	0 (0.00)	0 (0.00)	0 (0.00)	0 (0.00)	2 (0.62)	325 (100
11-20	1 (0.17)	0 (0.00)	0 (0.00)	0 (0.00)	0 (0.00)	0 (0.00)	1 (0.17)	578 (100)
21-30	1 (0.20)	3 (0.60)	1 (0.20)	2 (0.40)	0 (0.00)	2 (0.40)	6 (1.19)	504 (100)
31-40	1 (0.32)	1 (0.32)	1 (0.32)	0 (0.00)	0 (0.00)	0 (0.00)	3 (0.96)	312 (100)
41-50	1 (0.56)	0 (0.00)	3 (1.67)	0 (0.00)	1 (0.56)	0 (0.00)	3 (1.67)	180 (100)
51-60	5 (2.65)	2 (1.06)	3 (1.59)	0 (0.00)	2 (1.06)	0 (0.00)	8 (4.23)	189 (100)
61-70	8 (9.52)	5 (5.95)	3 (3.57)	0 (0.00)	0 (0.00)	0 (0.00)	13 (15.48)	84 (100)
71-80	4 (12.90)	2 (6.45)	3 (9.68)	1 (3.23)	3 (9.68)	0 (0.00)	5 (16.13)	31 (100)
Total	22 (1.00)	14 (0.64)	14 (0.64)	3 (0.14)	6 (0.27)	2 (0.09)	41 (1.86)	2203 (100)
P value	<.0001	<.0001	<.0001	0.0004	<.0001	0.456	<.0001	

Figure 3 Prevalence of disability in different age groups with confidence intervals depicted as box with whiskers representing means and confidence intervals.

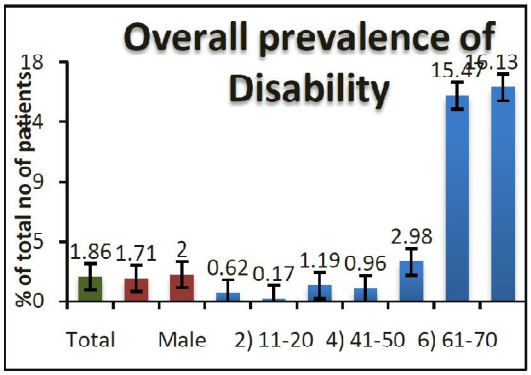

Figure 3 shows age distribution of disability. Disability is highest in the age group 71-80 (16.13 %) In the age group 11-20 yr it was the lowest (0.17 %). Table 3 tabulates individual types of disability against age. The pattern is similar with increase in disability with age Figure 4 shows the overall prevalence of the different disabilities. Visual impairment was the most common and was responsible for more than half of all disabilities.

We looked at ROC for individual domains also. The results are shown in Table 4.

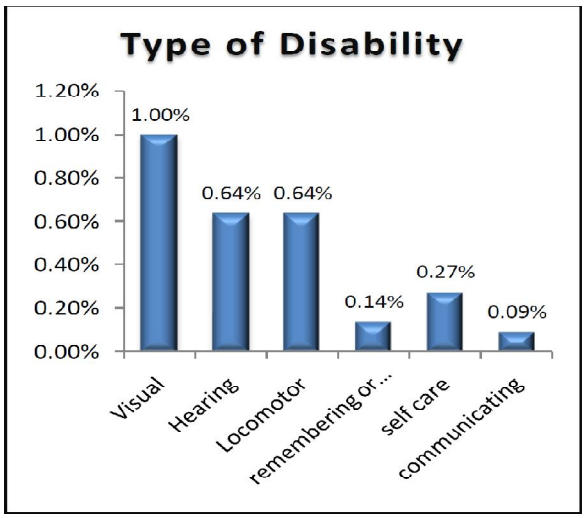

Figure 4 Prevalence of different types of disability in the population

Disability Type		AUC (95% CI) (p-value)	Age Criterion	Odd of disability above Age criterion(95% CI)	Sensitivity	Specificity
All Disability		0.806 (0.789-0.823)(p <0.0001)	>44	10.11 (5.12 to 19.99)	70.73%	80.71%
Visual		0.854(0.839-0.869)(p-<0.0001)	>54	26.03 (9.52-71.15)	77.27%	88.45%
Hearing		0.773(0.755-0.790)(p- =0.0004)	>51	11.88 (3.95-35.70)	64.29%	86.84%
Communicating		0.531(0.510-0.552) (p- =0.523)	<=25	4.41 (.21-92.06)	100%	46.89%
Remembering or concentrating		0.645(0.625-0.665) (p- =0.416)	>20	4.87 (.25-94.49)	100%	41.05%
Walking or climbing		0.882(0.868-0.896 (p-value =0.036)	>37	36.75 (4.80-281.56)	92.86%	73.87%
Washing all over or dressing		0.938(0.928-0.948)(p-value <.0001)	>44	51.87(2.92-922.49)	100%	79.97%

Table 4 ROC Findings for disability domains

We looked at the ROC curve for all disability, to assess the age at which prevalence increases – the age at which disability can be picked up with highest sensitivity and specificity. 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 Figure 5

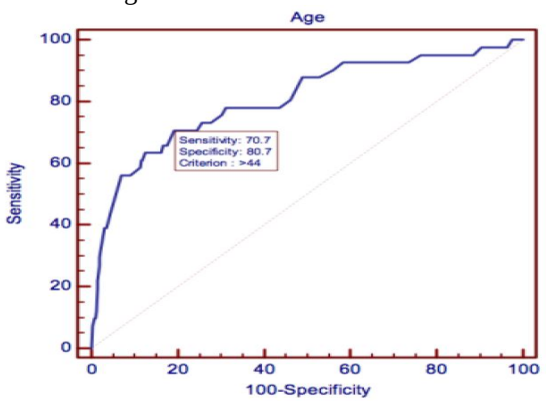

Figure 5 ROC for disability against age

DISCUSSION

The prevalence of disability in the MIS data at the community health project stands at 1 % (CI 0.92% to 1.08%). We found using the WGQ, the prevalence of reported disability in our sample 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.

This area was considered ideal to test the WGQ because it comprised of people from a number of North Indian states. The population is not representative of the population of India nor even of North India, and so the disability prevalence data from here cannot be extrapolate to other areas and income groups. We anticipate however, that difficulties we encounter here with the use of the WGQ would be replicated in other states of North India.

Our finding on prevalence of disability is comparable to the Indian census data which has reported disability at 2.21 % (4). These estimates are much lower than the WHO estimates which suggest that 15% of the world population is disabled (1). We had assumed that using the WGQ, we would tap data on participation restrictions besides impairments and activity limitations and that our study would show up more disability than the census data.

The findings seem to suggest that the population in the area we studied do not feel empowered to bring up complaints regarding participation restriction, other than those directly related to their activity limitation caused by their physical impairments. This suggests to us that the open-ended questions of the WSQ are not adequate in these circumstances and more direct and leading questions may be needed, to allow the disabled to feel empowered to point to impediments caused by their surroundings and society, which prevent their full participation.

Furthermore, the expectations of persons in developing countries are limited by their own lack of experience of better facilities for the disabled. Thus, as the majority of the population have not come across auditory cues for the blind at pedestrian crossings, it would not occur to them to consider its absence as an impediment to their participation in societal activities.

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 (9).

One of the motivations for developing the WGQ was to get internationally comparable data. Mont has observed that the choice of activities used for identifying people as having a disability is complicated if the desire is to have a measure that is internationally comparable. "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 (9).

There are few studies using the WGQ in India. Our study was from North India. A study done in Telangana in South India employing the WGQ (10) found self-reported activity-limitation was 3.8 % (CI 2.9-4.9). However, they found the overall prevalence of clinical impairments was 12.2 % (CI 10.6-14.1) when they used clinical assessments. They report that 41% of those considered to have a disability in the study did not self-identify as having significant activity limitations (10). To another question (not a part of the WGQ), "Do you consider yourself [your child] to have a disability?" only 30% of those who were identified to have a disability answered "yes", highlighting the drawback of direct questioning approaches.

We found significantly more disability among the aged and it is similar to the findings from Telangana (10). This is because new cases of disability, that are not treatable, keep getting added and accumulate till they die, often of unrelated causes. On the other hand the Telangana study reports that physical impairment due to cause such as trauma, visual impairment due to cataract and age-related hearing disability can be preventable and are treatable. These disabilities can be avoided if there is community-level education about causes, prevention and treatment of these problems (10).

The WSQ is said to help collection of uniform and comparable data but the critique by Mond [6] suggests that local cultural influences and parochial

connotations of the words used in the questionnaire, may vitiate this effort.

Given that our study was done in a specific area in the capital city, and it was not a multi-centre study, the prevalence figures from here need not be generalizable for the rest of the country. However, the learnings from the study with regard the usefulness of the WGQ are likely to be generalizable, given the similarity with the findings from the Telangana study.

Use of ROC

We used ROC curve to find the age above which the odds of the prevalence of disability was higher. This was an innovation we used in this study. Most studies like the Telangana study and the studies in Cameroon and Guatemala (10, 16, 17) use an arbitrary cut off, whereas the method we employed is better able to discern the age above which the prevalence is higher.The prevalence ROC curve can provide information on the optimal age for the screening of the population (for the specific disability) looking for the best sensitivity and specificity.

We have also looked at the ROC in the context of each of the domains of disability. A major limitation of that analysis is the fact that sample size calculations done a-priori, was estimated bearing the incidence of 'all-disability' and not for individual disabilities. Thus while it can be used as a proof of concept, larger samples will need to be studied to understand the ROC of individual disability.

There is an effort to use WGQ in the census (11). About 69 countries are using WGQ for their census. Our study and that of others who used self-reporting of disability have found that there is considerable under-reporting of disability compared to other more comprehensive methods to assess the prevalence of disability.

Strengths of the study

In this study, we have used a structured survey methodology to evaluate 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 non-professional survey officers.

In our study, we have used ROC to look at the age above which disability is reported with the highest specificity and sensitivity.

Weaknesses of study

The single centre nature of the study makes generalizability of the findings difficult. The population studied were mostly from North India and it may not mirror the findings in South India. Another limitation of the study was that the sample size was calculated estimating prevalence of 'all disability' and it was not adequate for each individual 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 WGQ in various Indian languages and dialects makes for difficulties in reproducibility which may not have been completely overcome by our methods. 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 WGQ 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 WGQ can be modified with perhaps including more leading questions to improve the pick-up of persons with participation-restriction.

CONCLUSIONS

In summary, we found that the self-reporting tool (WGQ) did not greatly increase the pick-up of disability in the community and it does not seem to bring out the problems in participation of persons with disability. These findings need to be conformed in larger studies.

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