

Understanding community perception and disability weights – A qualitative exploration of reasons associated with values in two states of India

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ABSTRACT

Background: Health state valuation attempts to evaluate health states based on the perception of individuals. The values are used to derive disability weights (DWs) —an important metric for estimation of disability-adjusted life years and thereby calculation of the burden of diseases. Several studies have calculated DWs using different methods of valuation, however, very few have attempted to explore the underlying cause for assigning values to different health states. This study aims to document the perceptions, preferences, and social context in assigning DWs to given health states. **Methods:** A total of 42 community members and 21 service providers (from public and private sectors) across urban and rural Odisha and Telangana were interviewed between July to September 2018. A face-to-face in-depth interview and a rank ordering technique through card sort exercise was employed to explore reasons and perceptions of individuals in the context of health states using the thematic framework approach. **Findings:** Six themes emerged through analysis: awareness of the health state, nature of the disease, disease consequences, treatment-related issues, social implications, and case burden. Each theme captured an individual's reason for valuing one health state as different from the other, with differences and/or similarities between community members and service providers. **Conclusion:** Our study provides a comprehensive comparison between contrasting groups of individuals, thereby suggesting mere acceptance of 'experts' reasoning may not always suffice. Further research studies in the future need to be conducted for a better insight into the health perspective of a culturally diverse community. It can also help estimate the burden of disease for decision making and resource allocation in developing countries.

Keywords: Card sort, disability weights, health state valuation, Odisha, service providers, Telangana

Introduction

In developing countries like India with increasing burden of disease and low resource allocation achieving sustainable development goals can be a daunting task.^[2] Efficient allocation

of resources is required to reduce the disease burden and thereby improve the health of the populace.^[3] The Global Burden of Disease (GBD) studies initiated by Murray *et al.*^[4] provided concrete and reliable data on the burden of diseases that needed prioritization in health research, interventions, and funding from donors.

Health state valuation is highly subjective. A qualitative understanding of reasons for disability weights should be

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explored. Evidence from several studies on disease burden shows that the value of health has been determined using expert opinion worldwide. Several studies have attempted in understanding the ‘value’ of a certain health state or disease using various health state valuation methods.^[5–7] An important metric—Disability-adjusted life years—a product of the GBD studies, is a measurement of the disabling power of a disease or health condition required for calculating the burden of diseases using the ‘value’ or ‘disability weight for a health state’.^[8] However, previous GBD studies have garnered criticism for the manner of estimation of disability weights, especially for its “one size fits all” approach and selection of health states, where unaffected individuals and community perception of health conditions were unaccounted for.^[9]

Health state valuations quantify the reduction in health associated with a particular disease or health condition as perceived by the unaffected population—an insight into the societal construct of participation-restriction associated with certain health conditions. Various methods of health state valuation, such as Person trade-off, Time trade-off, and Paired comparison have been used to determine disability weights (5,11). However, these methods may not be suitable for use across different communities and populations due to their cognitively demanding nature.^[10,11] Numerous studies across the globe have captured the values or disability weights assigned to each selected health state. These are more often cohorts comprising of the educated elite that include health care providers, economists, or academicians. However, it is well known that health perceptions vary extensively among individuals, between population groups, societies, cultures, and nations. The valuation of a health state by individuals largely reflects their values, assumptions and beliefs about health and illness in general, and “lived” experience with actual episodes of ill-health, impairment and handicap in particular. However, in valuation surveys, emphasis on perceptions and qualitative features of illness and disability are neglected to the benefit of a numerical value.^[9] Due to the relative dearth of such qualitative evidence from health state valuation studies in India, especially at the community level, we attempted a methodological pilot, to obtain perceived disability weights from the community as well as from an expert panel—consisting of medical and non-medical professionals. Through anecdotal learnings, we decided to further explore the reasons behind the values obtained for computing disability weights. Since obtaining disability weights from an expert panel alone may not be representative of the community at large,^[12] we aimed at obtaining values assigned by community members, and service providers—ranging from primary care physicians to specialist providers, for an array of health states ranging across the spectrum of mild to severe in two states of India at both the urban and rural setting. Furthermore, we also explored the perspectives behind assigning these values, which would provide valuable insights into why and how experts and non-experts alike rank diseases. As per our knowledge, our study is the first of its kind to be conducted in India, especially among rural and urban populations. Therefore, we believe this study would provide a better understanding of the relationship

between health status and the individual’s perspective (reflective of the community).

Our study envisaged to document the following:

- a) What are the factors behind people’s preferred ranks to his or her health state?
- b) How different are the reasons between service providers (experts) and community members for assigning values?

Methods

Study setting and sampling

A qualitative study was conducted to explore perceptions of community members and service providers from Odisha and Telangana. Odisha and Telangana were selected based on the fact that the previous similar study was conducted in the erstwhile undivided Andhra Pradesh—of which Telangana was a part. Odisha, although a neighbouring state of Telangana, had a less favourable human development index and a higher proportion of the tribal population. This selection offered the diversity needed for the study, which was a primarily exploratory pilot in nature. The participants for in-depth interviews were recruited from both urban and rural areas in each state, from the same location as the quantitative study. The study locations were villages and municipal corporations from Wanaparthy (Telangana) and Gajapati (Odisha) districts each, and slums and non-slums in the capital cities of both states—Bhubaneswar (Odisha) and Hyderabad (Telangana).

Health states and valuation method

A thorough and meticulous review of literature from the GBD studies across the years and prevalent health states in India, with a focus on the selected study locations (Odisha and Telangana), was done using PubMed and Google scholar. A tentative list of 50 health states was shortlisted and further narrowed down with medical expert consultations from the public health facilities across Odisha and specialists from tertiary care hospitals in Bhubaneswar. The medical experts were consulted on multiple occasions to gather valuable information on diseases prevalent in the urban and rural areas. Based on the responses, 14 health states were finalized, These were further categorized into eight health states common for all participants (tuberculosis, malaria, diarrhoea, diabetes, osteoarthritis, asthma, quadriplegia due to stroke, and upper limb fracture), two exclusively for females (anaemia and breast cancer), and two for males (alcohol use disorder and oral cancer).

Furthermore, to understand the perceptions of the participants regarding the selected health states, card sort, a simple and less exhaustive method was used. For the participants to better understand the CS method, the ranking order from 1 to 11 was divided into three parts viz. 1-4 for mild/least severe health states, 5-8 for moderately severe health states, and 9-11 for the most severe health states. The participants were then asked to arrange

the health states in order of their severity. Multiple iterations were carried out while ranking the health states to derive the final responses from the participants. While they assign a particular rank to various health states, reasons for giving such weightage were explored.

Study participants and data collection

From July to September 2018, experienced and trained qualitative field investigators conducted face-to-face in-depth interviews using semi-structured qualitative guides. The guide domains included: socio-demographic details, followed by card sort rank for the 14 selected health states and finally questions with minimal probes to explore the various reasons underlying individuals ranking preferences for different health states.

Study participants included adult (above 18 years) community members and service providers from rural and urban locations of both states that is, Odisha and Telangana, of all genders. The study participants were selected using a purposive sampling technique. A total of 63 participants, 33 males and 30 females, with the age range of 20 to 67 years from Odisha and 20 to 80 years from Telangana were interviewed. Twenty-one service providers were interviewed in total, with 10 from Odisha and 11 from Telangana; while 21 community members from Odisha and 21 from Telangana were included in the study. They were selected from both urban and rural locations viz. state capitals- 15 in Bhubaneswar and Hyderabad each, along with 16 in Gajapati and 17 in Wanaparthy districts, respectively.

After establishing contact, the purpose of the study was explained to the potential participants and informed consent was obtained. In most cases, the interviews were conducted at the same time as initial contact, unless an appointment was needed as in the case of medical officers. All interviews with community participants were conducted at participants' homes, while service providers were interviewed at their place of work. Each interview lasted from 30 to 45 minutes and was mostly conducted in the preferred local language (Odia and Telugu). A total of 63 in-depth interviews with 42 service provider interviews and 21 community participant interviews were conducted. The in-depth interviews were audio-recorded upon the consent of the participant to ensure the accuracy of the data. Data collection ended after a saturation point was obtained. Community participants and service providers (except medical officers) were compensated monetarily for their time after the successful completion of interviews. Table 1 represents the participant profiles for the in-depth qualitative interviews.

Quality control

To protect participants' confidentiality, each participant was given a unique identity code, and access to audio recordings and transcripts was restricted to members of the research team only. Initial interviews were accompanied, and supervisory visits were made by senior team members during in-depth interviews, with the regular quality check of the audio recordings.

Analysis

All interviews were transcribed verbatim and translated by outsourced experts to English. The in-depth interviews were analyzed using the thematic framework approach^[13] by two researchers of the study, using Atlas Ti version 7. During familiarization, researchers thoroughly read the translated files and made memos wherever necessary. Further, line-by-line coding of 'open codes' was done for all that were identified as relevant from as many different perspectives as possible. Both researchers independently coded the first few transcripts. After coding the first ten interviews, a discussion with the co-investigator was done to compare the set of codes to apply to all subsequent transcripts. A similar discussion was carried out after half the transcripts were coded and refined to develop a working analytical framework with similar codes grouped under common families. Almost all of the transcripts coded further had a repetition of the codes and families.

The findings were presented under the following six themes that have emerged from the study (i) awareness of the health state, (ii) nature of disease, (iii) disease consequences, (iv) treatment-related issues, (v) social implications, and (vi) case burden. Individuals' reasons for valuing one health state are different from the other, with differences and/or similarities between community members and service providers have been captured through each theme.

Findings

Participants' profile

Awareness of the health state

Community members from rural and urban locations of our study admitted that knowledge and awareness about different health states were very important for them to categorize any health states as more or less severe. Certain health states namely diabetes, and anemia, and the subsequent management of these diseases were perceived as severe health states by the community members.

Participants also reported that due to high levels of awareness—including precautionary measures (use of nets, reduced contact with diseased individuals or allergens/triggers, and regular advertisements) for diseases such as TB, malaria, asthma, and diarrhea—they do not deem the diseases as severe.

A 42-year-old, salaried male from Hyderabad quoted:

"Malaria was once a grave disease and people from villages had to seek treatment from the city. However, nowadays people are aware of it, so it is not considered serious."

A 51-year-old government dispensary female doctor from Bhubaneswar reported:

"Currently with the increase in awareness regarding tuberculosis through advertisements people seek treatment from hospitals at an early stage. They understand the value of time during the treatment."

Perceived nature of disease

Respondents perceived health states as ‘dangerous’ or ‘normal’ based on whether the disease was curable or not. The use of home remedies and oral rehydration solutions leads participants to believe that diarrhea was manageable. Similar views on malaria—in terms of ‘easy treatment’, anemia—by intake of nutritious food and vitamins, and tuberculosis—definite cure within six months of regular treatment were reported.

A 22-year-old, female domestic worker from Gajapati district reported on the nature of the disease:

“Anemia depends on our eating habits and, if we consume a proper diet with, vegetables, fish and meat then our blood will increase?”

“Tuberculosis is not considered a grave disease if people seek treatment at the right time. In our government hospitals, TB medications are provided for 6 months or 1 year for the treatment. If the patients adhere to the treatment properly they will easily be cured. That’s the reason I do not consider this disease serious.” A 33-year-old male farmer from the Gajapati district reported. Majority of the respondents including service providers considered Osteoarthritis as ‘normal’ or ‘common’ as it generally affected the older population.

A 31-year-old male salaried participant from Wanaparthy district quoted:

“Osteoarthritis is considered a normal disease and anybody will get it automatically. With the increase in age, you and I also will get the disease.”

A 29-year-old male primary health care medical officer from Gajapati district: *“Osteoarthritis is common nowadays, and generally occur in old age”*

Diseases were perceived as severe due to their fatal nature by doctors and community members alike. However, few diseases were not considered severe, but considered fatal if correct treatment was not provided., For instance, in the case of Asthma—if immediate treatment was not provided; Diabetes and Malaria—if proper medications are not given; and Tuberculosis—if complete course treatment is not taken, the prognosis would be death.

A 50-year-old homemaker from Gajapati district quoted:

“Asthma is considered a disease wherein the patient finds it difficult to breathe and if untreated the patient might die”.

Perceived disease consequences

The dreadful consequences of any disease were recognized as an important measure for ranking a disease as severe. Most people regarded both breast and oral cancer, quadriplegia due to stroke, osteoarthritis, and diabetes as more severe health conditions because of their severe symptoms, the subsequent painful consequences as well as associated complications. Further,

respondents believed that the sufferers of the above-mentioned diseases would be under constant ‘psychological pain’ and ‘stress’ as a result of these diseases, thereby making the lives of the patients all the more difficult.

A 50-year-old homemaker from Gajapati district’s view on disease consequences: *Sir, she suffered a lot of pain and will be unable to move, or walk, or do her work., She will not be able to feed herself as she is paralyzed, and will not be able to do anything else. Due to these reasons, I consider this disease.”*

The respondents from Odisha and Telangana had similar views for Cancer, as any form of the disease was considered ‘dangerous’. Many of the respondents believed that the survival of a cancer patient is difficult, though there is no immediate death. The patient suffers a lot despite the treatment provided. This includes experiencing pain, difficulty in eating or swallowing, or speaking, with the addition of facial deformation.

“In case of oral cancer, the patient is not able to eat and talk. He is always in psychological pain. He cannot even refresh his mind so his life seems to be terrible.” A male community health worker from Bhubaneswar quoted

Moreover, from the service providers’ perspective, cancer of any form is difficult to diagnose at an early stage (especially in rural settings), thereby reducing the chances of survival of the patient.

A female primary health care medical officer from Wanaparthy district said:

“Breast Cancer is considered the most severe disease as it cannot be diagnosed in early stages. Educated people understand the condition immediately but the villagers, do not.”

Treatment-related issues

The respondents believed that the availability of medical services was a very important parameter for categorizing a health condition as severe or not. For instance, most respondents unanimously recognized TB to be less severe as compared to other diseases because of the medical services readily available for the treatment of TB and the awareness amongst the people about the services.

“Nowadays, there are facilities for treatment everywhere. Earlier there was no availability of treatment facilities, clinics, medical shops for immediate treatment and medications. Recently with the availability of such facilities diseases like tuberculosis (TB) is not so considered grave and can be cured easily” As quoted by 38-year-old homemaker from Bhubaneswar.

Similarly, the absence of proper treatment facilities for health conditions such as cancer, diabetes, and episodes of stroke was regarded as a primary reason for considering these health conditions as more severe.

“For any form of cancer, surgery must be done. If it is treatable by surgery, they will proceed with surgery. If not, they have to do chemotherapy and radiotherapy. Both are costly and least available in India.” (A 22-year-old male government hospital doctor from Hyderabad quoted)

“If he (patient) has money then he can stay alive for more days with proper treatment. But for the poor it becomes hard to survive with this disease as there is no proper treatment available for cancer in government hospitals” A 35-year-old homemaker from Bhubaneswar reported.

Further, according to the respondents from the rural areas of both states—cancer, diabetes, and quadriplegia due to stroke, were ranked among the severe health states due to their complex high-level treatments required and the huge expenses incurred during the treatment. Service providers also admitted that the above-mentioned diseases required a multifaceted approach (disease management, physiotherapy, counseling), and confirmed a regular treatment procedure would not suffice.

A 64-year-old homemaker from Wanaparthy district:

“Both Breast Cancer and stroke incur high-cost treatment and medicines, and the patient is bedridden.”

A 37-year-old male salaried participant Gajapati district:

“The treatment (oral cancer) is difficult and even if you decide to seek treatment then lakhs of rupees are needed”.

A 34-year-old male government hospital surgeon from Wanaparthy district quoted:

“After an episode of stroke, the patient requires a physician for management. A physiotherapist and a counseling for the family members would also be needed.”

A male community health worker from Bhubaneswar reported:

“I have heard that there is no medicine for cancer and oral cancer patients would die. Operation is the only cure and if proper treatment is not provided this could be fatal.”

Similarly, a shorter duration for treatment as well as recovery from disease was an important reason for perceiving a disease as less severe. An upper limb fracture due to a road traffic accident and health conditions namely asthma and osteoarthritis that have ‘slow cure’ was therefore considered as more severe than malaria or diarrhea that can be cured within a shorter period.

A 32-year-old male salaried participant from Bhubaneswar quoted:

“Diarrhoea patients are cured with proper treatment and medication within one or two days but in case of diseases like malaria a minimum of three days are required to get cure the ailment. During those three days, suffering

is more painful than that of diarrhoea. In three days when the patient has a fever, it causes a great deal of exhaustion and suffering.”

A 32-year-old male participant from Bhubaneswar:

“Yes, because if the bones have not have been joined properly it will take more than 2 or 3 months to recover”

Social implications

Many respondents’ perceptions regarding some diseases were, it would affect not only the sufferer (patient) but have an impact on their family, neighbors, and surroundings as well. Quadriplegia due to stroke, and mental disorders—schizophrenia and depression, ranked the highest, with quadriplegia as one of the most severe diseases as the sufferer would entirely depend on his family for the smallest of activities related to daily living.

A 42-year-old male government specialist provider from Bhubaneswar:

“A paralysis patient is not only going through pain but is also unable to move. He always needs some assistance with his work. It is a very severe condition and the patient is a liability to his family.”

A 29-year-old male primary health care medical officer from Gajapati district quoted.

“Even family members do not co-operate with the patients. They either demean him (sufferer) or boycott him labeling him as insane. He does not have family support and our society also does not approve cases of mental depression. They consider it as hopeless.”

Respondents also mentioned that people suffering from schizophrenia are not only dependent on their family members but may also pose a threat to their surroundings since their behaviour ‘maybe unpredictable’ with their family members and neighbours.

A 57-year-old male community member from Bhubaneswar quoted:

“A schizophrenia patient does not know anything that is happening. He is unable to recognize his family and friends. He can neither feed nor dressup himself. He may sometimes get away from home and return after many days or he may even run naked. His family helps him with his work. They help him to bathe and dress.”

A 30-year-old homemaker from Gajapati district: *“No, she (schizophrenia patient) will obviously depend on someone to do the tasks and she cannot be left alone at home at any time or she cannot be taken anywhere. It is always dangerous to take her out as anything can happen anytime.”*

Additionally, a service provider also accepted that people considered mental illnesses and gender-related illnesses like

breast cancer as a ‘taboo’ and believed that visiting a psychiatrist or seeking help is still socially unacceptable.

“It is a taboo in public to go see a Psychiatrist for mental health. People will not accept and understand.”

“Patients (Breast cancer) especially the uneducated seek care at the hospital at a very late stage wherein cancer has spread, and there is excessive bleeding. Due to social taboo, they (women) are not even able to share their symptoms with family members also.” (A 23-year-old female government hospital doctor from Hyderabad quoted)

Case burden

The caseload of a particular disease in a given area was recognized as an important criterion, especially from the service providers’ perspective to consider the disease as more or less severe. Hence diseases such as malaria, TB, and diarrhea were considered relatively more severe in the rural locations of Odisha, owing to the reporting of a high number of cases to the health facility.

A 30-year-old male primary health care medical officer from Gajapati district quoted:

“Malaria, Dengue, TB, and Diarrhoea are considered as national diseases and are given primary priority.”

Tuberculosis was considered severe by most of the service providers due to its infectious nature, and also the highest global burden that the disease afflicts on the community as a whole.

“Most severe because TB is the biggest burden on India so this is an important disease.” (30-year-old male primary health care medical officer Gajapati district)

Tuberculosis is considered the most severe because of the national burden of the disease. Due to this reason, TB is considered an important disease.

However, in the rural villages of Wanaparthy, Telangana, similar diseases like malaria and Diarrhoea were considered less severe by the virtue of fewer cases reported in these areas.

“Malaria cases are very rare. I have been working here since 3 years, and I have hardly seen 4-5 cases, whether clinically for treatment or diagnosis.” A 34-year-old male government hospital surgeon from Wanaparthy district.)

While asthma and diabetes were considered relatively more severe because of the high case burden and low awareness within the community.

“Asthma is a very common problem, and at least 5 to 10% of the cases that come into OPD are such cases (sick).” As quoted by a 34-year-old male primary health care medical officer from Wanaparthy district.

Discussion

The findings presented in the sections above attempt to explain the reasons underlying the disability weight scores given by the valuers as a conglomeration of health as well as non-health factors. Awareness towards a particular disease condition was believed to be one of the primary reasons from both the community as well as the services providers’ perspective for reducing the fears associated with particular disease condition and also considering the disease as less severe and availing services for its treatment. Adequate awareness about malaria, TB, and diarrhea has led these diseases to be recognized as less severe, and thereby a lesser disability weight scoring is given especially among the rural population. The urban dwellers, however, seemed to be more informed about non-communicable diseases such as diabetes, asthma, and stroke owing to the increasing burden of NCDs in the urban sphere. Therefore, most of the community members considered non-communicable diseases (NCDs) to be more severe than communicable diseases, hence diabetes, cancer, mental disorders are being allotted a higher severity rank than malaria, diarrhea, and TB. Higher treatment cost, lack of services in public health facilities, low levels of awareness, and the indefinite cure have led to a change in perception towards NCDs.^[14,15]

The consequences of a health condition in terms of physical dependency, dietary restrictions, loss of or absence from work, pain and discomfort as well as its impact on the family was recognized particularly by the community as a major reason for considering a given health state as more or less severe. Evidence from a study conducted by Karimi *et al.*^[16] further supports our findings on disease consequences and elaborates how an individual’s visualization of the quality of life after being affected by a disease influences the decision of whether a disease should be considered as severe or not. Quadriplegia, a consequence of an episode of stroke was unanimously considered as one of the most severe diseases by all the urban as well as rural community members because the health condition leaves the patient in a dilapidated state and also completely dependent on their family.

Non-health factors such as stigma, impact on social life and financial implications also have an equal role to play in moulding one’s perception towards a disease especially among the community members. Interestingly the non-health or social factors remain unaccounted for in the epidemiological data.^[17] Respondents in our interviews admitted the persistence of stigma relating to mental illness and gender-related illnesses—breast cancer. Visiting a psychiatrist was considered taboo mostly in the rural sphere. However, the perspective of the providers and community revealed that generating awareness is the key to removing all fears and disease-related stigma from the community. The fear of unacceptability often led to self-blame and withdrawal of the patients from society. Therefore, there is a false impression about the low prevalence of such diseases thereby misguiding decision making at the policy level. Hence, improving awareness related to different disease conditions is of utmost importance in the community. This shall enable

Table 1: Participant profile for the qualitative in-depth interviews

Categories	Odisha (n=31)	Telangana (n=32)	Total (n=63)
Age (in years)			
Mean age±SD	41±12.4	43±14.9	
Range	20-67	20-80	20-80
Gender n (%)			
Males	17 (55%)	16 (50%)	33 (52%)
Females	14 (45%)	16 (50%)	30 (48%)
Participant type n (%)			
Community members	21 (67%)	21 (66%)	42 (67%)
Service Providers	10 (33%)	11 (34%)	21 (33%)
Location n (%)			
Urban	15 (48%)	15 (47%)	30 (48%)
Rural	16 (52%)	17 (53%)	33 (52%)

the community members to avail themselves for health-related services efficiently.

Finally, affordability towards care was noted as a major factor during the ranking exercise. The high cost of treatment especially for NCDs and cancers deter people from availing the medical services and even assuming these diseases as ‘incurable’ in comparison to other infectious diseases—TB, malaria, and diarrhea—for which medicines and treatment are easily available either for free or at low cost.

On the contrary, the opinion of the services providers irrespective of the study location was mainly driven by the clinical evidence, signs symptoms, burden of disease, and its treatment modalities. Malaria in Telangana was considered less severe due to a lesser case burden while TB in Odisha was recognized as more severe owing to its higher case burden. TB in comparison with Asthma, although considered as less severe by the community due to the availability of medical services at low cost, was regarded as relatively more severe by the service providers owing to its contagious nature and side effect of drugs. However, there were few health states regarding which the perspectives of both the community members and health providers converged. For instance, both the groups unanimously foresighted quadriplegia due to stroke and cancer in any form as the most severe health conditions. This suggests that the perspective of the community is as important as the medical experts or service providers for an accurate estimation of disease burden and efficient policy-level decisions.

Limitations

This study was conducted in only two states of India which made it difficult to capture the cross-cultural variability completely. Though translations were performed by experienced language experts, few words and expressions obtained through the interview could not be captured accurately after translations. India is a culturally rich and diverse country, further research is needed to gain greater insight into the effects of cultural

differences on disability weights and health perceptions, across the country in varied settings.

Conclusion

Our qualitative study was designed to explore the reasons and beliefs underlying the process an individual goes through while quantifying health states. The understanding at an individual level, through community-based interviews, helps us dissect the community health perspective through simple exercises, yet difficult to comprehend the reasons for ranking various health conditions. We explored the perception of the community rather than mere acceptance of ‘experts’ reasoning and provided a comprehensive comparison. As expected, with our backdrop of rural-urban, community-service providers, and differences in perceptions, the disparity in severity differed in their reasons trailing the ranks. Using the experiences of our study, a finer look into the health perspectives of various stakeholders- needs to be conducted. We believe that through our study we have captured the reasons underlying an individual’s perception regarding the severity of disease and this shall provide a more accurate and robust estimation of disease burden in the community. Moreover, disability weights obtained from such a diverse populace as mentioned above will help us to better determine disease burden and facilitate better decision making, prioritization, and intervention designing thereafter.

Key Messages

The individual (valuer) values health state irrespective of their method of valuation based on a variety of non-health factors, assumptions, and beliefs about health and illness in general.

Our study documents the perceptions, preferences, awareness, and social context to develop a better understanding of the relationship between assigning disability weights to given health states and an individual’s perception.

Ethics consideration

Ethical approval was obtained from the Indian Institute of Public Health, Bhubaneswar vide IEC no. IIPH/IEC/2017/20.

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Declaration of patient consent

The authors certify that they have obtained all appropriate patient consent forms. In the form the patient (s) has/have given his/her/their consent for his/her/their images and other clinical information to be reported in the journal. The patients understand that their names and initials will not be published and due efforts will be made to conceal their identity, but anonymity cannot be guaranteed.

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Conflicts of interest

There are no conflicts of interest.

References

1. Yadav S, Arokiasamy P. Understanding epidemiological transition in India. *Glob Health Action* 2014;7(Suppl 1):1-14.
2. Lozano R, Fullman N, Abate D, Abay SM, Abbafati C, Abbasi N, *et al.* Measuring progress from 1990 to 2017 and projecting attainment to 2030 of the health-related Sustainable Development Goals for 195 countries and territories: A systematic analysis for the Global Burden of Disease study 2017. *Lancet* 2018;392:2091-138.
3. Hay SI, Abajobir AA, Abate KH, Abbafati C, Abbas KM, Abd-Allah F, *et al.* Global, regional, and national disability-adjusted life-years (DALYs) for 333 diseases and injuries and healthy life expectancy (HALE) for 195 countries and territories, 1990–2016: A systematic analysis for the Global Burden of Disease Study 2016. *Lancet* 2017;390:1260-344.
4. Murray CJ, Lopez AD, World Health Organization. The global burden of disease: A comprehensive assessment of mortality and disability from decesses, injuries and risk factors in 1990 and projected to 2020: summary. World Health Organization; 1996.
5. Sung YT, Wu JS. The visual analogue scale for rating, ranking and paired-comparison (VAS-RRP): A new technique for psychological measurement. *Behav Res Methods* 2018;50:1694-715.
6. Green C, Brazier J, Deverill M. Valuing health-related quality of life. A review of health state valuation techniques. *Pharmacoeconomics* 2000;17:151-65.
7. Stouthard ME, Essink-Bot ML, Bonsel GJ, Barendregt J, Kramers P, Van de Water HP, *et al.* Disability weights for diseases in the Netherlands. Rotterdam: Department of Public Health, Erasmus University. 1997.
8. World Health Organization. WHO methods and data sources for global burden of disease estimates. WHO 2017;1:17.
9. Sommerfeld J, Baltussen RM, Metz L, Sanon M, Sauerborn R. Determinants of variance in health state valuations. *Summ Meas Popul Heal Concepts, Ethics, Meas Appl.* 2002;549-80.
10. Read JL, Quinn RJ, Berwick DM, Fineberg H V, Weinstein MC. Preferences for health outcomes. Comparison of assessment methods. *Med Decis Making* 1984;4:315-29.
11. Ock M, Ahn J, Yoon S-J, Jo M-W. Estimation of disability weights in the general population of South Korea using a paired comparison. *PLoS One* 2016;11:e0162478. doi: 10.1371/journal.pone.0162478.
12. Neethling I, Jelsma J, Ramma L, Schneider H, Bradshaw D. Disability weights from a household survey in a low socio-economic setting: How does it compare to the global burden of disease 2010 study? *Glob Health Action* 2016;9:31754.
13. Kannuri NK, Anchala R, Murthy GVS, Gilbert CE. Strengthening diabetes retinopathy services in India: Qualitative insights into providers' perspectives: The India 11-city 9-state study. *Indian J Endocrinol Metab* 2016;20(Suppl 1):S59-66.
14. Sharma K. Burden of non communicable diseases in India: Setting priority for action. *Int J Med Sci Public Health* 2013;2:7-11.
15. Elias MA, Pati MK, Aivalli P, Srinath B, Munegowda C, Shroff ZC, *et al.* Preparedness for delivering non-communicable disease services in primary care: Access to medicines for diabetes and hypertension in a district in south India. *BMJ Glob Health* 2018;2:e000519.
16. Karimi M, Brazier J, Paisley S. How do individuals value health states? A qualitative investigation. *Soc Sci Med* 2017;172:80-8.
17. Weiss MG. Stigma and the social burden of neglected tropical diseases. *PLoS Negl Trop Dis* 2008;2:e237.