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 widespread. 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 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 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.\[10\] 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 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.\[14,18\] 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 et al [13] | 2017 | Tamil Nadu, India | Secondary data analysis from Census 2011 | All ages | 73 Million | Semi-structured | 1.6 |
| Velayutham et al [14] | 2016 | India | Secondary data analysis from Census 2011 | ≥260 Years | 1.03 Million | Semi-structured | 5.1 |
| Sulania et al [15] | 2011 | Urban, Delhi, India | Community-based cross-sectional study | ≥260 Years | 120 | Semi-structured | 43.3 |
| Office of the Registrar General and Census Commissioner, New Delhi [16] | 2011 | Urban, Delhi, India | Community-based cross-sectional study | All ages | 1.2 Billion | Semi-structured | Total - 2.21 |
| Velayutham et al [17] | 2016 | India | Secondary data analysis from Census 2011 | All ages | 4,868 | Semi-structured | 3.9 |
| Ganesh et al [18] | 2014 | Karnataka | Community-based cross-sectional study | All ages | 954 | Semi-structured | 6.3 |
| Pati [19] | 2004 | Rural, Karnataka | Community-based cross-sectional study | 5-60 Years | 6,708 | Semi-structured | 2.02 |
| NSSO [20] | 2002 | India | Community-based cross-sectional study | All ages | Rural - 45,571 households | Semi-structured | 1.8 |
| Office of the Registrar General and Census Commissioner, New Delhi [21] | 2001 | India | Community-based cross-sectional study | All ages | 1.02 Billion | Semi-structured | Total - 2.1 |

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. Five of them used Barthel Index for Activities of Daily Living (ADL) scale for measuring activity limitation. It measured difficulty in feeding, bathing, grooming, dressing, bowels, bladder, toilet use, transfers (bed to chair and back), mobility (on level surfaces), and stairs. Two studies had used Instrumental Activities of Daily Living for measuring activity limitation. Another study had used a Rapid Assessment of Disability scale among adults ≥18 years of age. A prospective longitudinal study done among ≥60 years used Pune-Functional Ability Assessment Test which was validated by Nagarkar and Kashikar. 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%. For studies that included age group ≥60 years, the prevalence ranged from 16.2% to 87.5%. Inclusion of younger age group in the studies decreased the prevalence of activity limitation. Seven of these studies were conducted in rural areas.

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

**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. In the study by Biritwum et al., disability threshold was set at above 10th percentile in the summary score of WHODAS 2.0. 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. The lower prevalence of disability reported by Sinalkar et al. could...
have been due to inclusion of 32-item version of WHODAS 2.0.\textsuperscript{40}

**Quality of life**

The Quality of Life indicator was used in seven studies.\textsuperscript{42-48} All these referred to the term “quality of life” \textsuperscript{[41]} [Table 5]. Only four studies defined it based on the WHO concept of quality of life.\textsuperscript{43,46-48} For measuring quality of life, all these studies had used the World Health Organization Quality of Life – Brief Version (WHOQOL-BREF).\textsuperscript{49} except the study by Kuvalekar et al.\textsuperscript{45} This had used the Short Form – 36 (SF 36) Version 2.\textsuperscript{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.\textsuperscript{42,44-48} Two of the studies showed a significant association of quality of life with sex – women had lower mean scores than males.\textsuperscript{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.\textsuperscript{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.\textsuperscript{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 75\textsuperscript{th} percentile, moderately good – scoring between 75\textsuperscript{th} and 50\textsuperscript{th} percentile, moderately poor scoring between 50\textsuperscript{th} and 25\textsuperscript{th} percentile, and very poor scoring <25\textsuperscript{th} percentile. Poor QOL was maximum with 43.1%.\textsuperscript{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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