Chapter-7:

Results from the community survey in Andhra Pradesh to measure health state valuations.

The methodological aspects of the Andhra Pradesh Health State Valuation study 1999 (APHSV99), reliability, and validity of these measurements were described in chapters 2-6. To recapitulate, the study consisted of two arms, namely (a) multiple method deliberative health state valuation (MDHSV) workshops, and (b) community based measurement of health state valuations through household survey of Kondakkal village in Andhra Pradesh. A six-dimension five-level (6D5L) system was used to describe health states to valuers. The 6D5L description system was built by expanding upon the EuroQol five dimension three level system. Cognition was added as the sixth dimension. Severity levels were described in five categories. In addition, the 6D5L system includes a graphic description system to communicate with partially literate and illiterate valuers. The MDHSV workshops, and test or retest valuations by 100 respondents in the community survey provided data required to estimate reliability and validity of the measurements. The socio-demographic profile of the valuers in both arms of the study was also described earlier. Participants for the MDHSV workshops were urban professionals recruited by convenience, although efforts were made to broadbase their professional backgrounds. The sample for the community survey is randomly drawn from the voters list, with balanced representation of males and females and adults in all age groups. In this chapter, results from the community survey are presented and discussed. Findings of the APHSV99 study are summarised. We start with an examination of the distribution of valuations by the community for different health states. In the second section, disability weights obtained from this (APHSV99) study with results from other studies in the world are compared. The next section deals with operational issues of how to incorporate local health state valuation into National Burden of Disease (NBD) estimate. Then a few future research needs for health state valuation, based on our experience in this study and unresolved issues are discussed. The fifth and final section presents the summary and conclusions from the health state valuation study.

Distribution of valuations for different health states:

The distribution of disability weights, as measured through the community survey, was plotted for each health state. The following three pages, show these plots for 22 health states in Figures-7.1-3. The X - axis in all these plots is the disability weight obtained through VAS. The Y - axis is the fraction of total valuations for the respective health state. The total number of valuations range from 230 - 280 for most health states, except for the core conditions. The reader may recall that the core conditions, namely watery diarrhoea, mild diabetes, mild tuberculosis, severe continuous migraine, unipolar major depression and quadriplegia, were included in all sets of health states. So the total number of valuations for these six core health states is around 1010 each. One characteristic that stands out for most health states valued in this study is that the distributions are unimodal. A few health states, like continuous moderate back pain and severe heart failure show a bimodal distribution. The two modes in these cases are close to each other. Unimodal distributions for most health states would suggest that members of the community do share some commonality in the valuation of health states. This is important for measurement of population health status. Without any consensus on valuations to be assigned to different health states, it would be impossible to combine non-fatal health outcomes into a measure of population health status. However, the crystallisation of the valuations for different health states clearly vary. The distribution plots in Figures-7.1-3 have been arranged on the basis of the extent of diffuseness and clarification of valuations for different health states, and labelled as Group A, B, C respectively for identification (Table-7.1). The classification is based on a visual examination of the frequency plots for each health state and hence is subjective. As we gather more experience from examination of health state valuation distributions, it will be useful to develop objective criteria for the classification. For example, we have used size of tallest frequency bin as a criteria to aid our judgement. The valuations for Group A health states in Figure-7.2 are all quite diffused. The tallest frequency bin is about 0.2 or less. Take, for example, the distribution of disability weights for infertility. The valuation for infertility appears to be distributed more or less uniformly between 0 to 0.7 and tapers off thereafter. This tells us that most people would not consider infertility to be worse than, say 0.7. But within the broad range of (0, 0.7), opinions vary a lot.

Figure - 7.1 Distribution of disability weights. Group - A health states.

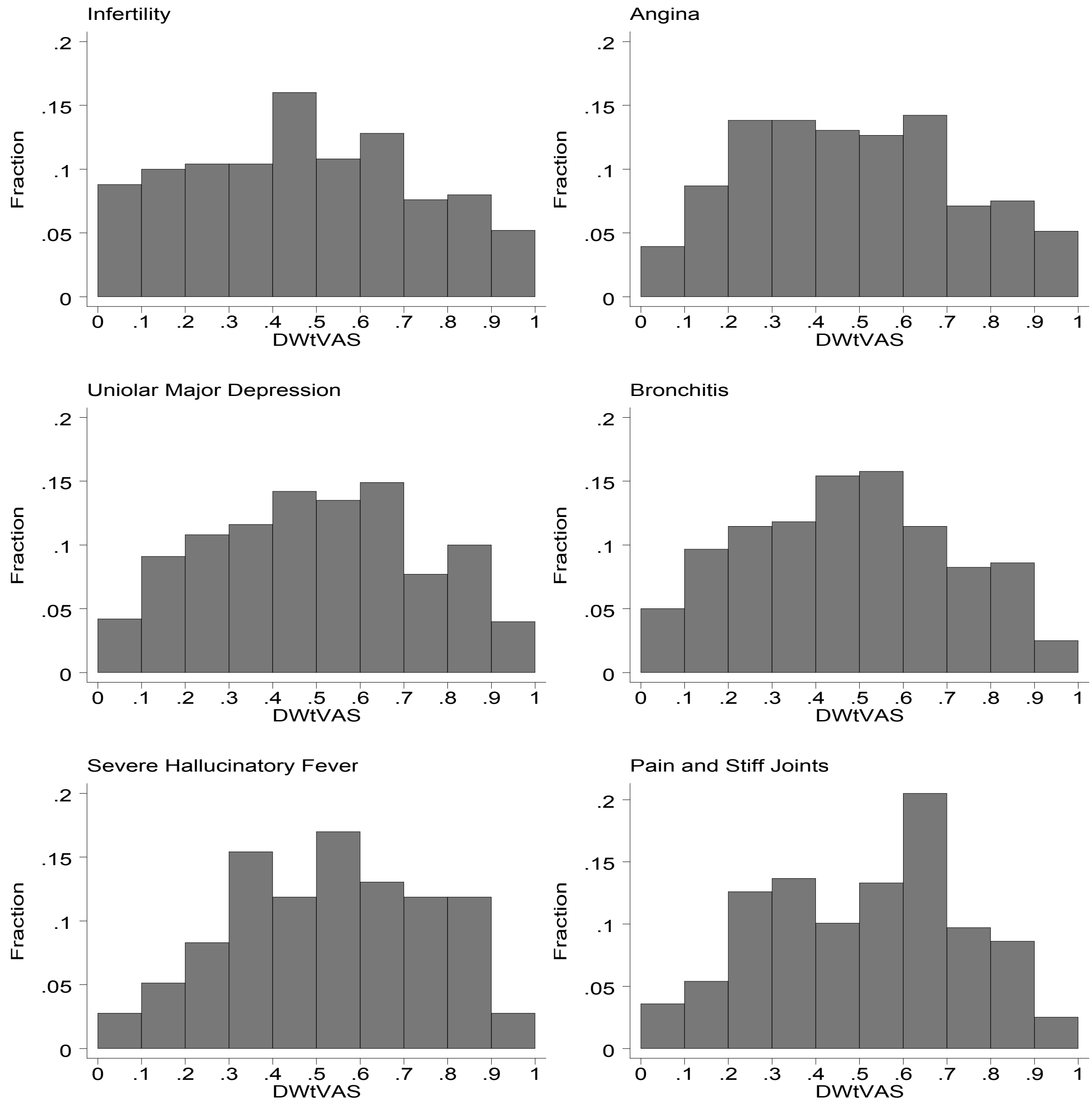

Infertility
Angina
Uniolar Major Depression
Bronchitis
Severe Hallucinatory Fever
Pain and Stiff Joints
Fraction
DWtVAS
0
.05
.1
.15
.2
0 .1 .2 .3 .4 .5 .6 .7 .8 .9 1

Figure - 7.2 Distribution of disability weights. Group - B health states.

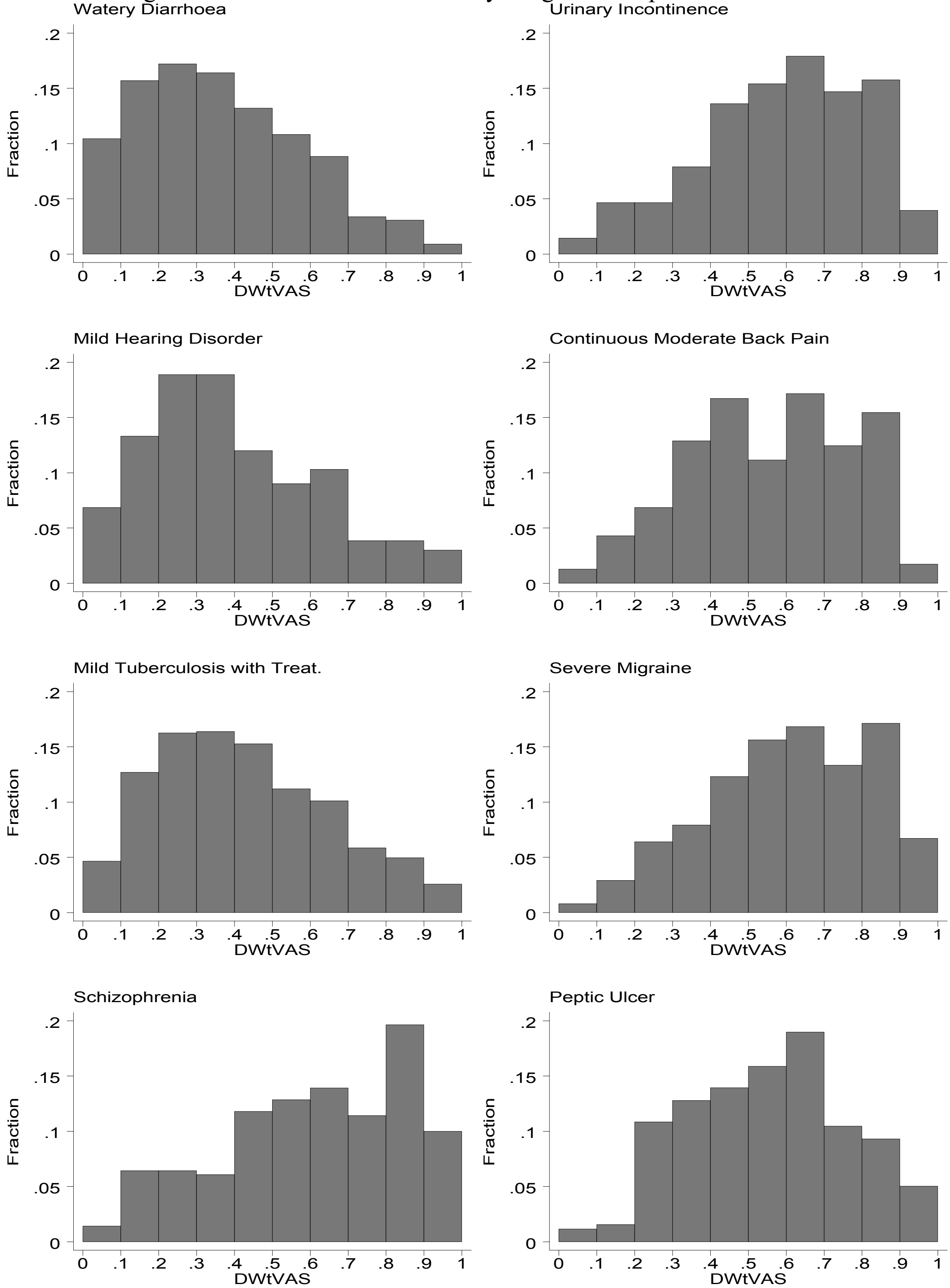
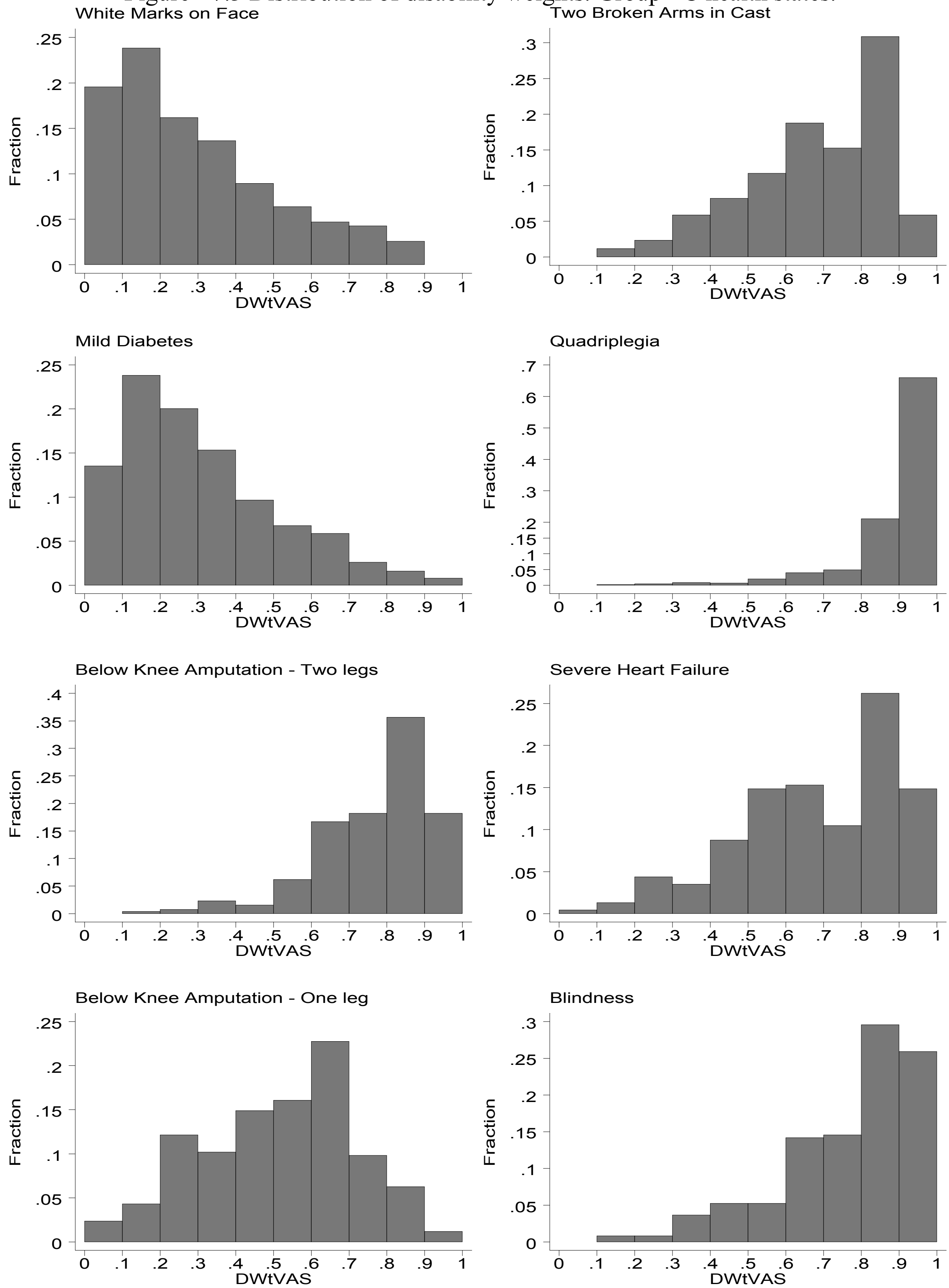


Figure - 7.3 Distribution of disability weights. Group - C health states.



The eight health states organised into group B show less diffused and more crystallised valuations. The tallest frequency bin for all these plots is about 0.2 or less, i.e., same as in case of group A. However, the distributions are less diffuse and show increasing mass around the peaks. The Group C plots in Figure-7.3 show more peaked distributions, usually skewed to the right or left, depending on whether the health state concerned has low or high disability attached to it. For example, the distribution for quadriplegia has concentrated disability weights in the range (0.9, 1). The distribution for quadriplegia is unique in the sense that the fraction of valuations in the tallest bin is about 0.7, i.e. 70% valuers valued disability due to quadriplegia in the range (.9,1). The fraction of valuations in the tallest bin, for all other health states included in group C is in the range of (0.25, 0.4).

Table-7.1 Classification of health states by degree of crystallisation of community valuations

Group A: Diffused	Group B: Intermediate	Group C: More crystallised
Infertility	Watery diarrhoea	White marks on face
Angina	Urinary incontinence	Two broken arms in cast
Unipolar major depression	Mild hearing disorder	Mild diabetes
Bronchitis	Continuous moderate back pain	Quadriplegia
Severe hallucinatory fever	Mild tuberculosis with treatment	Below knee amputation- two legs
Pain and stiffness in joints	Sever continuous migraine	Severe heart failure
	Schizophrenia	Below knee amputation - one leg
	Peptic ulcer	Blindness

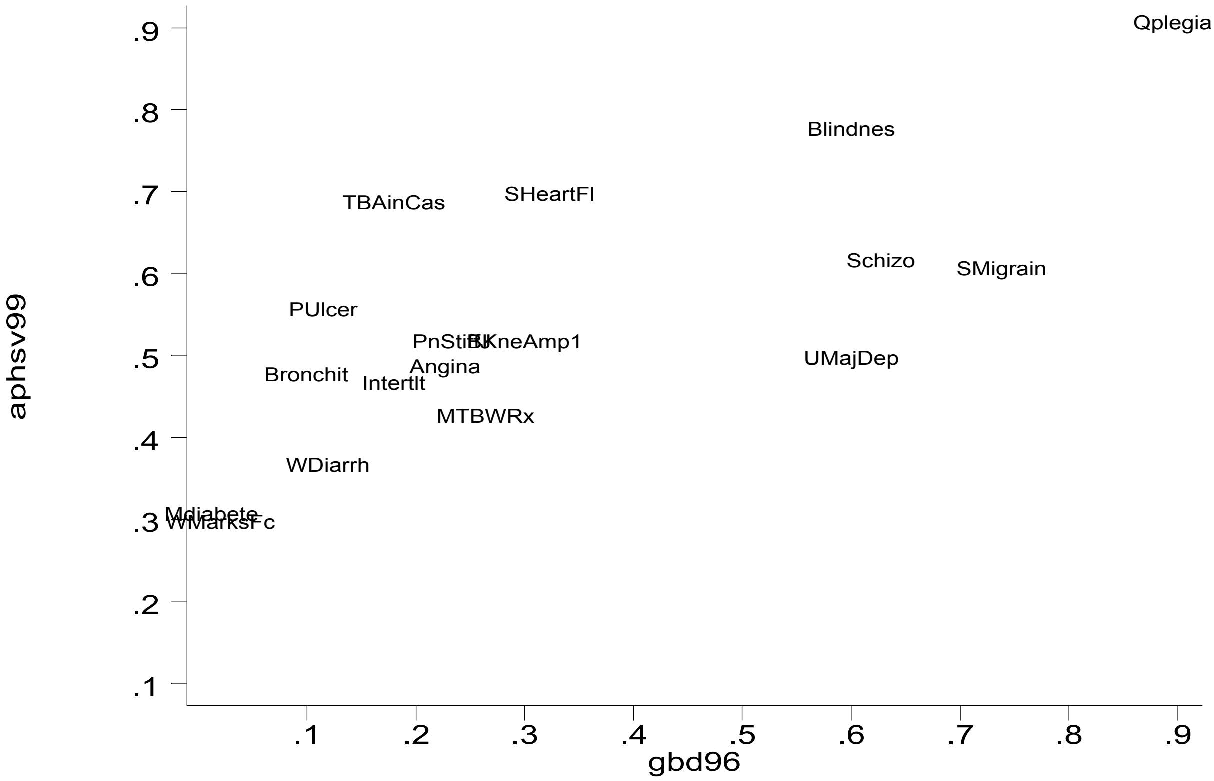
The differences in the degree of crystallisation of valuations in the community are consistent with our hypothesis about the nature of health state valuation process described earlier. Individual level valuations defined in fuzzy sets with different degrees of clarification would explain different degrees of crystallisation of the distributions at the community level. The degree of crystallisation of valuation in the community for different health states has important implications for NBD estimation. The range of disability weight inputs for each of the health states included in the sensitivity analysis should depend on distribution of the valuation in the community. Health states with diffused valuations would call for a wider range of disability weight inputs. For the health states with crystallised valuations in the community, a narrower range would suffice. Parametric[1] description of the distributions should facilitate uncertainty analysis of NBD estimates, and will enable further analysis to

[1] We conjecture is that the sub family of unimodal beta distributions $(\alpha > 1, \beta > 1)$ may serve well to describe distribution of health state valuations. Further work is needed to examine goodness of fit, estimate the distributions and study factors that may contribute to differences in the distribution of health state values. For a description of the family of beta distributions, see Cassela and Berger (1990, p107-110).

improve our understanding of what contributes to diffuseness and crystallisation of community valuation of health states.

Comparison with disability weights reported by other studies:

Figure-7.4 Scatter plot of GBD96 disability weights versus APHSV weights



The GBD96 study generated a set of disability weights for the global burden of disease estimates (Murray and Lopez, 1996), referred here as the GBD96 disability weights. More recently a group in Netherlands have elicited a set of disability weights (Stouthard and others, 1997). These are commonly referred to as the Dutch disability weights. The Dutch study used PTO and VAS valuation methods. All 38 valuers were urban professionals. Most of them were from medical and health background and some from other areas.

Table-7.2: Comparative statement of mean disability weights from different studies.

Health state	This study			GBD96	Dutch study	
	6D5L	Wkshp	Survey		6D3L	Mean
Angina	111321	0.460	0.480	0.227	111121	0.080
Below knee amputation one leg.	322211	0.510	0.510	0.300		
Below knee amputation two legs	433221	0.690	0.780			
Blindness	323122	0.640	0.770	0.600	123121	0.430
Bronchitis	112311	0.350	0.470	0.099	112211	0.170
Common cold	112211	0.120		0.000	111211	0.020
Continuous moderate back pain	212321	0.360	0.550		212211	0.060
Infertility	111131	0.370	0.460	0.180		0.110
Mild hearing disorder	112211	0.210	0.390		112111	0.110
Mild tuberculosis with treatment	111221	0.420	0.420	0.264	112211(40%) 222221(60%)	0.290
Moderate anaemia	112121	0.290		0.011		
Mild diabetes	111121	0.290	0.300	0.012	111111(90%) 112221(10%)	0.070
Peptic ulcer	112321	0.360	0.550	0.115	111111(20%) 111211(60%) 112211(10%) 112221(10%)	0.020
Pain and stiffness in joints	222331	0.490	0.510	0.233	122211	0.210
Quadriplegia	554341	0.860	0.900	0.895	332111(70%) 333221(30%)	0.840
Severe hallucinatory fever	444333	0.770	0.530			
Severe heart failure	434531	0.730	0.690	0.323	223321	0.650
Severe migraine	113431	0.500	0.600	0.738		
Schizophrenia	234244	0.790	0.610	0.627-0.667	222223	0.810
Two broken arms in cast	154321	0.590	0.680	0.137-0.180		
Unipolar major depression	124142	0.600	0.490	0.600	223232	0.760
Urinary incontinence	113331	0.500	0.590			
Watery diarrhoea	111211	0.250	0.360	0.086-0.119		
White marks on face	111131	0.240	0.290	0.020		

[1] Following mappings are used for comparisons with GBD96 disability weights: Bronchitis Ë Lower respiratory infection - chronic sequela, Common cold Ë Upper respiratory infections - episodes, Below knee amputation - one leg Ë Amputations leg, Mild tuberculosis Ë Tuberculosis HIV zero negative cases age 15-44, Mild diabetes Ë Diabetes cases, Severe heart failure Ë Congestive heart failure,

Table-7.2 shows the disability weights obtained by this study from the MDHSV workshops and community-based survey along with 6D5L profiles of the health states. In addition, the GBD96 weights and Dutch disability weights are indicated for the closest comparable conditions. For the Dutch disability weights, the 6D3L profiles are also shown. Actually the authors (Stouthard and others, 1997) named this as the EQ5D+ profile. The profile consists of six dimensions as in this study but has three severity levels instead of the five levels in this study[2]. We have substituted EQ5D+ with 6D3L to reflect the similarity and differences between profiles from the two studies.

The GBD96 and Dutch disability weights are quite similar to each other. They differ from the weights obtained in this study (APHSV99) by a fairly wide margin in most cases. Figure-7.4 shows the scattered plot of GBD96 weights versus the weights obtained by this study. At first sight, the APHSV99 disability weights appear to be a linear function of the GBD96 weights, with the former giving higher disability weights to most health states. In other words, the community in Andhra Pradesh effectively adds a fixed disability weight of about 0.3 to the valuations obtained by the GBD96. But there are some exceptions. In lower end of the disability scale (0.1,0.4), a few health states are given much higher disability weight by the APHSV99 study than what a linear function would predict. Such as , bronchitis, two broken arms in cast, peptic ulcer, and severe heart failure for instance. In the upper end of the scale, the gap in the two valuations is relatively smaller. Unfortunately there are not many common estimates in the middle range disability weight around 0.5. If we assume that the valuations from two studies, in the mid- range would be more similar and closer to each other, then the relationship of the two estimations would be sigmoid. In lower range, APHSV99 weights would be much higher, followed by a flattening of the curve in middle ranges and higher weights by APHSV99 again in the upper ranges.

One reason why the APHSV99 disability weights appear higher could be due to the fact that these are essentially VAS measurements. Although, we did not find much difference in magnitude of the VAS and TTO weights in this study, we cannot rule out the possibility that the VAS response is overestimating true disability weights for milder conditions. To see how APHSV99 weights compare with VAS measurements elsewhere, we obtained results from a health state valuation study among public health professionals using VAS. These valuations were done in the Burden of Disease and Cost-effectiveness workshop held at Lorne, Australia in November, 1999. Let's call this the BODWorkshop99-VAS weights.

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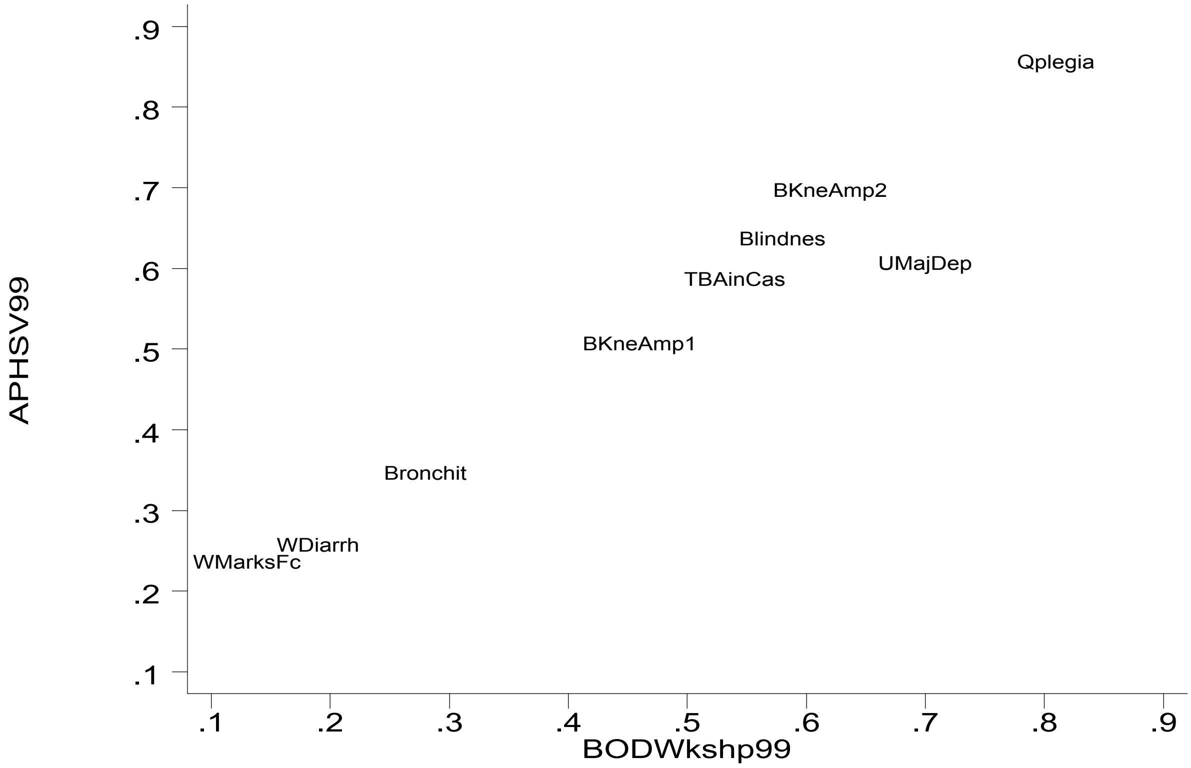
[2] Also note that the Dutch study has labelled their results as disability weights but has in fact provided health state weights. So their weights were transformed to disability scale (disability weight = 1- health state weight) for purposes of this comparison.

Figure-7.5 shows a scatter plot of APHSV99-VAS weights and BODWorkshop99-VAS weights. Data for nine health states, common to both studies, is used. Clearly, the APHSV99-VAS weights are higher by about 0.1 for all the nine health states.

Figure-7.5 Mean VAS disability weights from APHSV study and BoD workshop 1999



In Table-7.3 we compare the APHSV99-VAS disability weights with the Dutch disability weights for five indicator conditions found to be common to both the studies. Table-7.3 shows the mean disability weights from these two studies, as well as the 6D3L (in case of the Dutch study) and 6D5L (for APHSV99) descriptions. For four out of five conditions APHSV99-VAS weights are higher than the corresponding Dutch study weights. The difference is 0.17 for mild diabetes and more than 0.2 for the remaining three conditions. In case of pain and stiffness of joints (rheumatoid arthritis) the Dutch study weight is higher. This exception can be explained by the fact that the Dutch study valued severe rheumatoid arthritis and the APHSV study used a less severe description of pain and stiffness of joints. Overall, APHSV99-VAS disability weights appear to be higher than the Dutch disability weights by about 0.2.

Table-7.3: Mean VAS disability weights from APHSV99 and Dutch health state valuation study 1997

Health State	Dutch Study 1997		APHSV99	
	6D3L	Disab. Wt	6D5L	Disab. Wt
Angina	111211	0.16	111321	0.46
Blindness	123121	0.38	323122	0.64
Back pain	212211	0.13	212321	0.36
Mild diabetes	112221	0.12	111121	0.29
Pain and Stiff Joints	222331	0.70	222331	0.49

It is worth while to ponder, what could be reason for higher disability weights assigned by the community in the APHSV99 study? Firstly, we can not rule out measurement error altogether. Further improvements in description of the health states may increase the spread of valuations toward endpoints of the scale, particularly in the low disability direction. Secondly, differences in method of valuation would explain a part of the difference between the APHSV99 weights and GBD96 weights. Thirdly, real differences in valuations by the community from the valuations given by the public health experts in the GBD96 group of valuers is also plausible. We have seen that the VAS valuations by the community in AP are higher than the VAS valuations by urban professionals in the Dutch study and public health experts in the Burden of Disease workshop 1999. One possible explanation is that the community in AP views any disruption in perfect health as substantial deterioration. If we suppose the community in Andhra Pradesh views any deviation from perfect health more seriously, such that a fixed disability weight is attached to the binary states of perfect health versus illness. In that case, the disability weight assigned by the community to a specific illness will be a combination of the fixed disability weight for the state of any illness plus the additional disability specific to the concerned health state. Based on the comparisons of APHSV99 data with results from other studies, we conjecture that the size of the fixed disability weight may be any where between 0.1 to 0.3. However, each of the above possibilities and other unknown factors need to be investigated further, for us to have a more define opinion about the determinants of differences in valuation of health states by different persons and at different sites.

Incorporating Local Health State Valuation into NBD estimate:

How do we integrate the findings from the local health state valuation studies into the NBD estimation? We could use the local values directly as inputs for the computation of the YLD component, if we have valuations for all disabling sequela of the health states included in the NBD study. Two possibilities, in the absence of direct measurements for all disabling sequela, would be:

1. To identify 6D5L profile for all disabling sequela. Statistically predict the disability weights for all disabling sequela using the data from local community valuations.
2. To use the GBD96 system of disability weights with appropriate modifications to account for local differences in the valuation of health states.

A procedure for identification of 6D5L profile for health states has been described earlier. We used this process to identify 6D5L profile for the index health states. One option would have been to continue with that process and identify 6D5L profiles for all disabling sequela. Using health state valuations for the index states, we can thus statistically estimate a bridging model to predict the disability weight for every 6D5L profile. See for example Dolan (1997) where data for estimation of the bridge model has been collected. However, identification of 6D5L profiles for all disabling sequela could not be pursued, mainly due to lack of funding. However, further studies are planned for identification of 6D5L profiles and further analysis of data collected in this study.

In the meanwhile, I follow the second option, to estimate disability weights for the AP Burden of Disease Estimate, using the GBD96 system of disability weights. Two sets of disability weights are estimated. These are: (a) APHSV99-VAS weights, and (b) APHSV99-Torrance-TTO weights. The APHSV99-VAS weights are based on the mean disability weights obtained from the community survey in Kondakkal village. The APHSV99-Torrance-TTO weights are a transformation of the APHSV99-VAS weights through the power function estimated by Torrance (1976) modelling the relationship of VAS and TTO valuations. For the APHSV99-VAS weights, the following three models were fitted to the 17 matching pairs of mean disability weights from the APHSV99 and GBD96 studies. The GBD96 system of disability weights describe weights by age and sex. For most sequela, the weights are similar across age sex groups. Hence, disability weights for the adult females in age group 15-44 were taken from the GBD96 study to estimate the relationship with APHSV weights.

Model	Adjusted R2
$DWt^{AP} = 0.3878 + 0.4514G$	0.52
$DWt^{AP} = 0.375 + 0.5547G - .1214G^2$	0.49
$DWt^{AP} = 0.28 + 1.925G - 4.214G^2 + 3.144G^3$	0.59

Figure-7.6 APHSV99-VAS weights for AP versus GBD96 weights

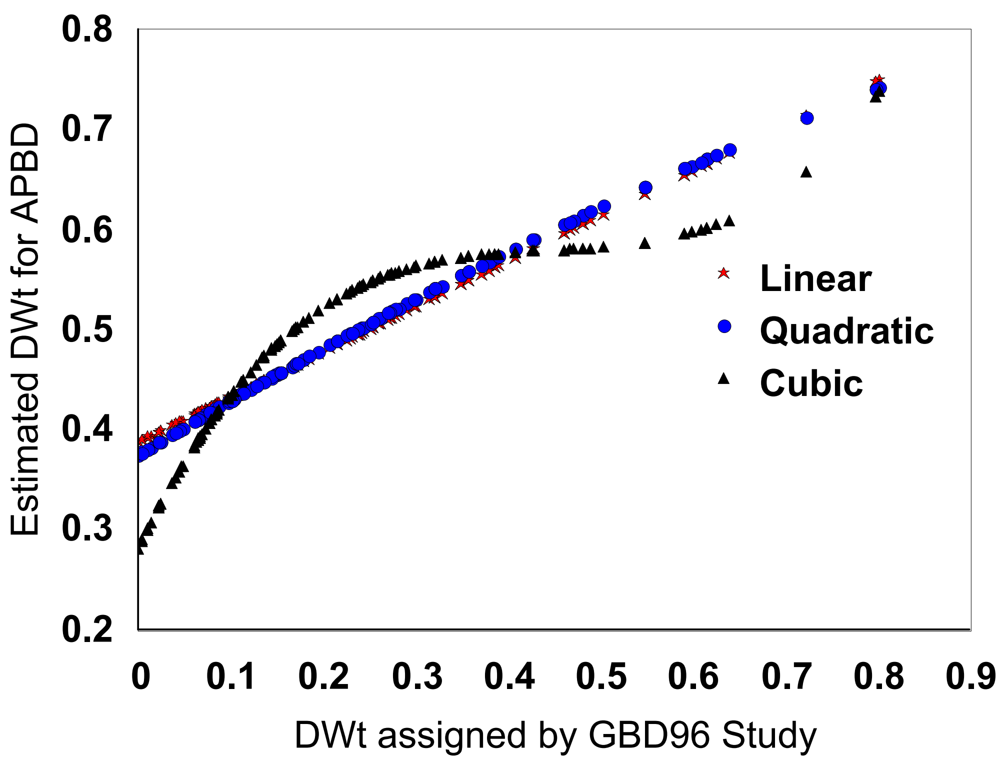


Figure-7.6 compares plots of predicted values from the three models. The linear and quadratic functions are similar in terms of the projected estimates. The cubic model appears to fit the two data slightly better. This model has a comparatively higher adjusted R2. I have used this function to project disability weights of all sequela to estimate the burden of disease in Andhra Pradesh. The projected weights have not been provided, since they can be computed from the weights published by Murray and Lopez (1996, p412-416).

Future research needs for health state valuation:

More extensive research is required if community-based measurements of health state valuations are to be used in summary measures of population health status. Apropos, the nature of the valuation function and its characteristics for different health states, we have seen, from test and retest data, that ordinal rankings are not consistent with conventional notion that the individual has a single valued function. Conventional economic theory of well-ordered preferences assumes that an individual has a clear pair wise ordering of alternatives. Our observations in this study suggests that the valuation in a person's mind for a given health state may be a multivalued function. The range of values over which the valuation function is defined is a function of the health state and the extent of cumulative deliberations by the individual. This hypothesis needs to be tested through more studies. There are two research questions here: whether the health state valuation functions are multivalued or single valued and if the health state valuation function is indeed multivalued, which factors determine the range of values (i.e. the image space) it can assume. The incidence/prevalence of the health state, associated taboo, severity level, health state description system, and deliberations by the individual are some factors worth exploring . The extent to which a person has deliberated about a health state may affects the size of the health state valuation image space. Our conjecture is that, upto some point, increased opportunity for deliberations about the value of a health state would narrow down the health state valuation image space. This has important implications for the methodology to be adopted for community measurement of health state valuations. If increased opportunity for deliberations do indeed lead to narrowing of the health state valuation image space, then repeated measurements accompanied by an opportunity for deliberation and reflections on the concerned health state would improve the reliability of measurements. If there are no such relationships, then a larger sample size may be the only means to improve reliability of health state valuation measurements from a community.

So far health state valuation studies have used a set of indicator conditions to obtain valuations from a community and have used various interpolation strategies to assign disability weights to other health states. Such interpolated values are estimates of mean health state values that might have been measured from the community. This study has clearly brought out the reference that health states vary in the extent to which community has crystallised valuations for it. The extent to which community valuations for a health state is diffused or crystallised has important implications for its use in summary measures of population health status. The mean disability weight may be adequate enough for health states with crystallised community valuations. In case community valuation for a health state is diffused, the mean does not have much significance as an input for summary measures of population health state. For such health states, either an uncertainty analysis by multiple simulations or a sensitivity analysis giving endpoint values from the range of valuations would be desirable. In other words, the distribution of valuations in the community is of as much importance as the estimated mean of health state valuations. It is difficult to predict the distribution of all health states from the distribution of indicator conditions. Hence, future research will have to directly measure valuation by communities for all health states. Operationalising such measurements in single studies may be difficult. But appropriate strategies can be found out once we are clear of the need for direct measurements from communities for as many health states as is possible.

Thirdly, more research is required to study the efficacy of health state description systems in reliably communicating the same state to all individuals. This line of research will be more culture-specific. Two areas need attention: the semantic content of statements used to describe the severity levels along each dimension and the validity and reliability of the graphical description system. In this study we have developed a graphical description system. The graphics were chosen from out of about five to six alternatives, by showing the pictures to a convenience sample of persons. It will be useful to study more formally the validity and reliability of the graphical description system in communicating a given health state. Such research projects should include plans for further refinement of the graphics. These studies are important for measurement of health state values in partially literate, as well as multicultural communities. Once we know enough about semantically equivalent statements of severity levels and have equivalent graphics, it should be possible to develop multimedia description systems.

Finally, more studies are required about the nature of relationship between different measurement methods. For example, the VAS and TTO valuations in the study was found to be similar. This is different from earlier findings that TTO generally gives lower disability weights for milder conditions, compared to VAS. Future studies should carefully document details of measurement techniques, measurement context, interviewer and valuer characteristics, so that factors contributing to differences in valuations between the two methods and between sites can be identified.

Summary and conclusions from the AP Health State Valuation study, 1999 (APHSV99):

An important contribution of this study is the advancement of methodological aspects of health state valuation in developing country communities. A health state description system incorporating a graphical description component was developed to facilitate communication in partially literate communities. Some deliberative tools for conduct of health state valuation workshops for educated persons were developed. The experience gained for valuation of health states in developing country settings, we hope, will help in future research.

Apropos the substantive aspect of the subject, this study has shed some light and raised many questions about the nature of the health state valuation process in our minds. Analysis of test and retest data on ordinal ranking of health states, valuation of own health state and differences in distribution of valuations at the community level, all lead us to hypothesise that the true health state valuation in our minds is a multivalued fuzzy set with different degrees of clarification. Conventional theory that the true valuation is a single valued function is not consistent with our observations, and appears intuitively less appealing.

Health state valuation studies will have to contend with the problem of measurement error, as is the case in most other areas of psychometric measurement. Unfortunately, we do not yet have a fully worked out measurement model for health state valuations. Most studies use reliability measures conceived under the classical test theory developed in the context of educational testing and measurement. In the field of educational measurement, it is generally assumed that the object of measurement is distributed normally with some variance. If the variance component attributable to subjects is high, then educational tests are considered reliable. We have seen that community valuation of health states follow different distributions. Health state valuations are not personal endowments that can be assumed to be distributed normally in a fashion similar to, say, intelligence. If community valuation for a health state is well crystallised, then the true variance of subjective valuations will be less as compared to health states where the valuation is more diffused. The generalisability theory allows for a more realistic modelling of the measurement process. Reliability of the health state valuations in this study can be said to be moderate, on the basis of obtained generalisability coefficient (0.56 to 0.67) and conventional reliability measures like ICC (0.6), within valuer correlation (around 0.6 to 0.8) and within valuer ICC (0.6 to 0.8). However, a more appropriate measurement model of health state valuation will help in correct estimation of reliability.

The incidence of measurement error and our present understanding about the nature of valuation process would suggest that community level valuation of health states requires a large sample size as also repeated measurements. Large sample sizes would help minimise the measurement error for mean values estimated form community surveys. Repeated measures, it is anticipated, will occasion repeated deliberation by the valuers and thereby help clarification of their value sets. The tradeoffs between sample size and repeated measurements will have to be studied.

The health state valuation instruments used in this study have good content validity, considering that they have been derived by many people working from similar conceptual definitions of health and are based on empirical listing of health state attributes by some large studies. The criterion validity of health state valuation instruments cannot be tested, since we do not have a good standard for this purpose. The instruments have shown good convergent validity. Measurements from multiple methods like, the visual analogue scale, time tradeoff, and person tradeoff agreed quite well with each other. Incorporation of ordinal rank consistency requirement in valuation tasks appeared to facilitate deliberation.

Ordinal rank consistent visual analogue scaling (VAS) turned out to be a fairly valid tool for the measurement of health state values. The VAS valuations agreed quite well with valuations from other methods like time trade-off and person trade-off. In fact VAS did better in some cases. For example, the incidence of counterintuitive valuations was lower for VAS.

Considering its simplicity, and the feasibility for community surveys, VAS appears to be the instrument of choice for measurement of health state valuations.

So far, researchers have focused on the mean valuations. This study has demonstrated that community valuation of all health states do not follow the same distribution. The degree of crystallisation of valuations appears to be health state dependent. Valuations for some states are quite diffused, for example, infertility. Valuations for some others are well crystallised, for example, quadriplegia. Differences in distribution of valuations by the community for different health states has policy implications, and hence, should be the subject of further research. This implies that health state valuation studies using a few indicator conditions will not provide required inputs for summary measures of population health. Data on indicator conditions, allow for statistical decomposition of multiattribute valuations and model based estimation of disability weights for other health states. These statistical models can estimation mean valuations only, but can not provide any information about distribution. The only way to understand distribution of valuations for all health states is to measure valuations for each of them in the concerned community.

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