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Disability prevalence: comparing four types of disability measures in the community

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Abstract

Background: There is no general consensus on how to measure disability and disability prevalence rates. The results of previous estimates could not be compared due to the varied nature of the methodologies used and the lack of standardization in the measurement of disability. The primary objective of the study was to estimate the prevalence of disability using a population-based disability survey and questions selected by the National Center for Promotion of Employment for Disabled People (NCPEDP). The secondary objective is to determine whether there was any relationship between the severity of disability and essential sociodemographic factors.

The survey was carried out in the Indian state of Gujarat's Piplag village. Eight final-year physiotherapy students gathered sociodemographic data and answers to the four disability-related questions—disability question asked in India census 2011, Washington Group (WG)-suggested question, United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)-based question, and National Sample Survey Organization (NSSO)-based question.

Results: A greater percentage of the population was classified as having a functional limitation in the questions based on the UNCRPD (28.29%) (95% *CI* 25.1–31.3%) and the WG (29.69%) (95% *CI* 26.0–34.4%). Our findings demonstrated that there were significant relationships between the questions in different questionnaires ($p < 0.01$). Female gender strongly influences how people self-identify as having a disability (by 5.7 to 12.07 times), and the predictor variables based on the Indian census 2011 questions explained 61.7% of the variation in prevalence of disability.

Conclusions: The prevalence statistics may vary based on the questions used to gather information about disabilities. As gender and socioeconomic status can impact the prevalence of disabilities, it is important to focus on ways to improve economic growth, especially for women.

Keywords: Disability evaluation, International classification of functioning, disability, and health, Data collection, Prevalence, Surveys and questionnaires

Background

Disability is defined as any physical or mental impairment that prohibits a person from participating in regular activities and social interactions in their environment [1]. It can be conceptualized in various ways. In medical science, disability is considered as a feature originating directly from diseases, disorders, traumas, or other health issues, necessitating medical therapy or intervention with the primary goal of 'fixing' the problem in the individual [2]. In contrast, the social model considers disability as a social problem rather than a personal attribute [3]. In this case, rather than the individual, the problem is identified in the hostile social context that needs to be addressed [2]. The biopsychosocial model is the end product of a full integration of the two approaches and considers disability as an interaction among biological,

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psychological, and sociocultural variables, each of which limits the individual's functioning to some extent [4]. In this context, the World Health Organization (WHO) describes disability as 'the outcome or result of a complex relationship between an individual's health condition and personal factors and of the external factors that represent the circumstances in which the individual lives'. Notably, the extent to which impairment develops into a disability depends not only on the severity of the impairment but also on the individual's aptitude for social interaction [5].

Disability is presently considered as part of normal human ageing, and it is widely acknowledged that every individual will face disability during lifetime. The disability incidence rate is increasing worldwide with population ageing, and an increase in chronic health conditions is being observed [6, 7]. Disability statistics are crucial for identifying the needs of people with disabilities (PWDs), providing assistive technology to those who require it, tracking policy outcomes, and assessing the cost-effectiveness of PWD-specific programmes. However, understanding the needs of PWDs is difficult in low- and middle-income countries (LMIC) because of limited availability of global health statistics and difficulty in measuring disability among the general population [8].

PWDs have been incorporated into society at large because of numerous national and international initiatives, including the United Nations Standard Rules on the Equalization of Opportunities of Persons with Disabilities. Disability was mentioned in five of the 17 Sustainable Development Goals issued by the United Nations under the guiding concept of 'leaving no one behind' [9]. Among all stakeholders, it is broadly agreed that a reliable conceptual framework for disability statistics has to be established. However, no consensus exists on how to calculate disability rates or prevalence rates.

The estimated number of persons with disabilities in India has been inconsistently reported in different surveys. The National Sample Survey Organization (NSSO) [10] reported that PWDs in the population were 1.8%; however, the percentage reported in the census 2001 of India was 2.13% [11]. The disparities in estimates are attributed to the lack of widely accepted definitions and criteria for disabilities, which makes it impossible to compare disability statistics over time. Ramdass et al. in 2018 conducted a review of studies examining the prevalence of disability among India's general population [12]. The study revealed that several tools have been used to evaluate various aspects of disability (impairments, activity limitations, participation restrictions, and quality of life), and it concluded that the results could not be compared because of the varied nature of the methodologies used and lack of uniformity in the measurement of disability. Measurement errors can occur when people, particularly

in developing nations, are misdiagnosed or uninformed of their disability status [8]. Furthermore, because of the varied sociodemographic variables among the studies, determining how these variables affected the prevalence of disability was challenging.

The National Centre for Promotion of Employment for Disabled People (NCPEDP) conducted a pilot study with 100 representatives from the disability sectors in India to understand the type of questions to be asked in the census questionnaire 2011 and thus improve the enumeration and collection of accurate disability data. Further details may be accessed at https://deoc.in/wp-content/uploads/2018/03/Census-Advocacy-Document-Draft-5-April-2014-6.pdf. The question based on the categories covered by the Indian disability legislation was the respondents' second favourite, after the question based on the UNCRPD (with modification). The census 2011 disability questions were structured based on the responses. Despite these efforts, the survey was criticized for several flaws; most notably, the questionnaire was not field tested with the actual population to understand how they responded, and the survey underestimated the incidence of mild forms of disabilities [13].

Given that population censuses are the only trustworthy data source for determining the incidence of disabilities in developing nations [13], a more thorough and complete data collection method is urgently required. The existing questions and survey tools collect various measures, such as clinical impairment and reported functional limitation, to estimate disability prevalence, thereby preventing comparisons. For example, Simo Fotso et al. evaluated the comparability of the various disability measures used in Cameroon in 2019. They demonstrated that none of the Cameroonian survey questions or tools produced disability prevalence rates that were comparable to those of the Washington Group (WG) disability screening tool. The authors speculated that one cause of the discrepancy could be the use of diverse surveys based on varied samples to assess screening methods [14]. Therefore, we proposed that measuring the prevalence of disability in the same population based on various questionnaires would reduce the methodological issues observed in earlier study designs and enable data comparison. We hypothesized that various questions and measurements would provide different disability estimates in the same population, additionally investigating how sociodemographic characteristics such as socioeconomic class and education, which have received less attention in previous research, affect the prevalence of disability [15]. Therefore, we assessed whether the fundamental sociodemographic characteristics had any influence on the prevalence of disability. The objectives of current study were to assess the prevalence of disability

based on the questions selected by the NCPEDP and examine the relationship between the degree of disability and fundamental sociodemographic traits in a village in the state of Gujarat in India.

Methods

Design

The procedure was approved by the CRC, Lucknow Ethical Committee. This cross-sectional study on the prevalence of disability included 867 families [16] and a population of 3937 people (2042 men and 1895 women). Between June 2019 and January 2020, questionnaire responses were collected in person.

Setting

The survey was conducted in the village of Piplag in the Nadiad Taluka of the Kheda district, Gujrat. The disability data for Piplag village were not available with the village administration. Although the purpose of this survey was not to estimate the prevalence of disability in Piplag village, we attempted to provide an overall assessment of the NCPEDP questions. Therefore, the results may be considered preliminary.

Study population and sampling strategy

Considering the nature and objectives of study, the entire population of Piplag village was selected as the study sample. No limitation on the selection of subjects existed in terms of study eligibility, except for the fact that responses were obtained from persons with intact cognition.

Data collection

Two expert translators used back translation techniques to translate all the questions from English to Gujarati. The translators were encouraged to translate concepts rather than words or terminology. The research team discussed and examined the backward translations and made any necessary modifications in case any discrepancies were noted between the translated and original versions. The translators and majority of the authors were proficient in both the languages, well-versed with Gujarati culture, and they ensured that the translated version was appropriate for use in terms of feasibility and understanding. This version was distributed to a sample of Gujarati population ($n=30$) to examine the comprehension of each item to ensure consistency and resolve any misinterpretation. As no problems were noted with this version, we decided to use it as the final version. The translated version was clear enough for the interviewer and every respondent to read and understand.

For the analysis, we decided to consider only 4 questions: the disability question from the 2011 census of India, the question from the WG based on the International Classification of Functioning (with some revisions), the UNCRPD question, and the NSSO question. The questions are listed in annexure 1. The other questions (disability questions from the 2001 census of India and UK, disability questions from the pre-test questionnaire for the 2011 census of India, and questions based on categories covered by Indian disability laws) were omitted because they were subjected to heavy criticism and deemed to be outmoded.

For this study, eight final-year physiotherapy students were chosen as the enumerators. These students were divided into 4 teams; 2 persons per team were chosen for each question. All teams received 10 days of training in surveys, general research, and disability sensitivity.

Training was provided because insufficient preparation can lead to improper provision of questionnaire and responses. The enumerators were asked to treat the respondents with courtesy and respect. Additionally, they were expected to establish a rapport with the respondents and guarantee the privacy of the information gathered. The purpose of the data collection was explained to the enumerators, who were instructed to ask questions covering the entire family. The enumerators were asked to refrain from assuming either the presence or absence of a disability and from changing the questions with terminology from another survey. Before the actual survey, a practise session with 30 volunteers was conducted, and any inter- and intra-rater variation observed was addressed.

For this study, the Piplag village was split into 4 zones. All participants provided their verbal, informed permission. Randomization was used to determine the sequence in which each region received a question, and a 1-week 'washout' interval was provided in between each one. One enumerator per team administered the survey, and another team observed the process and documented the results. Data on demographics (age, gender, and education), socioeconomic standing [17], and responses to questions about disabilities were gathered. The data of each household were gathered, and at least one resident provided all the necessary details. Individuals having 10 or more years of education and those who had appeared for the secondary school examinations were considered as literate, whereas those with no formal qualifications were considered illiterate. Similarly, people falling under socioeconomic categories 3, 4, and 5 were grouped together as belonging to lower socioeconomic status, whereas those falling under categories 1 and 2 were deemed to be part of the upper strata.

Data analysis

SPSS 20.0 was used to analyse the data (IBM Corp., Armonk, NY, USA). To calculate prevalence estimates, a descriptive analysis was performed and reported as a percentage [95% confidence interval (CI)]. The association between the questionnaires used to measure the disability and functioning was examined using the McNemar-Bowker test as the same participant answered all the questionnaires at various time points. The participants were either categorized as having disability (functional limitation) or no disability for each questionnaire employed. All the predictor variables that were significant at $P < 0.10$ were included in the multivariate model analysis. The impacts of age, gender, literacy, and socioeconomic position on the tendency of participants to self-identify disability based on 4 separate questions were specifically assessed in a multivariate analysis using a backward stepwise logistic regression. A P-value < 0.05 was considered significant.

Results

The demographic details of the participants are presented in Table 1. The overall results revealed that the prevalence of disability estimated by the India census 2011 and NSSO was 5.60% (95% *CI*: 3.75–8.27%) and 8.96% (95% *CI*: 7.31–9.10%), respectively. The questions based on WG and UNCRPD disability identified 29.69% (95% *CI* 26.0–34.4%) and 28.29% (95% *CI* 25.1–31.3%) of the population with functional limitations, respectively. The various categories of functional limitations or disabilities identified by the questionnaires are presented in Table 2. Overall, more numbers of persons with physical or locomotor limitations or disabilities were identified in this population than those with other types of disabilities.

McNemar-Bowker's test indicated a significant association between the various questionnaires used to evaluate disability prevalence estimates ($\chi^2 = 7.770$, $P < 0.001$)

Table 1 Sociodemographic characteristics of participants

Baseline characteristic	*N*	%
Gender	357	
Male	172	48.17
Female	185	51.82
Socioeconomic status	101 households	
I (upper)	1	0.99
II (upper middle)	46	45.54
III (lower middle)	35	34.65
IV (upper lower)	17	16.83
V (lower)	2	1.98
Literacy status		
Literate	333	93.27
Illiterate	24	6.72

(Table 3). When the Indian census 2011 question was used, the predictors could explain 61.7% (Nagelkerke R2) of the variance in prevalence of disability and correctly classified 96.4% of the population. The results further revealed that female gender has a strong role to play in determining disability (by 5.7–12.07 times). Lower socioeconomic status could predict identification of disability when questions were based on the Indian census 2011 and NSSO (Table 4).

Discussion

The purpose of this study was to examine the comparability of estimates of the prevalence of disability using four distinct survey questions on the same population sample and to explore the relationship between disability and sociodemographic traits. The overall disability or functional limitation prevalence estimated in the study varied from 5.60 to 29.69% in the Piplag village depending on the questionnaires used. The results of our study provided evidence to the theory that disability is an umbrella concept and disability rates could be varied for the same group based on the questions asked.

Previous studies have reported that by merely expanding the categories and coverage of disability, the disability prevalence in Zambian census increased from 0.9% in the year 1990 to 2.7% in the year 2000 [18]. In 2002, a global study, namely the European Labour Force Survey, used a standard definition of disability in 25 nations (translated and with national adaptations). According to the findings, disability rates ranged from approximately 6% (in Romania and Italy) to > 30% (in Finland) [19]. Studies using data from the European Social Survey and the European Community Household Panel have reported similar variations in the disability rates [20]. Our results are consistent with those reported by Bourke et al. (2021) [21] and Amilon et al. (2021) [22]. Bourke et al. conducted a large representative survey on adults to compare the agreement between a binary disability question (do you have a disability that restricts activities?) and the WG short set measurements. Their findings revealed that although a good agreement existed between the binary disability question and WG question, discordance was observed to be highly uneven, and agreement was only fair. The authors concluded that various queries produced significantly diverse disability estimations. Amilon et al. (2021) reported that the measurement tool of disability used has a significant impact on within-survey estimates of disability prevalence. It is unclear how much of this is influenced by cultural differences in disability concepts, welfare policies, and linguistic differences when the same topic is translated into various languages or other elements.

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Table 2 Various categories of disabilities reported as per different questions

Disability measure	Male	Female	Total	Severity	Percentage
India census 2011			**(20)**		
In seeing	2	2	4	NA	20
In hearing	1	4	5	NA	25
In speech	0	1	1	NA	5
In movement	0	6	6	NA	30
Mental retardation	1	1	2	NA	10
Mental illness	0	0	0	NA	0
Any other	0	1	1	NA	5
Multiple	0	1	1	NA	5
NSSO			**32**		
Mental	1	1	2	NA	6.25
Visual	2	6	8	2, 4, 4, 4, 3, 2, 2, 4	25
Hearing	0	2	2	4, 4	6.25
Speech	1	1	2	4, 4	6.25
Locomotor	3	12	15	3, 3, 4, 4, 4, 2, 4, 4, 4, 4, 4, 2, 2, 2, 3	46.87
Multiple	1	2	3	3,4,4,	9.37
UNCRPD			**101**		
Physical impairment (e.g. impairment of movement, muscles, joints, limbs, balance, impairment of touch)	21	48	69	NA	68.31
Psychological and psychosocial impairment (e.g. impairment of behaviour, attention, concentration, thoughts, mood, interaction with others)	1	2	3	NA	2.97%
Learning impairment (e.g. intellectual impairment, specific learning impairment, and impairment of applying knowledge)	0	0	0	NA	0%
Hearing impairment	3	7	10	NA	9.90%
Visual impairment	6	11	17	NA	16.83%
Speech impairment	1	1	2	NA	1.98%
Multiple impairments	0	0	0	NA	0%
Long-term disabling health condition (dysfunction of body organ/s leading to long-term functional limitation)	0	1	1	NA	0.99%
WG			**106**		
Do you have difficulty seeing, even if wearing glasses?	4	8	12	NA	11.32
Do you have difficulty hearing, even if using hearing aid?	4	1	5	NA	4.71
Do you have difficulty walking or climbing steps?	25	51	76	NA	71.69
Do you have difficulty remembering or concentrating?	1	6	7	NA	6.60
Do you have difficulty (with self-care) such as brushing, washing all over or dressing?	0	4	4	NA	3.77
Using your usual language, do you have difficulty communicating (for example understanding or being understood)?	0	2	2	NA	1.88

NSSO, National Sample Survey Organization; *UNCRPD*, United Nations Convention on the Rights of the Persons with Disabilities; *WG*, Washington group; *NA*, not applicable

Table 3 Results of the McNemar-Bowker test of association showing relationship between the questionnaires used for identifying disability/functional restrictions among community dwellers in Gujarat, India ($n = 357$)

Questionnaire	India census 2011	NSSO	UNCRPD	WG	Total	McNemar–Bowker (*p* -value)
Yes	20 (7.72%)	32 (12.35%)	101 (38.99%)	106 (40.92%)	259	7.770
No	337 (28.82%)	325 (27.80%)	256 (21.89%)	251 (21.47%)	1169	0.0002*

NSSO, National Sample Survey Organization; *UNCRPD*, United Nations Convention on the Rights of the Persons with Disabilities; *WG*, Washington group. *Indicates agreement between the questionnaires evaluated. *P*-values < .05 were considered to indicate statistical significance (McNemar-Bowker test)

Table 4 Regression analysis of significant variables predicting disability prevalence among community dwellers in Gujarat, India ($n = 357$)

Predictors	B	S.E	Wald	Sig	95% *CI*	
					Lower	Upper
India census 2011 (Nagelkerke $R^2 = 0.617$; cut value $= 0.500$)						
Gender	2.118	0.881	5.776	0.016*	1.478	46.773
Economic status	1.476	0.451	10.693	0.001*	1.806	10.591
Constant	2.60			0.00	1.24	3.94
NSSO (Nagelkerke $R^2 = 0.531$; cut value $= 0.500$)						
Gender	1.508	0.578	6.800	0.009*	1.455	14.045
Economic status	0.715	0.293	5.944	0.015*	1.151	3.635
Constant	2.35			0.00	1.36	3.34
UNCRPD (Nagelkerke $R^2 = 0.574$; cut value $= 0.500$)						
Gender	1.170	0.352	11.017	0.001*	1.614	6.426
Constant	1.89			0.00	0.99	2.79
WG (Nagelkerke $R^2 = 0.579$; cut value $= 0.500$)						
Gender	1.214	0.350	12.072	0.001*	1.698	6.682
Constant	2.19			0.001	0.88	3.50

NSSO, National Sample Survey Organization; *UNCRPD*, United Nations Convention on the Rights of the Persons with Disabilities; *WG*, Washington group. *Multivariate logistic regression analysis found that female gender and lower socio-economic status were independent influencing factors of the prevalence of disability, and the difference was statistically significant ($P < 0.05$)

Previous studies have focused on direct questioning, for example 'Do you consider yourself to have a disability?' [23], activity limitations [24, 25], or clinical impairments [26] in the measurement of disability. Measuring clinical impairment evaluates the 'body function and structure' component of the International Classification of Functioning, Disability and Health (ICF). Reporting activity limitations focuses on the 'activities' component of the ICF. The WG on Disability Statistics [27], the WHO Disability Assessment Schedule, and the Model Disability Survey [28, 29] assesses disability status in this way. Even though India approved ICF in 2001, its use is not much widespread.

A recent review of globally conducted disability surveys reported that the definition for disability outlined in the WHO's ICF has been widely accepted in disability surveys over the past years; the definition is as follows: 'the interaction between an individual (with a health condition) and that individual's contextual factors (personal and environmental factors)' [30, 31]. However, nations frequently modify this broad definition to fit their demands and the objectives of particular data collection initiatives.

In India, census 2001 and 2011 measured disability by using the medical model of disability [11, 16]. Direct questions like 'Do you have a disability?' [23] have been demonstrated to cause under-reporting of disabilities [8, 26] and only produce prevalence rate of 1–3%. It has been noted that historically, high-income nations have

used a functional metric, whereas low- and middle-income countries have used an impairment measure [32]. Estimating severe disability using impairment-based screenings is preferred because public resources and services for people with disabilities are limited in developing nations [8].

The greater responses to UNCRPD and WG questions can be attributed to the fact that questions about activity constraints catch functioning problems that might also be caused by any disability or medical comorbidities. Without revealing the underlying causes of limitations, the ICF model and WG of questions assess a person's abilities in their current setting, which leads to greater prevalence rates. In addition, using this collection of questions maximizes the amount of information that may be affordably acquired [6]. However, the measurement of the effect of environmental influences on functioning is inherently challenging with these questions. For example, it may be difficult to distinguish between people without disabilities and those with impairments who have proper accommodations and enabling surroundings.

Although these questions revealed the existence of a functional impairment, determining the extent of disability remains challenging. The traditional method of gathering data on disabilities involves screening the population to identify 'those with disabilities' at the outset and then following up with this subpopulation to inquire about the challenges they encounter on a daily basis. Screeners might be either impairment- or function-based

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questions [8]. It is crucial to distinguish between those who are disabled and those who are not; many cut-off points may be used for this classification. This might be achieved, for example by introducing additional criteria stating that a person will be regarded as disabled only if he/she has limits that have persisted for longer than a year. These extra, country-specific criteria have a significant impact on disability estimates and the comparability of these estimates across countries.

Our findings indicated that the participants' socioeconomic position and gender can have an impact on the prevalence rate. Our results supported those of previous studies reporting that sex has a significant effect on disability [33, 34]. According to Bora and Saikia (2015) [35], women report more disabilities than men; moreover, they experience disabilities for a longer period. This is because a person's gender determines their social role, performance, and associated social expectations [36]. Individuals' capacity to participate in social activities related to their sex may be compromised if they are identified as having a disability, which could have an impact on their self-esteem and relationships with their family [37]. A recent study reported that female patients with poliomyelitis can individually predict the physical and psychological domains of quality of life [38]. The correlation between disability and economic position is mixed. The South African statistical office [39], Bajekal et al. (2004) [40], and UNSD [41] indicated a negative correlation between functional impairments and socioeconomic position. On the other hand, Mitra et al. (2013) [42] reported that in the majority of the 16 developing nations included in their study, disability was positively correlated with poverty. Higher prevalence of disability, activity limitation, and participation restriction were linked to economic dependency [12]. This association may be because of the responders' insufficient resources for controlling the health condition.

The major implications of the study are as follows. First, the study helped in identifying population with functional limitations. Providing rehabilitation services and developing health policies that focus on non-fatal debilitating illnesses can aid patients in recovering from illness, thereby delaying the onset of disability. Second, all policy- and decision-making processes must prioritize PWDs, particularly women, and focus on the unmet needs of PWDs. Equal opportunity in school and employment for PWDs must be provided because socioeconomic status is a representation of numerous physical and psychosocial pressures. People from lower socioeconomic groups who complain of functional difficulties may be the focus of early rehabilitation efforts.

Our results of the comparison of disability prevalence only apply to Piplag village and cannot be generalized to other locations. One of the key strengths of our study was the evaluation using various questionnaires was done at participants' homes, which might have included issues with daily functioning, social services, care, and health services. The limitations of this study are the overall low response rates, exclusion of disability duration, lack of knowledge regarding whether the limitations are permanent or temporary, self-reported measurement of disability or functional restrictions, and lack of evaluation of the impact of assistive equipment. Moreover, employing physiotherapy students with technical knowledge as enumerators might have influenced the results. We considered the role of limited numbers of sociodemographic characteristics in the prediction. Future studies should include factors such as healthcare access, awareness of existing medical issues, employment status, or physical activity. Disability surveys including questions on functioning (activity and participation), impairment, and contextual factors that have been approved for use by the global scientific community should be developed. Additionally, questionnaires that can help distinguish people who require assistance with mobility, self-care, and communication from those who require aid with job-related responsibilities should be developed. Setting cut-off points to convert functional constraints into disability rates may also be attempted.

Conclusion

The prevalence statistics may vary based on the questions used to gather information about disabilities. Questions based on functional limits tend to identify a larger proportion of people than those focused on impairment. Though the translation of functional challenges into the degree or prevalence rates of disabilities may not be always possible, this population possibly represent a subgroup that would greatly benefit from interventions and assistive technology. Future studies are required to transform functioning-based surveys into metric-based questionnaires.

Supplementary Information

The online version contains supplementary material available at https://doi.org/10.1186/s43161-022-00114-7.

Additional file 1.

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Declarations

Ethics approval and consent to participate
Ethical clearance was provided by CRC, Lucknow (CRCL/Data Collection/2019–20/06), and participants gave verbal informed consent.

Consent for publication
All authors have approved the manuscript and agree with its submission to this journal.

Competing interests
The authors declare that they have no competing interests.

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