Chapter 11.2

Are disability weights universal? Ranking of the disabling effects of different health conditions in 14 countries by different informants[1]

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Summary measures of population health (SMPH) provide a "common metric" for a wide range of health evaluations such as effectiveness of interventions or efficiency of health systems (WHO 1996). This metric adds "disability" (i.e. non-fatal health outcomes) to mortality, and thus results in a more realistic measure than what is obtained by measuring mortality alone (Murray and Lopez 1997). In the course of this book various attempts are made to develop composite health measures that combine information on mortality and non-fatal health outcomes to represent population health in a single number. However, the cross-cultural applicability of these methods as well as the equivalence of derived preferences has not been standardized globally, regionally and nationally.

Because of international comparability, great care must be taken in the construction of SMPH which involves value judgements in the calculation of the disability component in these measures captured in "disability weights" (also known as *preferences, valuations, or utilities*). A disability weight assigns a single numerical value to a given state that is worse than perfect health. We convert multiple aspects of disability (e.g. cognition, mobility, self-care, interpersonal relations, work or household activities, etc.) into a single number. The health status descriptions of some selected domains are transformed through a "*cognitive exercise*" to a value or preference that is usually elicited by the importance given to the condition, or by trading risks, time, money or personal lives. Usually a perfectly healthy state is given a weight of 0, and death is equivalent to a weight of 1. This disability weight, as a matter of fact, has the same anchor value for disability-adjusted life years (DALYs) or quality-adjusted life years (QALYs). The main difference is the sign. For DALYs the value is taken negatively (disability), for QALYs positively (quality of life).

In the original Global Burden of Disease (GBD) study these weights were determined with professional health care providers through the person trade-off (PTO) method (Nord 1995). Professional health care providers were chosen because they are thought to be familiar with health conditions and their outcomes, a familiarity that makes it easier to draw the often complex comparisons between the impacts of different disease states required by the PTO protocol.

These professionals were assumed to be representative of society as a whole. This theoretical assumption, however, requires empirical support. For empirical testing, preference measures should also be obtained from a variety of other groups such as policy-makers, persons with disabilities and others to see how these measures converge. Moreover, these disability weights are presumed to be universal, that is, equal across countries and cultures. There is a clear need for more systematic testing across different cultures, different informant groups, and alternative forms of measurement. The present study was in fact motivated by these concerns about the universality of the disability weights used in the construction of SMPH.

To obtain disability weights, a range of tools exist that measure the importance given to the condition (visual analog scales), or trading risks (standard gamble), time (time trade-off), money (willingness to pay) or groups of individuals (person trade-off). Of these methods none was perfectly suited to our needs for this study because we aimed to use the simplest possible method to test the invariance across various cultures and informants. Within a larger study on the cross-cultural applicability of a proposed revision of the *International Classification of Impairments, Disabilities and Handicaps* (WHO 1980; 1997), a sub-study examined whether expert ratings on the disabling effects of different health conditions were universal, in the sense of being stable across cultures and informant groups. Ranking was the chosen method rather than PTO because ranking requires less specialized participants, less time and no technical knowledge. The original GBD study protocol also used an ordinal ranking exercise in addition to a variant of the PTO protocol and required respondents to reconcile the discrepancies between the two during a deliberative phase (Murray and Lopez 1996).

The current study is the first independent attempt to replicate the results of the exercise carried out within the framework of the GBD study in different cultures with different informants. It should, however, be pointed out that because of the difference in methods, this study can only test the assumptions of the GBD study (e.g. stability of disability scores across cultures and informant groups). With the ranking exercise *disability weights cannot be derived* because no cardinal value was obtained with this method. Since the main aim of this present study is to test the underlying assumptions of the original GBD work, and since the alternative of using PTO requires much more time (two days per group compared to 10–15 minutes per person for rankings), the choice of method is justified be-

cause it was conceptually understandable, culturally meaningful and applicable in different cultures.

Specific aims of the study

1. Are there statistically significant differences in the ranking of the disabling health conditions by key informants from different countries?
2. Are there statistically significant differences in the ranking of the disabling health conditions by respondents from different informant groups (medical professionals, allied health professionals, health policymakers, consumers or caregivers)?
3. Could the ranking of the disability weights of the GBD study be replicated with a different methodology?
4. What are the underlying patterns in respondent ratings of disabling effects of health conditions?

Methods

Participants

The ranking was part of the key informant interviews. Informants from a total of fourteen countries participated in this study: Canada, China, Egypt, Greece, India, Japan, Luxembourg, the Netherlands, Nigeria, Romania, Spain, Tunisia, Turkey, and the United Kingdom of Great Britain and Northern Ireland. Thus, all WHO regions were represented.

"Key Informants" were defined as those who by virtue of their position and knowledge have an understanding of disability that makes them representative spokespersons for their culture. For each site, 15 informants were to be selected, composed of three individuals from each of the following five groups:

- Medical professionals (e.g. MD, psychiatrist, psychologist, nurse)
- Allied health professionals (e.g. social worker, case worker)
- Policy-makers or opinion leaders in the area of disability services
- Individuals with a disabling physical health condition (or their caregivers)
- Individuals with a disabling health condition in the area of alcohol, drugs or mental health (or their carers).

The final number of participants included in this study ($N = 241$) varies slightly by country, but essentially, the quota of 15 was achieved in each country (see Table 2).

Materials

Informants responded to a questionnaire including both open-ended and closed-ended items. In rank-ordering disability, key informants were presented with a deck of 17 cards listing different health conditions with short descriptions (see Table 1). They were instructed to rank them from the most disabling to the least disabling condition. The "most disabling condition" was described as that which would make daily activities such as dressing, feeding, moving around, and meeting basic day-to-day responsibilities very difficult; the least "disabling" as that which would not interfere with these daily activities. Codes were assigned to the 17 conditions, with 01 representing the most disabling, and 17 the least disabling. Thirteen of the 17 health conditions were adapted from the 22 indicator conditions of the GBD study (see Table 1) to measure the burden of disabilities and diseases within the DALY framework. The selection of the original indicator conditions was based on pre-tests showing that certain diseases were difficult to grasp by the respondents in certain cultures. Methodologically, ranking 22 conditions has also been shown to be too much of a burden on the respondent (Trotter et al. 2001). In addition to the original conditions, we had a special interest in including alcohol and drug use disorders and HIV infections, which were assumed to rank with "medium" disabling consequences and to show cultural differences (Mäkelä et al. 1981).

Procedure

Each key informant was presented with a brief overview of the interview and its purpose. The interviewer then began by asking questions about demographic variables and their experience in the area of disabilities, followed by open-ended questions on language and disability, identification of and societal reactions to disability associated with selected conditions (e.g. difficulties with walking, psychotic symptoms, low intelligence, alcohol and drug related problems). The interview included the collection of demographic data, and questions about the language of disability in the culture, about existing compensation systems for disability, about the social stigma of disabilities, and about other societal reactions to disabling health conditions. This process served to frame the issue of the ranking exercise within the context of understanding the disabling consequences of health conditions. The assessment of social disapproval or stigma for different health and social conditions was identified using an 11-point rating scale with the endpoints labelled as none (= 0) and extreme (10). Once the open-ended portion of the interview was completed, the interviewer presented the respondent with the 17 different cards, and administered the instructions to rank the conditions in terms of their disabling effects. Finally, the respondent was asked to complete a self-administered questionnaire that addressed expected difficulties with everyday activities in a selection of health conditions and included the assessment of stigma related to various disabilities.

Non-parametric statistics for ordinal level variables were used to analyse the data. Overall ranking was established on the basis of median ranks. For conditions with the same median the arithmetic mean of rankings was taken as a second criterion.

To test for differences between countries or informant groups, the Kruskal-Wallis rank order analysis of variance for one factor was used. Kendall Tau-B correlations were computed to measure the association between different rank orders (Hays 1973). Statistical analyses were carried out with SYSTAT 8.0 and with StatXact 3.1 (exact calculations of Kendall Tau correlation and its confidence intervals).

Results

Table 1 gives an overview of the relative rank order for the 17 different health conditions, ranked from most disabling to least disabling. Overall, quadriplegia was considered the most disabling condition, followed by dementia (rank 2), active psychosis (rank 3), and paraplegia (rank 4). At the opposite end of the spectrum, having vitiligo on the face (least disabling = rank 17), being infertile when a child is desired (rank 16), and having

Table 1 Rank order of disabling effect of health conditions by severity

Health condition	*Rank*	*Median*	*Mean*	*Standard deviation*	N
Quadriplegia*	1	2	3.3	3.2	241
Dementia*	2	4	4.9	3.6	241
Active psychosis*	3	4	5.3	3.6	241
Paraplegia*	4	5	5.9	3.3	241
Blindness*	5	6	6.8	4.0	241
Major depression*	6	6	7.2	3.8	241
Drug dependence	7	8	7.8	3.9	222
HIV-positive	8	9	8.8	5.2	239
Alcoholism	9	9	9.2	3.6	241
Total deafness*	10	10	9.4	3.7	241
Mild mental retardation*	11	10	9.9	3.6	241
Incontinence	12	10	10.2	4.1	239
Below the knee amputation*	13	11	10.2	3.7	241
Rheumatoid arthritis*	14	12	11.5	3.6	241
Severe migraines*	15	12	11.6	3.8	240
Infertility*	16	16	14.6	3.6	238
Vitiligo on face*	17	16	15.0	2.4	238

* Adapted from the 22 conditions used in the GBD Study; the other 9 conditions were severe sore throat, fractured radius in a stiff cast, Down syndrome without cardiac malformation, severe anemia, recto-vaginal fistula, watery diarrhoea, 2 standard deviations below height/weight, erectile dysfunction, and angina.

severe migraines (rank 15) were deemed least disabling. Overall, the conditions at both ends of the spectrum, that is the most disabling and the least disabling conditions showed lower variability than the conditions in between.

There were, however, deviations from this order across countries. Table 2 shows that in the Netherlands, for instance, active psychosis is seen as more disabling compared to the overall sample rank. Interestingly, being HIV-positive is considered relatively less disabling in Japan, Luxembourg, Spain, Turkey and the United Kingdom, whereas it is considered the most disabling in Egypt and Tunisia. In general, HIV is the health condition with the most rank variation which may be due to relative frequency and special views about this particular disorder. In Egypt and Tunisia, HIV ranks as more disabling than quadriplegia. This is mainly because of the image of HIV as a stigmatizing illness in these countries.

Statistically, the differences between countries were significant for 13 out of 17 health conditions on the Kruskal-Wallis test. Only quadriplegia, paraplegia, below the knee amputation and mild mental retardation did not show rank differences between countries at the 0.05 significance level. It is interesting to note that three out of the four conditions that are judged uniformly across countries are prototypical physical disabilities. The fourth, mild mental retardation also shows little variation though it is less uniformly rated compared with the other three.

Although there are statistically significant differences of ranking between countries, the convergence of judgments is also quite evident. The Kendall Tau rank correlations between different countries averaged 0.61, which can be considered relatively high given the variability of cultures and experts participating. Within this average, there are, however, clear cultural differences for some comparisons, e.g. Turkey and the Netherlands have a Kendall Tau rank correlation of 0.41 (95% confidence intervals CI: 0.14–0.69), while the Netherlands and Tunisia correlate at 0.29 (CI: 0.03–0.56). On the high end, Luxembourg and Spain correlated at 0.87 (CI: 0.74–0.99), and Romania and India at 0.82 (CI: 0.72–0.92). The overwhelming majority of rank correlations ranged between 0.5 and 0.7 (typical confidence intervals: Kendall Tau: 0.50; CI: 0.27–0.73; Kendall Tau: 0.60; CI: 0.35–0.85. A table with all bivariate correlations between countries can be obtained from the first author).

The rank order ratings of different informant groups are summarized in Table 3. Only five out of 17 health conditions had significantly different rank orders between different informant groups: quadriplegia, HIV, total deafness, mild mental retardation, amputation below the knee. Interestingly, physical disorders are again the most prominent, but in this case as conditions with the most significant differences. The rank orders of Table 3 also reveal significant differences between some informant groups that might be expected to have convergent views. For example, the ratings between health professionals in the physical rehabilitation sector show the largest differences compared with consumers/caregivers in the

Table 2 Disability ranks associated with different health conditions by country

Health condition (Rank order in total sample)	Country													
	Canada	*China*	*Egypt*	*Greece*	*India*	*Japan*	*Luxem-bourg*	*Nether-lands*	*Nigeria*	*Romania*	*Spain*	*Tunisia*	*Turkey*	*UK*
Quadriplegia (1)[a]	2	1	2	1	1	2	1	3	1	1	1	2	1	2
Dementia (2)	3	8	3	3	2	1	2	2	6	2	2	3	2	1
Active psychosis (3)	1	5	4	2	5	3	3	1	3	3	4	6	4	4
Paraplegia (4)[a]	4	4	8	4	4	5	7	7	2	4	5	4	3	5
Total blindness (5)	8	3	5	9	3	4	4	9	5	5	6	5	5	8
Major depression (6)	5	6	7	7	6	8	6	4	4	7	3	7	11	3
Drug dependence (7)	7	2	6	6	11	7	5	6	10	11	8	11	7	M
HIV-positive (8)	10	9	1	5	7	13	15	12	8	8	13	1	14	14
Alcoholism (9)	9	10	11	8	10	10	8	5	13	13	7	12	10	6
Total deafness (10)	11	12	10	13	9	6	9	11	15	9	9	13	12	12
Mild mental retardation (11)[a]	6	11	9	12	12	15	10	13	11	10	10	9	8	7
Incontinence (12)	15	13	13	10	8	14	13	15	7	6	12	10	6	11
Below-the-knee amputation (13)[a]	12	7	12	11	14	9	11	14	12	12	11	8	9	13
Rheumatoid arthritis (14)	14	14	17	15	13	11	14	10	14	15	15	16	13	10
Severe migraines (15)	13	15	16	14	15	12	12	8	9	14	14	17	15	9
Infertility (16)	16	17	14	16	17	16	17	16	16	16	17	15	17	16
Vitiligo on face (17)	17	16	15	17	16	17	16	17	17	17	16	14	16	15
N	15	15	16	15	43	18	16	13	15	15	18	15	15	12

Note: Ranking ranges from 1 (most disabling) to 17 (least disabling). Most disabling condition defined as that which would make carrying out the activities of daily life very difficult; and the least disabling condition that which would not interfere with activities of everyday life. M=missing data; item not given.

a. no significant differences between countries on $\alpha = 0.05$ level (Kruskal Wallis rank order analysis of variance).

Table 3 Disability ranks of different health conditions by informant group

Health condition (Rank order of total sample)	*Medical professionals*					*Allied health prof. (N=51)*	*Health policy-makers (N=35)*	*Consumers/ Caregivers*	
	Physical (N=14)	*ADM (N=35)*	*Ph&ADM (N=14)*	*Other (N=11)*	*Total (N=74)*			*Physical (N=30)*	*Mental (N=45)*
Quadriplegia	1	1	3	1	1	1	1	1	1
Dementia	2	2	1	2	2	3	2	4	2
Active psychosis	5	3	2	4	3	2	3	2	3
Paraplegia	3	4	4	3	4	5	4	6	4
Blindness	6	5	5	5	5	6	7	5	5
Major depression	4	6	6	6	6	4	5	8	6
Drug dependence	9	7	7	8	7	7	9	7	8
HIV-positive	10	11	15	11	11	12	6	3	7
Alcoholism	13	10	10	9	9	8	10	9	9
Total deafness	12	8	9	7	8	10	11	11	12
Mild mental retardation	14	13	8	12	13	9	8	10	13
Incontinence	7	12	14	13	12	11	12	12	11
Below the knee amputation	8	9	12	10	10	13	13	13	10
Rheumatoid arthritis	11	14	11	15	14	14	14	15	14
Severe migraines	15	15	13	14	15	15	15	14	15
Infertility	16	16	17	16	16	16	17	17	16
Vitiligo on face	17	17	16	17	17	17	16	16	17

same sector, with respect to rankings in the above conditions, and physical conditions in general. Overall, the rank orders between different informant groups had an average correlation of 0.76.

The research design allowed us to measure the influence of social disapproval or stigma on disability rankings for a subset of the conditions. There was a consistent effect for all tested relationships in the direction that higher stigma was associated with higher disability rankings, although the effect size was small (less than 0.10 on average for Kendall Tau correlations). In summary, stigma has a measurable but very small effect on disability rankings.

The resulting summary ranking across all judgments is very similar to the ranking of the experts in the GBD study (Murray 1996), derived with a different methodology (PTO). The respective rank order correlation is 0.77 for Kendall Tau (CI: 0.40–1.0; $z = 3.66$, $p < 0.01$). The only notable difference occurs for severe migraine, which ranked third in the GBD exercise, and eleventh in the present study. However, conditions varied in the way in which judgements were elicited for migraine in the two exercises. In the GBD exercise experts were continuously reminded that

they should consider the artificial case of one continuous year of severe migraines with the consequence of staying in bed most of the time, in making their judgements. The failure to remind respondents repeatedly of this may have led to the comparability of the nominally same condition, severe migraine, being compromised. Without severe migraine, the respective correlations increase to 0.97 in the case of Kendall Tau (CI: 0.89–1.0; $z = 4.39$; $p < 0.01$). This level of convergence is so high that we can actually speak of almost identical rankings.

Discussion

The main result of this study is that the rankings of the disabling effect of health conditions were found to be relatively stable across countries, informant groups, and methods, although there is some variation. The very high correlations between the GBD study and this study, as well as the fairly high level of agreement between the 14 countries in this study, and between eight informant groups, provide support for this statement. Thus, in the eyes of the respondents, the relative burden of different health conditions in terms of disability is fairly similar across the world. However, the results also indicate that there are sometimes quite pronounced differences between cultures and informant groups. These differences are large enough to be further explored in a systematic way.

From a theoretical point of view, there is no reason for disability weights to be universal. The actual burden of disability or activity limitations is modulated by many factors such as the environment, e.g. the burden of disability for individuals with paraplegia is likely to depend on the availability of helpful devices (wheelchairs, specialized cars, specialized workplaces) and social support. Clearly, in this respect there are differences between countries, and these differences should be reflected in the disability weights attached to certain health conditions. Thinking of differences of frequencies and interventions available to quadriplegic or blind persons in different cultures, it is tempting to think that disability weights would naturally vary from country to country. Since countries differ in providing treatments for different conditions (e.g. quadriplegia, HIV or depression), in our research we separated treated and untreated populations in order to evaluate the impact of interventions to reduce disability.

A secondly conclusion of this study is that valuation and description in the terminology of the GBD study may not be strongly related. The ranking exercise is directed exclusively at the extent of disabling conditions. All diseases have to be ranked solely on the basis of their disabling effects. On the other hand, the PTO methodology asks for a valuation (i.e. trade-off of persons with that disease). The basic comparisons are obtained through questions comparing the lives of 1 000 healthy people for one year versus 2 000 blind people dying. Thus, other aspects than just the disabling effects of health conditions (e.g. prognosis, pain, mood impact, public opinion) may drive the valuations.

In general, it can be said that the physical conditions are ranked more uniformly than the mental conditions across countries. This implies that though physical conditions such as quadriplegia, paraplegia and below-the-knee amputation are as a group viewed differently from conditions such as active psychosis, any differences are more likely to be a feature of individual respondent characteristics than of cultural differences. Also of note is the fact that the conditions with the most variation are mental conditions that lie in the mid-range of the rankings.

Any ordinal ranking can only indicate the relative effects of disability from different health conditions (e.g. active psychosis results in more disability than major depression), and not the absolute effects, which may vary tremendously between countries because of different formal and informal health and social support systems. Also, high agreement of health professionals or other key informants as experts does not necessarily mean that the real disability associated with the different health conditions is similarly uniform across countries. In different instances in the past, the consensus among experts has been shown to be at variance with actual behavior of subjects (Rehm and Gadenne 1990; Single 1997). Thus, the next step should be to conduct empirical studies to examine whether selected health conditions really have the same disabling effects in different countries and cultures across the world, and if they are stable with respect to different assessment methods and different informant groups.

It is indeed important to explore the methodology to elicit disability weights for cultural variation. Concepts of death, birth, time as well as valuation across these constructs may vary across cultures. While the use of disability weights assume an "etic" anthropological perspective, the "emic" qualities of these constructs may provide valuable insight and context such as framing of questions, and elicitation techniques. Our field experience has yielded important reactions from the subjects that their personal characteristics (e.g. risk aversion) or personal ethics may play an important role in determining how they rank these conditions. Therefore the elicitation technique, interview and tools provided for deliberation are of prime importance. Professionals may show a better understanding of different health conditions but they may also show professional prejudices towards the interventions and spontaneously relate them to resource allocation.

Finally, we would like to emphasize the importance of empirical data on disability and their universality. The valuation function is largely determined by the health status. We should objectify the components of health and study their interactions. The more these measures are based on empirical data, the more robust and universal will they become. An actual measurement of how subjects function with different health conditions in different cross-cultural contexts ought to be coupled with valuation exercises across cultures and respondent groups (Üstün and Chatterji 1998). This may then provide valuable insights into the determinants of values that people assign to disabling health conditions. If public policy decisions

like resource allocation and priority setting are to be based on evidence, we need to make sure that they are formed by all parties concerned and based on "real life" data obtained by using the highest scientific standards.

Notes

1 A more detailed version of this paper has been published previously in the *Lancet* (Üstün et al. 1999).

2 In collaboration with WHO/NIH Joint Project Advisors and Principal Investigators—Robert Battjes (NIDA, USA), Bridget Grant (NIAAA, USA), Cille Kennedy (NIMH, USA), Shen Yu Cun (China), V. Mavreas (Greece), R.S. Murthy (Bangalore, India), Hemraj Pal (Delhi, India), R. Thara (Chennai, India), M. Tazaki (Japan), C. Pull (Luxembourg), H. Hoek (the Netherlands), A. Odejide (Nigeria), R. Vrasti (Romania), J.L. Vazquez-Barquero (Spain), A. Chaker (Tunisia), A. Gogus (Ankara, Turkey), N. Dedeoglu (Antalya, Turkey), K. Ogel (Istanbul, Turkey), D. Mumford (United Kingdom).

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