

Prevalence of disability and its association with sociodemographic factors and quality of life in India: A systematic review

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ABSTRACT

Disability is complex, dynamic in nature, multidimensional, and most contested. Quality of life is an abstract concept that is related to the level of disability in the population. Approaches to measuring disability vary across different regions, and purpose and application of the findings. We systematically reviewed the studies that have been undertaken to study the prevalence of disability and its association with sociodemographic factors and quality of life among the general population in India, between January 2000 and June 2018. The prevalence of impairment ranged from 1.6% to 43.3%. In major surveys, males had higher impairment than females. Studies that used the International Classification of Functioning, Disability and Health concept for measuring disability reported prevalence ranging from 70.0% to 93.2%. Most studies used semi-structured questionnaires for measurement of disability. Some studies have used Barthel Index for Activity of Daily Living, Instrumental Activities of Daily Living, Indian Disability Evaluation and Assessment Schedule, Rapid Assessment of Disability scale, and Standard Health Assessment Questionnaire. The quality of life was low among females. This review brings out the heterogeneity in the concepts for measuring disability and quality of life. Lack of standardization in the measurement of disability restrains any comparison between these studies.

Keywords: Disability, disability in India, prevalence of disability, quality of life

Introduction

Worldwide, rates of disability are increasing due to population aging and increases in chronic health conditions, among other causes.^[1,2] Health is defined as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.”^[3] Though this broad definition of health was framed half a century ago, health is still measured narrowly in terms of morbidity and mortality. To overcome this, the World Health Organization (WHO) developed a framework for measuring health and disability

at both individual and population levels called International Classification of Functioning, Disability and Health (ICF).^[4] In the Fifty-Fourth World Health Assembly, the ICF was officially endorsed by all 191 WHO Member States as the international standard to describe and measure health and disability.^[5]

In September 2015, the United Nations General Assembly adopted 17 Sustainable Development Goals (SDGs) on the principle of “leaving no one behind.”^[6] Disability was referenced in five goals related to education, growth and employment, inequality, accessibility of human settlements, as well as data collection and monitoring of SDGs.

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ICF defines disability as an umbrella term for impairments, activity limitations, and participation restrictions, referring to the negative aspects of the interaction between an individual (with a health condition) and that individual's contextual factors (environmental and personal factors).^[7] In India, Census 2001 and 2011 measured disability using the medical model of disability.^[8,9] Even though ICF was ratified by India in 2001, its usage is not wide spread. Various scales and questionnaires are used in surveys and studies which measure different aspects of disability. Due to these variations in measurements, comparison of these studies is difficult.

Quality of life is a broad multidimensional concept that usually includes subjective evaluations of both positive and negative aspects of life. WHO defines quality of life as an individual's perception of their position in life in context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns.^[10] The concept of health-related quality of life and its determinants has evolved since the 1980s to encompass those aspects of overall quality of life that can be clearly shown to affect health.^[11] These wide-ranging concepts are influenced by physical health, psychological state, levels of independence, social relationships and environmental factors. Disability *per se* will not decrease the disabled individual's quality of life.^[12]

Due to these wide-ranging concepts of disability and quality of life, their measurement was always contested and nonuniform. The aim of this study was to systematically review the available literature on the prevalence of disability and its association with sociodemographic factors and quality of life among the general population in India.

Methods

Electronic databases such as PubMed, Embase, Web of Science, and Government of India websites were searched to retrieve studies published during the period of January 2000–June 2018.

The following keywords were selected from MeSH heading and terms and texts (titles and abstracts): disabled persons, persons with disabilities, people with disabilities, physically challenged, physically disabled, physically handicapped, persons with hearing impairments, visually impaired persons, mentally disabled persons, quality of life, and health related quality of life.

Scrutiny of abstracts led to a selection of studies dealing with prevalence of disability and quality of life. These two categories of studies were analyzed considering the scales and components of disability that have been used to measure disability and its association with sociodemographic factors and quality of life. Age group and place of study were also analyzed.

Results

For a period of 19 years covered by literature research, 564 studies were retrieved [Figure 1]. After removal of duplicates and screening of the title and abstract, 32 full-text studies were

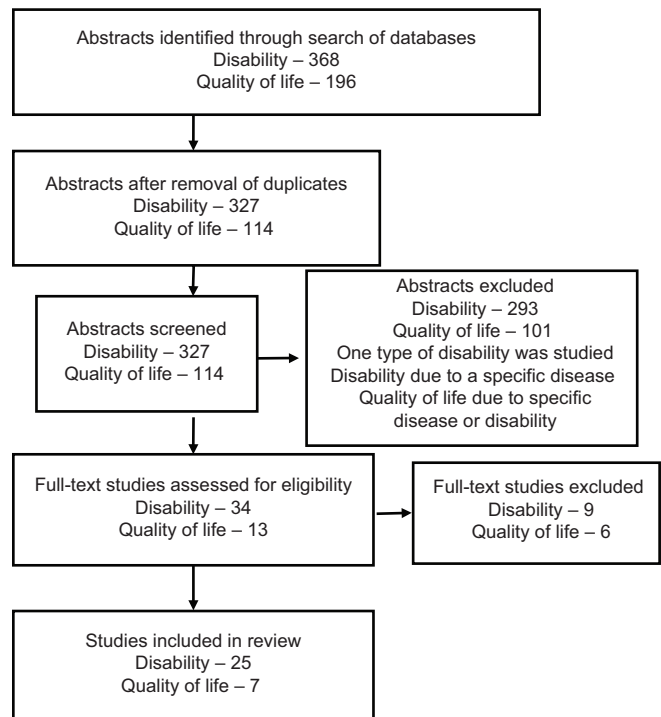


Figure 1: Flow of studies in the systematic review

used for review. The studies have been classified with respect to the components of disability, and finally with quality of life.

Impairment component of disability

Impairment component of disability was used in five studies and three surveys [Table 1]. In Census 2001 and 2011, a single question of self-reported impairment was used.^[8,9] The question was “Is this person mentally/physically disabled?” If the response was “Yes,” then type of disability was coded. In Census 2001, information on five types of impairment and in Census 2011 eight types of impairment data were collected. The National Sample Survey Organisation (NSSO) in its 58th round in 2001 included a survey on disability.^[19] In this survey, disability was defined as “a person with restrictions or lack of abilities to perform an activity in the manner or within the range considered normal for a human being.” Five types of impairments were assessed. This survey had included 4,637 rural villages and 3,354 urban blocks as samples. All the four studies had used a semi-structured questionnaire. The study by Ganesh *et al.* used the Indian Disability Evaluation and Assessment Schedule (IDEAS) for measuring mental disability in addition to a semi-structured interview schedule for other physical disability.^[17] This study also used a separate semi-structured interview schedule for measuring impairment in children less than 5 years developed by Action Aid India.^[20] All these studies were done as cross-sectional community-based studies. The prevalence of impairment ranged from 1.6% to 43.3%.^[13,15] In studies that included all age groups, the prevalence of impairment ranged from 1.6% to 6.3%.^[13,17] In studies that included age group ≥ 60 years, the prevalence of impairment was higher.^[14,15] In major surveys, males had higher prevalence of impairment than women.^[8,9,19] Locomotor impairment was the most common in Census 2011

Table 1: Studies that used impairment as a major component of disability measurement

Author	Year	Place	Study design	Study population	Sample size	Scale used	Prevalence of impairment (%)
Velayutham <i>et al.</i> ^[13]	2017	Tamil Nadu, India	Secondary data analysis from Census 2011	All ages	73 Million	Semi-structured	1.6
Velayutham <i>et al.</i> ^[14]	2016	India	Secondary data analysis from Census 2011	≥60 Years	1.03 Million	Semi-structured	5.1
Sulania <i>et al.</i> ^[15]	2011	Urban, Delhi	Community-based cross-sectional study	≥60 Years	120	Semi-structured	43.3
Office of the Registrar General and Census Commissioner, New Delhi ^[8]	2011	India	Community-based cross-sectional study	All ages	1.2 Billion	Semi-structured	Total - 2.21 Proportion: In vision - 18.8 In hearing - 18.9 In speech - 7.5 In movement - 20.3 Mental retardation - 5.6 Mental illness - 2.7 Any other - 18.4 Multiple disability - 7.9 3.9
Borker <i>et al.</i> ^[16]	2005 to 2006	Rural, Mandur, Goa	Community-based cross-sectional study	All ages	4,868	Semi-structured	Visual impairment was most common
Ganesh <i>et al.</i> ^[17]	2004	Karnataka	Community-based cross-sectional study	All ages	954	For mental disability - IDEAS Other disability - semi-structured For children less than 5 years - semi-structured questionnaire based on Action Aid India	6.3 Mental impairment was most common
Pati ^[18]	2003	Rural, Karnataka	Community-based cross-sectional study	5-60 Years	6,708	Semi-structured	2.02 Locomotor impairment was commonest followed by visual impairment
NSSO ^[19]	2002	India	Community-based cross-sectional study	All ages	Rural - 45,571 households Urban - 24,731 households	Semi-structured	1.8
Office of the Registrar General and Census Commissioner, New Delhi ^[9]	2001	India	Community-based cross-sectional study	All ages	1.02 Billion	Semi-structured	Total - 2.1 In vision - 1.0 In speech - 0.2 In hearing - 0.1 In movement - 0.6 Mental - 0.2

IDEAS: Indian Disability Evaluation and assessment schedule

and NSSO 2002. Visual impairment was the most common in Census 2001. Women had higher prevalence of disability in individual studies.^[14-16,18]

Activity limitation component of disability

Activity limitation component of disability was used in 13 studies [Table 2]. Four of these studies defined functional disability.^[21-23,26,29,30] Five of them had used Barthel Index for Activities of Daily Living (ADL) scale for measuring activity limitation.^[21-23,29,30,32] It measured difficulty in feeding, bathing, grooming, dressing, bowels, bladder, toilet use, transfers (bed to chair and back), mobility (on level surfaces), and stairs.^[34] Two studies had used Instrumental Activities of Daily Living for measuring activity limitation.^[28,32,35] Another study had used a Rapid Assessment of

Disability scale among adults ≥18 years of age.^[24] A prospective longitudinal study done among ≥60 years used Pune-Functional Ability Assessment Test which was validated by Nagarkar and Kashikar.^[36] It measured activity limitation on 14 items covering lifting, walking, climbing, arising from bed/chair, dressing, and so on. The prevalence of activity limitation ranged from 4.8% to 87.5%.^[31,33] For studies that included age group ≥60 years, the prevalence ranged from 16.2% to 87.5%.^[30,33] Inclusion of younger age group in the studies decreased the prevalence of activity limitation.^[24,25,28,31] Seven of these studies were conducted in rural areas.^[22,23,29,30,32,33,38]

Participation restriction component of disability

Only one study had measured the participation restriction component of disability [Table 3]. It had used a semi-structured interview

Table 2: Studies that used activity limitation as a major component of disability measurement

Author	Year	Place	Study design	Study population	Sample size	Disability scale used	Prevalence of activity limitation (%)
Keshari and Shankar ^[21]	2017	Urban Varanasi, Uttar Pradesh	Community-based cross-sectional study	≥60 Years	616	Barthel Index for ADL scale	53.6
Gupta <i>et al.</i> ^[22]	2015	Rural Jhansi, Uttar Pradesh	Community-based cross-sectional study	≥60 Years	265	Barthel Index for ADL scale	23.4
Paul and Abraham ^[23]	2015	Rural Tamil Nadu	Community-based cross-sectional study	≥60 Years	340	Barthel Index for ADL scale	20.6
Ramachandra <i>et al.</i> ^[24]	2014	Prakasam, Andhra Pradesh	Community-based cross-sectional study	≥18 Years	4,134	Rapid Assessment of Disability scale	10.4
Mactaggart <i>et al.</i> ^[25]	2014	Telangana, Hyderabad	Community-based cross-sectional study	All ages	3,574	Semi-structured	12.2
Nagarkar and Kashikar ^[26]	2013-2014	Pune, Maharashtra	Prospective longitudinal study	≥60 Years	560	Pune-Functional Ability Assessment tool	67.1
Singh <i>et al.</i> ^[27]	2013	Rural, Fatehgarh, Uttar Pradesh	Community-based cross-sectional study	≥60 Years	335	Stanford Health Assessment Questionnaire	55.2
Padhyegurjar Manashi and Padhyegurjar Shekhar ^[28]	2011	Mumbai, urban slum	Community-based cross-sectional study	All ages	3,665	Self-structured, IADL score	5.6
Gupta <i>et al.</i> ^[29]	2011-2012	Rural Faridabad, Haryana	Community-based cross-sectional study	≥60 Years	836	Barthel Index for ADL scale	37.4
Chakrabarty <i>et al.</i> ^[30]	2007	Rural Kolkata, West Bengal	Community-based cross-sectional study	≥60 Years	495	Barthel Index for ADL scale	16.2
Singh ^[31]	2004-2005	Chandigarh	Community-based cross-sectional study	≥5 Years	1,210	Semi-structured	4.8
Venkatorao <i>et al.</i> ^[32]	1998-1999	Rural Villupuram, Tamil Nadu	Community-based cross-sectional study	≥60 Years	974	Semi-structured, IADL score, and Barthel Index for ADL score	68.0
Joshi <i>et al.</i> ^[33]	1999-2000	Rural Haryana and urban Chandigarh	Community-based cross-sectional study	≥60 Years	200	Rapid Disability Rating scale-2	87.5

ADL: activities of daily living; IADL: Instrumental activities of daily living

Table 3: Studies that used participation restriction as a major component of disability measurement

Author	Year	Place	Study design	Study population	Sample size	Disability scale used	Prevalence of participation restriction (%)
Srinivasan <i>et al.</i> ^[37]	August 2004-August 2005	Rural Bengaluru	Community-based cross-sectional study	≥65 Years	356	Participation section of ICF checklist version 2.1a	57.0

ICF: International Classification of Functioning, Disability and Health

Table 4: Studies that used three components (impairment, activity limitation, participation restriction) for measurement of disability

Author	Year	Place	Study design	Study population	Sample size	Disability scale used	ICF component	Prevalence of disability (%)
Sinalkar <i>et al.</i> ^[39]	2012	Rural Pune, Maharashtra	Community-based cross-sectional study	≥60 Years	227	WHODAS 2.0, disability present if summary score is >4	Imp, AL, PR	70.0
Biritwum <i>et al.</i> ^[40]	2007-2010	India	Community-based cross-sectional study	≥50 Years	6,559	WHODAS 2.0, 12-item version, cutoff is above 10th percentile	Imp, AL, PR	93.2

ICF: International Classification of Functioning, Disability and Health; AL: activity limitation; PR: participation restriction; WHODAS 2.0: World Health Organization Disability Assessment Schedule 2.0; IMP: impairment

schedule, which was prepared based on the participation section of the ICF Checklist Version 2.1a.^[38] The prevalence of participation restriction among study population age ≥65 years was 57%.^[37]

All three components of disability

Two studies had used the ICF concept of disability measuring Impairment, Activity Limitation, and Participation Restriction [Table 4]. The World Health Organization Disability

Assessment Schedule 2.0 (WHODAS 2.0) was used in both these studies.^[41] In the study by Biritwum *et al.*, disability threshold was set at above 10th percentile in the summary score of WHODAS 2.0.^[39] It had used WHODAS 2.0 (12-item version) among adults age ≥60 years. Sinalkar *et al.* considered summary score >4 as disabled. The prevalence of disability was 70.0% and 93.2% in studies by Sinalkar *et al.* and Biritwum *et al.*, respectively.^[39,40] The lower prevalence of disability reported by Sinalkar *et al.* could

Table 5: Quality of life and its association with disability

Author	Year	Place	Study design	Study population	Sample size	Quality of life scale used	Association with quality of life
Shah <i>et al.</i> ^[49]	2017	Urban Gujarat	Community-based cross-sectional study	≥60 Years	250	WHOQOL-BREF	Social domain had the highest and environmental domain had the lowest mean scores. Males had higher mean scores than females
Kumar and Majumdar ^[44]	2013	Urban Puducherry	Community-based cross-sectional study	≥60 Years	300	WHOQOL-BREF	Mean score (SD) - 49.74 (10.21) Older age, no schooling, without spouse, nuclear family, musculoskeletal disorder, low vision, and hearing impairment were associated with low QOL.
Kuvalekar <i>et al.</i> ^[45]	2013	Udupi taluk, Karnataka	Community-based cross-sectional study	≥18 Years who were permanently disabled	130	WHOQOL-BREF	Psychological domain score was observed to be low across all types of disabilities
Ghosh <i>et al.</i> ^[47]	2012	Urban slum, West Bengal	Community-based cross-sectional study	≥60 Years	120	WHOQOL-BREF	Environmental domain had the highest and psychological domain had the lowest mean scores. Income, education, and married individuals had significantly higher mean scores
Saxena <i>et al.</i> ^[46]	2010	Urban and rural areas of Bhind, Madhya Pradesh	Community-based cross-sectional study	20-45 Years	505	WHOQOL-BREF	20-29 Years highest mean score in social relationship Males had higher HRQOL than women
Rajasi <i>et al.</i> ^[43]	2009-2010	Pangappara, Thiruvananthapuram	Community-based cross-sectional study	Women ≥60 years	160	WHOQOL-BREF	Very good QOL - 2.5% Good QOL - 38.8% Poor QOL - 43.1% Very poor QOL - 15.6%
Lahariya <i>et al.</i> ^[42]	2005-2006	Delhi	Community-based cross-sectional study	≥60 Years	200	Short form - 36 version 2	Self-appraisal of health as excellent/very good - women 12%, males 35.9% HRQOL decreased with increasing age Women had lower mean scores than males

WHOQOL-BREF: World Health Organization Quality of Life –Brief Version; HRQOL: health-related quality of life; QOL: quality of life; SD: standard deviation

have been due to inclusion of 32-item version of WHODAS 2.0.^[40]

Quality of life

The Quality of Life indicator was used in seven studies.^[42-48] All these referred to the term “quality of life” [Table 5]. Only four studies defined it based on the WHO concept of quality of life.^[43,46-48] For measuring quality of life, all these studies had used the World Health Organization Quality of Life – Brief Version (WHOQOL-BREF)^[49] except the study by Lahariya *et al.*^[50] This had used the Short Form – 36 (SF 36) Version 2.^[51] SF 36 measured the self-appraisal of health. In all these studies, low summary scores meant low quality of life, and vice versa. Six studies showed a decreased mean summary scores among women.^[42,44-48] Two of the studies showed a significant association of quality of life with sex – women had lower mean scores than males.^[42,46] All these studies showed that as age increased, the quality of life mean scores decreased. Except the study by Kuvalekar *et al.*, all studies showed a significant

association with age. Three of the studies had lowest mean scores in psychological domain.^[43,45,47] Kuvalekar *et al.* studied quality of life among permanently disabled persons and found that the mean score of psychological domain was low across all types of disabilities.^[45] Rajasi *et al.* studied quality of life among elderly women age ≥60 years. The authors divided the WHOQOL-BREF summary scores as very good – scoring above 75th percentile, moderately good – scoring between 75th and 50th percentile, moderately poor scoring between 50th and 25th percentile, and very poor scoring <25th percentile. Poor QOL was maximum with 43.1%.^[43]

Discussion

The prevalence of the components of disability differed considerably across studies. This variability may reflect an actual difference in the prevalence of impairments, activity limitation, and participation restriction, or may be caused by factors such as those discussed below.

Age

Studies that included older age group had higher prevalence of impairments and activity limitation, whereas studies with younger age groups yielded lower prevalence.

Type of survey

Nationwide surveys had lower prevalence for impairment component of disability than studies conducted on a local or regional scale.

Type of scale used

Studies that used a semi-structured interview schedule showed a lower prevalence of impairment and activity limitation than studies that used validated scales like IDEAS, Barthel Index for ADL, Rapid Assessment of Disability scale, and Stanford Health Assessment Questionnaire. Two studies that used the ICF concept of disability measuring all three components showed the highest prevalence of disability.

Consistency and accuracy of measuring impairment

Impairments refer to problems in body function or alterations in body structure – for example, paralysis or blindness. A systemic disease may be made up of multiple impairments, depending on its clinical form. A standard procedure for identifying these impairments was not followed in these studies. Interobserver variation in the studies may have led to the variation in the prevalence of impairment.

Sociodemographic factors

Studies conducted in rural areas showed a higher prevalence of impairment and activity limitation than in urban areas. Literate population had lower prevalence of all three components of disability. Economic dependence was associated with higher prevalence of impairment, activity limitation, and participation restriction.

Prevalence of disability

The concept of disability was used in several classifications. However, the variety of ways in which it was defined has led to confusion about its meaning. This may explain the variability in its prevalence.

Association with quality of life

For assessing quality of life, subjective well-being, happiness, life satisfaction, and good life were used synonymously. Every age group, sex, socioeconomic status, and culture have different factors affecting quality of life. The nonuniformity in the concept of quality of life in different studies precludes any comparison between the studies.

Conclusion

This review highlights the heterogeneity in the concepts for measuring disability and quality of life. Heterogeneity can also

be observed in the age group included and the sociodemographic factor studied. There is no standardization in the measurement of disability or quality of life, and this largely impedes any comparison between these studies.

Estimating the prevalence of disability and its association with sociodemographic and quality of life may provide valuable information for optimizing the way in which health and social welfare organization deal with morbidities. To ensure the reliability of comparisons over time and between different geographic contexts requires greater homogeneity in the measurement of disability and quality of life and in their data collection methods. WHODAS 2.0 and WHOQOL-BREF may help in the standardization of these measurements.

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Conflicts of interest

There are no conflicts of interest.

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