

Prevalence of self-reported disability, activity limitation and social participation in Sri Lanka

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Abstract

Introduction The World Health Organization estimates that 15% of the global population has a disability. Available evidence from Sri Lanka shows variable estimates of the magnitude of disability.

Objectives Determine the prevalence of self-reported disability in the adult population aged ≥ 18 years, and associated risk factors in a nationally representative sample in Sri Lanka.

Methods The Washington Group short questionnaire was used to identify persons with self-reported disability. Data were collected from responsible adults aged ≥ 18 years in the selected households. A four point-scale: "no difficulty", "some difficulty", "a lot of difficulty" and "cannot do at all" was used. Individuals screening positive for disability were administered an additional questionnaire on activity limitations, social participation and their health and financial concerns.

Results Overall 41.5% (4131) [95% CI: 40.5-42.4] reported functional difficulty in at least one domain. The prevalence of disability, i.e. a lot of difficulty or cannot do at all was 3.8% (382) [95% CI: 3.5-4.2], while the prevalence of "some functional difficulty" was 37.6% (3749) [95% CI: 36.7-38.6].

The prevalence of disability increased with age and was higher among females, urban residents, and those with lower education and socio-economic status. Minor degrees of functional difficulties were more common among older people, females and people with lower education.

Conclusions The prevalence of disability and varying degrees of functional difficulty is high among the adult

population of Sri Lanka. Evidence shows that a strategic plan is required to address the magnitude of disability and functional limitations in Sri Lanka.

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Introduction

Current concepts of disability recognize the barriers 'created' by society in addition to the effects of an impairment or disease on an individual's activities and participation [1]. The preamble to the United Nations Convention on the Rights of Persons with Disability (UNCRPD) defines disability as an evolving concept and results from the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others [2].

This prompted the search for a valid universally acceptable definition which should be able to capture experiences across different types and grades of severity, across many areas of functioning, have flexibility to allow different uses including clinical or public health measurement and recognize the impact of the environment on persons with disability (PWD) [3]. The International Classification of Functioning, Disability and Health (ICF) provides a framework to measure these aspects and defines disability as "an umbrella term for impairments, activity limitations or participation restrictions which result

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from an interaction between a person with a health condition and environmental factors (e.g. the physical environment, attitudes) and personal factors (e.g. age or gender”) (Figure 1) [4].

Data on prevalence of disability is very important for planning programmes for persons with disability at local and national levels but available data shows wide variation with self-reporting during censuses showing figures of 1-2% while the World Report on Disability reports a global prevalence of 15% [2]. This report also drew attention to the need for robust evidence to facilitate well-informed decisions for policy and programmes targeting people with disabilities (PWD) [5]. The Report categorically stated that impairment data are not an adequate proxy for disability and measures should be developed to obtain more comprehensive information on disability [2].

In the quest for an appropriate measurement tool for disability, a number of instruments have been developed. These include the 34-Item Disability Screening Questionnaire (DSQ-34) [6], the WHO Model Disability Survey (MDS) [7], the Iganga and Mayuge Demographic Surveillance System (IM-DSS) [8], the WHO Disability Assessment Schedule 2.0 (WHODAS 2.0) [9], the Rapid Assessment of Disability (RAD) tool [10] and the Key informant method using participatory rural appraisal [11].

The United Nations (UN) Statistical Division constituted a voluntary working group called the Washington Group (WG), representing different stakeholders including international statistical experts and international and national disability organizations to draft a universally acceptable definition of disability and methods to measure it [12]. The ICF provided the framework for developing these measures. This resulted in the development of a short set of six disability-related questions for six functional domains – seeing, hearing, walking, cognition, self-care and communication, suitable for use in national censuses and surveys which identifies a majority in the population experiencing limited or restricted participation in society [12]. The WG questionnaire translated disability concepts into measurement tools using a mixed-methods approach [13]. The WG questionnaire addresses the challenge of a disability definition and measurement in a culturally neutral and reasonably standardized manner [14]. Many countries have used the instrument both as a short or an extended set [15-19].

Available evidence from Sri Lanka shows variable estimates of the magnitude of disability. The Census 2001 estimated that 1.6% of the nation’s population had a disability [20]. Data were also generated using a functionality definition in the World Health Survey, which included Sri Lanka over the period 2002-2004, and included the population aged ≥ 18 years [21]. This survey reported 12.9% of adults had disability in Sri Lanka [2]. Recently

the United Nations Economic and Social Commission for Asia and the Pacific (UN-ESCAP) conducted a Disability Survey using a functional definition of disability and estimated that the prevalence of disability among all-ages in Sri Lanka was 8.7% [22].

The literature suggests that disability is closely associated with poverty [23-25], and PWD have major barriers in accessing health services [26-28]. Therefore, information on the magnitude and socio-economic profile of persons with disability is of critical importance to plan and implement inclusive health and social services that benefit PWD, including those with visual impairment.

The National Blindness, Visual Impairment and Disability Survey was conducted in 2013-2014 in Sri Lanka. This paper presents the data on the prevalence of disability and varying degrees of functional difficulty in the adult population aged ≥ 18 years.

Methods

The overall aim of the survey was to determine the magnitude and causes of blindness and visual impairment. As part of this survey, information was gathered to estimate the prevalence and causes of disabilities in adults aged ≥ 18 years, living in enumerated households.

The blindness survey recruited a nationally representative sample of adults aged ≥ 40 years; to estimate the prevalence of disability those aged ≥ 18 years were included. All the nine provinces and 25 districts of Sri Lanka were included.

Based on an estimated prevalence of 25% for disability and functional difficulty based on the WG criteria of “some difficulty” in one or more of the six domains, 95% confidence intervals (CI), a response rate of 80% and a design effect of 2, the sample size required was approximately 2500. It was anticipated that the sample size for blindness (6800 people aged ≥ 40 years) would generate 2500 persons aged ≥ 18 years from the enumerated households.

The study protocol was reviewed and approved by the Institutional Ethics Committees of the London School of Hygiene and Tropical Medicine, London, UK, the Faculty of Medicine, University of Colombo, Sri Lanka and the Indian Institute of Public Health, Hyderabad, India. Written informed consent was obtained from all participants at the time of enumeration and re-verified at the clinical examination site.

The WG short set (WGSS) was used to identify self-reported disability. All adults aged ≥ 18 years in the selected households were eligible to be administered the WGSS. The WGSS was administered by trained investigators. These investigators were trained for one week on the administration of the questionnaire schedule and were

also monitored while they administered the questionnaire schedules during the pilot study and during monitoring visits. The questionnaire schedules were translated into Sinhala and Tamil and were independently back translated into English to ensure accuracy of the translated versions. The questionnaire schedules were administered in the vernacular (Sinhala/ Tamil).

The short set of 6 questions was used to assess whether the respondent had difficulty in seeing, hearing, walking/climbing steps, remembering/concentrating, washing/dressing or communicating with answers given on a four point-scale: “no difficulty”, “some difficulty”, “a lot of difficulty” and “cannot do at all”. The severity of self-reported functional difficulty/ disability was categorised based on the following responses: Some degree of functional difficulty: self-reporting of “some difficulty” in one or more domains. Disability: self-reporting of “a lot of difficulty” or the inability to undertake the activity in one or more domains.

Individuals who screened positive for disability or reported some degree of functional difficulty were then administered an additional questionnaire to elicit responses on activity limitations, social participation and the health and financial concerns.

A companion paper in this issue details the methodology used in the survey.

Data analysis

The data were analysed using STATA 13.0 (StataCorp LP, Texas, USA). Descriptive analyses and cross tabulations with calculation of Pearson chi squared tests were performed. Firstly, univariate analysis was done, to assess associations between socio-demographic factors and the risk of self-reporting functional difficulty or disability. The socio-demographic variables included age, sex, socio-economic status (SES), literacy status, place of residence, province of residence and ethnic group. Further analyses were undertaken using logistic regression. All tests are two sided, and the odds ratios (OR) and 95% CI quoted are derived from logistic regression models.

Results

A total of 12,549 individuals were enumerated of whom 9965 (79.4%) were available at home and responded to the WG short set. Some degree of functional difficulty in one or more domains was reported by 37.6% (3749) [95% CI: 36.7-38.6] while 3.8% (382) [95% CI: 3.5-4.2] reported disability. Difficulty in seeing was the most frequently reported functional difficulty (33.3%) and the second commonest disability (1.6%). Difficulty in walking/

climbing stairs (1.7%) was most frequently reported among those with disability and the second commonest for functional difficulty (12.5%).

Overall 41.5% (4131) [95% CI: 40.5-42.4] reported some degree of functional difficulty (Table 1). For analysis, age was categorised as <50 years and ≥50 years. The four quartiles of SES based on family assets was further categorised as ‘lower’ SES (lowest two quartiles of the SES scale) and ‘higher’ (top two quartiles of the SES Scale). Significant differences by age group, sex, place of residence, socio economic status and literacy status were observed both for functional difficulty and disability. The prevalence of disability increased with age and was higher among females, urban residents, and those from lower SES and poorer literacy (Table 1).

After adjusting for socio-demographic factors the following variables were significantly associated with disability: age, sex, place of residence, level of education and SES. Females were 40% more likely to report functional difficulty and 80% more likely to report disability compared to males. Those educated to secondary level and lower had 1.4 times higher risk of functional difficulty and 2.2 times higher risk of disabilities compared to those educated above secondary school level. Those residing in urban areas were two times more likely to report disability compared to people in rural areas; and those in lower socio-economic groups were 1.4 times more likely to report disability compared to their wealthier counterparts (Table 2).

Respondents reporting disability or functional difficulty were administered additional questions on social participation, barriers to performing regular activities and concerns about health issues. Respondents reporting disability experienced more barriers than those with some degree of functional difficulty (Table 3). One in five respondents with disability stated facing some or a lot of problems with social participation (74/361), while 10.8% (39/361) reported an effect of negative attitudes and actions from society (Table 3). 10.5% of those with disability also perceived that their disability had an adverse effect on the family finances (Table 3).

Visual acuity (VA) was measured for those aged ≥40 years (n=5739) and the level of agreement between objectively measured visual impairment (VI) and self-reported “difficulty in seeing even with glasses” was assessed. Among the 1,869 with any VI, 1277 (68.3%) reported difficulty in seeing; when only those with severe VI or blindness were compared, the proportion increased to 84.1% (169/201). Among the 3,870 survey participants who were not visually impaired (distant vision) only 1684 (43.5%) reported no problems in seeing (Table 4).

Table 1. Prevalence of self-reported disability among adults aged ≥18 years

Parameter	Some difficulty in performing activity (functional difficulty)			A lot of difficulty or cannot perform activity (Disability)	
	N	N	%	N	%
Adults aged 18+ years	9965	3749	37.6%	382	3.8%
Age group					
< 50 years	5342	954	17.9	80	1.5
≥50 years	4623	2795	60.5	302	6.5
		X ² -1900; p<0.001		X ² -170.4; p<0.001	
Gender					
Male	4651	1439	30.9%	142	3.1%
Female	5314	2310	43.5%	240	4.5%
		X ² -165.5; p<0.001		X ² -14.4; p<0.001	
Residence					
Urban	1176	492	41.8%	84	7.1%
Rural	8789	3257	37.1%	298	3.4%
		X ² -10.1; p=0.001		X ² -39.6; p<0.001	
Socio economic status					
Lower SES	5389	2145	39.8	263	4.9%
Higher SES	4576	1604	35.0	119	2.6%
		X ² -34.9; p<0.001		X ² -23.8; p<0.001	
Literacy Status					
Secondary school and lower	2109	1176	55.8	184	8.7
Beyond secondary school	7856	2573	32.7	198	2.5
		X ² -375.1; p<0.001		X ² -173.6; p< 0.001	

Table 2. Association of disability and functional difficulty with socio-demographic parameters (adjusted analysis)

Parameters	N	Some degree of functional difficulty			Disability		
		N (%)	Adj. OR	95% CI	N (%)	Adj. OR	95% CI
Age group							
< 50 years	5342	954 (17.9)	Ref		80 (1.5)	Ref	
≥50 years	4623	2795 (60.5)	6.6	5.9 - 7.3	302 (6.5)	3.2	2.5-4.1
Sex							
Male	4651	1439 (30.9)	Ref		142 (3.1)	Ref	
Female	5314	2310 (43.5)	1.8	1.7 - 2.0	240 (4.5)	1.4	1.1 - 1.7
Residence							
Rural	8789	3257 (37.1)	Ref		298 (3.4)	Ref	
Urban	1176	492 (41.8)	1.2	1.0-1.4	84 (7.1)	2.1	1.6-2.7
Socio economic status							
Higher SES	4576	1604 (35.0)	Ref		119 (2.6)	Ref	
Lower SES	5389	2145 (39.8)	1.03	0.9-1.1	263 (4.9)	1.4	1.2 - 1.8
Literacy status							
Beyond secondary	7856	2573 (32.7)	Ref		198 (2.5)	Ref	
≥Secondary	2109	1176 (55.8)	1.4	1.3-1.6	184 (8.7)	2.2	1.7 - 2.7

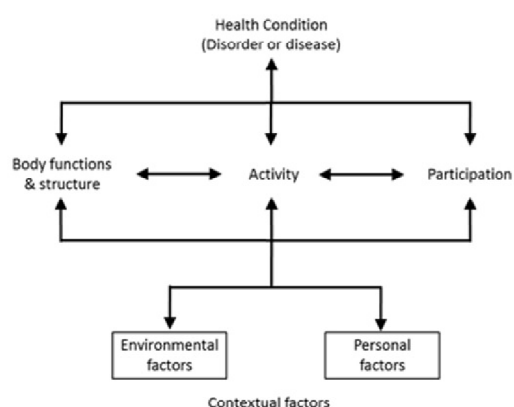
SES = socio-economic status

Table 3. Reported difficulty in social participation, activities and health concerns, by level of functional difficulty and disability

Difficulty in past 30 days	Some degree of functional difficulty (N = 3649)				Respondents reporting disability (N = 361)			
	Some difficulty		Lot of difficulty		Some difficulty		Lot of difficulty	
	N	%	N	%	N	%	N	%
Social participation & activities								
Joining in community activities	41	1.1	2	0.05	48	13.3	26	7.2
Living with dignity because of attitudes /actions of others in society	20	0.5	0	0	36	10.0	3	0.8
Living with dignity because of barriers or hindrance in the world around	20	0.5	1	0.03	21	5.8	3	0.8
Doing things yourself for relaxation or pleasure	18	0.5	0	0	29	8.0	3	0.8
Health concerns								
Spending time on a health condition or its consequence	20	0.5	0	0	21	5.8	4	1.1
Emotionally affected by health condition	20	0.5	0	0	20	5.6	2	0.6
Health being a drain on financial resources of the family	21	0.6	1	0.03	30	8.3	8	2.2
How much of a problem did you have due to a health condition	19	0.5	0	0	29	8.0	3	0.8

Table 4. Comparison of visual impairment based on visual acuity measurement and self-reported difficulty in vision among those aged ≥ 40 years

Visual acuity category	No difficulty in seeing (2276)		Some degree of difficulty in seeing (3463)		Total N=5739	
	N	%	N	%	N	%
No visual impairment	1684	43.5	2186	56.5	3870	100%
Mild visual impairment	278	35.5	504	64.5	782	100%
Moderate visual impairment	282	31.8	604	68.2	886	100%
Severe visual impairment or blind	33	16.4	169	84.1	201	100%

**Figure 1. Contextual framework of International Classification of Functioning, Disability and Health.**

Discussion

A recent review of the published literature on disability in Sri Lanka found significant gaps in disability research [13]. The review highlighted the fact that all major recommendations in the World Report on Disability were pertinent to Sri Lanka and it was suggested that a National Survey on disability was desirable [13]. The review explored the capability of an instrument to measure the prevalence of disability and concluded that none of the existing instruments measured population based prevalence accurately. This evidence prompted the use of the short set of WG questions with additional items related to activity limitation and social participation in the present survey.

The study found that 3.8% of the population aged ≥ 18 years in Sri Lanka reported disability. The World Report on Disability gives a prevalence of 12.9% based on the

World Health Survey (WHS) data [2]. The WHS looked at 16 domains. The present study highlights the difference in prevalence data depending on the survey methodology used and the difficulties in planning programs. Difficulty in mobility was the commonest disability followed by difficulty in vision. "Difficulty seeing" was the commonest domain leading to some degree of functional difficulty. An earlier study in Sri Lanka assessed physical disability among a comparable adult age group and reported a prevalence of 4.2% (95% CI: 3.5-5.1) [30]. Another study from southern India reported a prevalence of 4.7% for mobility-related disability and 2.1% for vision-related severe grades of disability [31]. It is very difficult to strictly compare the estimates from these studies because different assessment methods were used. One of the reasons why vision-related disability may have been reported by a large number of participants in the present study is because respondents were aware that this was primarily an eye survey and so some may have emphasised their eye problems, possibly that was why about 56% of persons 40 years and older with no visual impairment reported visual difficulty. However, a disability survey in Uganda also reported vision as the commonest reported disability [9].

In the present study, we were able to validate the findings of the eye examination against the WG question related to vision in those aged ≥ 40 years showing that 84.1% of those with severe visual impairment or blindness reported some degree of problem with vision. Similar findings were observed in Cameroon and India earlier [32]. In this study however the tool identified a large number of 'false positives' as over 56% of those for whom no visual impairment was diagnosed based on visual acuity measurement reported some problems with seeing. As this comparison was undertaken on those aged ≥ 40 years it is possible that a large number had reported problems in near vision. As the WG short set does not differentiate between distance and near vision, it is difficult to comment on this finding.

Our findings on socio-demographic associations of disability are similar to those reported from other disability prevalence studies conducted in low and middle income countries (LMIC). An increase in the prevalence of disability with increasing age [16,19,31,32] has been reported from a large number of studies, including those undertaken in LMIC. This is because many impairments causing disability are age-related, such as visual or hearing impairment or restriction of mobility. In LMICs, females and those with lower levels of literacy are also more likely to report disability [15,18,19,31,32]. This could be attributed to the poorer access to health care experienced by women in LMICs, particularly in South Asia. In Sri Lanka, since women have a significantly higher life expectancy compared to males, they constitute a greater proportion of the aged who are at a higher risk of functional disability.

The measurement of disability helps to identify the magnitude of disability and the number of people needing services for their disability and the characteristics and location of marginalized population groups. This helps in planning need-based policies, and to target specific interventions to redress gaps in relation to health and social inclusion of PWD. From a health perspective, many studies have shown a strong association between poorer health status and access to health services amongst PWD [24,26,28,34-37]. PWD have been reported to have significantly higher rates of chronic disease such as diabetes and depression compared to those without disability [28], and disabled women are more disadvantaged than men [28]. Ensuring inclusive health [38] is therefore, critical to improving the health of PWD and achieving universal health coverage [39].

From a social development perspective, it is now widely recognized that there is a strong association between disability and poverty [25] and that the inclusion of PWD is critical to achieving sustainable development goals [40]. It is therefore essential that disability statistics are effectively used to develop a two-pronged strategy that targets the specific public health concerns of PWD and sustainable development initiatives that promote equal participation of PWD in society. The evidence from the present study could help in establishing the baseline for Sri Lanka to monitor progress towards the sustainable development goals and the WG short set can be used in the 2021 census to explore temporal trends in disability.

Study limitations: the less than 80% response rate of the enumerated persons most of whom were absent, may have overestimated the prevalence of functionally difficulty and disability, as persons with disability may be likely to stay back at home for the survey

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Conflicts of Interest

All authors declare that they do not have any conflicts of interest.

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