

## Disability and Quality of Life

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**Citation:** Chakrabartty SN (2022) Disability  
and Quality of Life . Health Sci J. Vol. 16 No.  
12: 989.

### Abstract

**Objectives:** To review methodological issues of disability measuring tools (DMTs) and Health-related Quality of life (HRQoL) and to transform item-scores and health-profiles to continuous scores satisfying desired properties

**Method:** Using data driven weights, item score are converted to equidistant score (E) and value of Health-profile is obtained as weighted sum (Y). E-scores and Y-scores are standardized separately to Z-scores and further transformed to proposed scores (P) in [1, 100]. Scale score as sum of item-wise P-scores follow Normal distribution.

**Results:** P-scores offer better arithmetic aggregation, meaningful comparisons, relative importance of domains, predicting disability scores using HRQoL scores as predictors and statistical inferences for longitudinal or snap-shot data. Methods described to obtain responsiveness, theoretical reliability, factorial validity and equivalent scores of different scales.

**Discussion:** Proposed scores satisfying desired properties facilitate parametric analysis and computing psychometric concepts have theoretical advantages including meaningfulness of operations, better comparisons and use HRQoL scores as predictor of disabilities.

**Keywords:** Quality of Life; Likert item; Normal distribution; Reliability; Validity; Responsiveness

**Received:** 25-Nov-2022, Manuscript No. iphsj-22-13116; **Editor assigned:** 28-Nov-2022, Pre-QC No. iphsj-22-13116 (PQ); **Reviewed:** 12-Dec-2022, QC No. iphsj-22-13116, **Revised:** 19-Dec-2022, Manuscript No. iphsj-22-13116 (R); **Published:** 26-Dec-2022, DOI: 10.36648/1791-809X.16.12.989

### Introduction

Disability limits major life activities and refers to impairments resulting from disease or injury or old ages affecting physical, mental, emotional and psychosocial functions. Nature and extent of disability depends on types and severity of disease. Thus, people with disabilities form diverse and heterogeneous groups. Measurements of outcomes for different diseases and treatments need to satisfy desired properties of measurements and facilitate meaningful aggregation of item scores leading to meaningful comparisons of individuals or a sample of individuals. Assessing severity of disability and changes due to treatment, care, etc. are being done using bio-markers and patient-reported outcome (PROs) measures which gives discrete functional deficits like limitations in mobility or performance of daily living and socially defined life activities i.e. Health related Quality of life (HRQoL).

Large numbers of instruments are there to assess general and disease-specific disabilities including post-operation disabilities. Similarly, HRQoL instruments could be generic or disease-specific. Disease-specific HRQoL instruments are more responsive than

generic ones [1]. However, use of generic measure together with disease-specific measure is common.

Both disability measuring tools(DMTs) and HRQoL assessing tools usually use summative scores of Likert items with  $K$ -number of response-categories (levels) where  $K= 3, 4, 5, 6, \dots$  or combination of items with different values of  $K$  including binary items. However, dimensions covered, numbers of items (scale length), width of items (number of response-categories), scoring methods, distributions of test scores, etc. are different for different instruments and can influence areas like treatment effect, patient care, policy issues, etc. Mean and standard deviation (SD) of Likert scales with  $K$ -point items increase as  $K$  increases [2]. Ordinal, discrete, skew, ceiling and floor effects of Likert/rating data often produce bias, violate assumptions of parametric analysis and normality checks are required [3]. Issues regarding levels of rating scales emphasizing statistical perspectives in using such scales were reviewed [4]. No agreed criterion for assessment of HRQoL was observed [5] who favoured 'health-profiles' for patients reflecting perceived health (or departures from health) in each selected dimension. EQ-5D-5L is popular where health-profile of

a person is a 5 digit number, in five pre-selected dimensions. For example, health-profile 1-3-1-4-5 for the  $i$ -th person is different from 5-4-1-3-1 for the  $j$ -th person or any permutation of 1, 2, 3, 4 and 5 with repetitions. While 1-3-1-4-5 indicates extremely poor health-state in the 5<sup>th</sup> dimension, the reverse is indicated by 5-4-1-3-1 implying different types of disabilities and clinical needs of the two persons. However, assigning numerical value to an EQ-5D-5L pattern is not straightforward. Method of calculating value-sets for EQ-5D-5L with fixed upper bound 5-5-5-5-5 and lower bound 1-1-1-1-1 proposed by [6] can be questioned on soundness of estimates of each dimension-level combination and often lead to situations where variance may vary at different values i.e. heteroskedasticity.

The paper describes method of transforming raw scores of items and also health-profiles to continuous scores following normal distribution, parameters of which can be estimated from data. Desirable properties of such transformations discussed including statistical testing and better calculation of reliability, validity, responsiveness (changes over time), equivalent scores of tests, etc.

## Literature survey

Disability dimensions are different for different types of disease. HRQoL dimensions in leukaemia may vary depending on prognosis, disease-specific concerns, and treatment-specific concerns [7]. Evaluation of treatment-effect requires selection of appropriate HRQoL measure for the patient or patient groups receiving treatment. Such selection depends on health dimensions relevant to the set of patients and also psychometric qualities of the DMT and HRQoL instruments. For example, a tool to assess disabilities for patients after myocardial infarction (MI) should take into account the individual's responses to living with the disease, in terms of occupational, social, personal, sexual relationships, etc. and acute chronic physical consequences of the disease.

Measurements in the context of cardiovascular diseases (CVD) include assessment of outcomes, disease severity, impact of implemented interventions, patients' perception of their health-status before and after treatment, etc. Cervical spondylogenic myelopathy (CSM) is a disabling condition usually resulting from arthritic compression and consequent injury of the cervical spinal cord. Assessment scales are there for quantification of changes in CSM severity between pre- and post-operations to study outcome of surgery. Comparison of five stroke scales showed that measures of impairment are not adequate for describing health outcomes of surviving stroke patients [8]. Limitations in higher levels of physical functioning are not fully covered by these measures [9]. Four health-status measures were compared and no instrument performed uniformly as "best" or "worst" [10]. Scoring of Sickness Impact Profile (SIP) items are inconsistent, illogical, ambiguous, and overall scores are difficult to interpret [11]. Inconsistent Factor structures of Minnesota Living with Heart Failure (MLHF) questionnaire have been questioned [12]. Factor analysis of General Health Questionnaire (GHQ-12) showed multi-factors against the claim of one-dimensional tool [13]. Studies suggested on responsiveness and comprehensibility of Myocardial infarction dimensional assessment scale (MIDAS)

along with equivalence of measurement [14]. Responsiveness could not be evaluated for QoL after Myocardial Infarction (QLMI/MacNew) [15]. High Cronbach's alpha of Myelopathy Disability Index (MDI) got reduced for each category when MDI-items were splitted into 4-categories (walking, hand function, transfers and dressing) [16]. Raw scores of each dimension of Late-Life Function and Disability Instrument (LLFDI) are transformed to scaled scores [0–100] based on one-parameter Rasch model assuming only one latent dimension underlying all the items (unidimensionality) and local independence (uncorrelated items) [17]. If all the items are uncorrelated, sum of item variance = test variance  $\Rightarrow$  Cronbach alpha = 0. European Myelopathy Score (EMS) had lowest sensitivity to change among the seven scales of Severity of CSM and Post-Operative Improvement [16].

Observations from illustrative DMTs and HRQoL tests:

- Directions of scales differ. While higher score indicates less disability for LLFDI, SF 36

(Generic QoL scale), EMS, reverse is true for SIP, NHP, MDI, etc.

- Test length and test width, number of subscales are different.
- Total score of an individual in SF-36 is not provided. The same for EQ-5D-5L is not unanimous.
- Subscales with more number of items contribute more to total test scores. Need is felt to define battery reliability in terms of reliability of constituent sub-tests.
- Scales differ with respect to dimensional structure, cut-off scores, sensitivity of changes, etc. Better is to convert discrete test scores to continuous scores enabling detection of small changes and finding equivalent scores of different scales for integration of scales.
- Like most HRQoL measures, NHP does not provide relative-importance across dimensions. Thus, comparison of dimensions is difficult [18].
- Scales use binary items or  $K$ -point Likert items or combination of both. Barring EQ-5D-5L, other instruments primarily consider summative Likert scores, despite inherent problems of ordinal Likert scores described below:

## Major Problems of Likert scales

Response-categories like *very often*, *often*, *once in a while*, *almost never* and *never* could be dubious as individuals differ on frequency of an action to consider it as often. Pertinent question is how often is *often*? [19]

Patients differ on their subjective responses on physical, emotional and social functions and may not reflect true situations. For example, subjects reporting disturbed sleep showed normal sleep-patterns when monitored objectively [20].

Likert data fail to satisfy equidistant property thus, mean, SD are not meaningful [21]. Distance between successive response-categories is not uniform and unknown [22]. Validity of parametric analyses of Likert-type data is often unclear [23]. Equidistant property demands constant distance between two successive response-categories. Unknown and

different distributions of item scores and resultant dimension/ test scores make it difficult to interpret  $X \pm Y$  and to find joint distribution of  $X \pm Y$ . Addition of two random variables  $X + Y = Z$  is meaningful, if  $P(Z = z) = P(X = x, Y = z - x)$  for discrete case and

$$P(Z \leq z) = P(X + Y \leq z) = \int_{-\infty}^z \left( \int_{-\infty}^{z-t} f_{X,Y}(x, t-x) dt \right) dx$$

for continuous case. Thus, it is necessary to know probability density function (pdf) of each variable being added and their convolution.

Summative scores assigning equal importance to the items and dimensions are not justified due to different values of correlations of item/dimension scores with total score and different factor loadings.

Distribution of scale scores get distorted if "Zero" is taken as an anchor value of Likert items (e.g. MDI, SIP) etc. Frequent zero responses to an item lowers variance and correlation with the item. Better is to consider anchor values as 1, 2, 3, 4, 5 etc. Decomposition of Likert scores using multipoles for reduced heterogeneity of responses of the respondents/raters was proposed [24], where anchor values were changed suitably before calculation of multipoles moments. Replacement of anchor values by linear transformation, keep nature of generated data invariant.

Summative Likert scores do not consider patterns of getting a particular score. Different responses to different items can generate tied test score for several persons. Thus, the scale fails to discriminate the respondents with tied score.

Different values of  $K$  distorts shape of distribution of scores and influence item/test parameters like reliability, validity, more by number of levels than the underlying variable. 4, 5, and 7-point scales of the same items were administered and number of options influenced the psychological distance between options, particularly for the 7-point scale [25]. Studies to find optimum number of response-categories to maximize reliability, validity produced contrasting results.

To find equivalent scores of 5-point and 7-point scales, regression equations,  $X_7 = \alpha_1 + \beta_1 X_5$  and  $X_5 = \alpha_2 + \beta_2 X_7$  were used [26]. However, equating is different from forecasting [27]. Variance  $(\widehat{X}_7 \neq \text{Variance } X_7)$ . Equated scores by regression equations are not interchangeable.

## Proposed methods

### Pre-adjustments

Rename anchor values as 1, 2, 3 avoiding zero. Convert each item to be positively related to the test score i.e. higher item score indicates higher level of disability and impairments.

Transforming scores of Likert items and EQ-5D-5L items in stages proposed so that proposed item scores ( $P_i$ ) follows Normal distribution and  $1 \leq P_i \leq 100$  [28].

Convert raw score of each Likert item to continuous, monotonic equidistant scores through weighted sum ensuring  $5W_5 - 4W_4 - 4W_4 - 3W_3 = 3W_3 - 2W_2 = 2W_2 - W_1 = \text{Constant} > 0$  for  $K=5$  (say),

where positive weights based on frequencies of levels of items are different for different items. If a subject chooses say 4-th response-category, his/her weighted score for the item exceeds the transformed score if he/she had chosen 3<sup>rd</sup> response category

For sample size  $n$ , define  $W_{ij} = \frac{f_{ij}}{n}$  as proportion of responses in

$j$ -th level of  $i$ -th EQ-5D-5L item.  $W_{ij}$ 's are data-driven weights

satisfying  $W_{ij}$ 's and  $\sum_{j=1}^5 W_{ij} = 1$  and facilitate single value to health-

profile of a person as weighted sum. For example, profile of 1-2-3-4-5 for  $i$ -th person  $W_{11} + W_{22} + 3(W_{33}) + 4(W_{44}) + 5(W_{55})$

Which is different from 5-4-3-2-1 for  $j$ -th person?  $Y_j = W_{11} +$

$$W_{22} + 3(W_{33}) + 4(W_{44}) + 5(W_{55})$$

Scores as weighted sum are expected values and continuous [29].

II: Standardize  $E$ -scores or  $Y$ -scores of each item by

$$Z_i = \frac{E - \bar{E}}{SD(E)} \text{ or } Z_i = \frac{Y - \bar{Y}}{SD(Y)} \sim N(0,1)$$

III: Transform  $Z_i$ 's to proposed score  $P_i \in [1,100]$  by which follows normal distribution.

$$P_i = (99) \left[ \frac{Z_{ij} - \text{Min}_{Z_{ij}}}{\text{Max}_{Z_{ij}} - \text{Min}_{Z_{ij}}} \right] + 1$$

Proposed scale score of an individual is the sum of his/her scores in each dimension or sum of  $P$ -scores of all items, following normal where variance depends on covariance between pair of  $P$ -scores. Scale scores of QoL can also be converted to the proposed  $P$ -scores.

### Properties

1. Irrespective of item formats,  $P_i$ 's in  $[1,100]$  are continuous, monotonic, with normality and satisfy desired properties like:

$P_i$ : Meaningful arithmetic aggregation of item scores to get scale scores ( $P_{Scale}$ ) reflecting positions of individuals in the trait continuum.

$P_i$ : Computation of mean, variance and other moments of  $P_{Scale}$

$P_i$ : Same range of scores for each item

### Benefits of normally distributed $P_{Scale}$

Help in parametric analyses, estimation of population mean ( $\mu$ ), population variance ( $\sigma^2$ ), testing statistical hypothesis like

$H_0 : \mu_1 = \mu_2$   $H_0 : \sigma_1^2 = \sigma_2^2$  etc. either for longitudinal data or snap-shot data.

Provide unique ranks to the individuals.

Quantify effect of small change in  $i$ -th dimension ( $\Delta P_i$ ) to

scale score  $P_{Scale}$  by elasticity =  $\frac{\text{Percentage change in } P_i}{\text{Percentage change in } P_{Scale}}$ ,

facilitating ranking of the dimensions.

Find responsiveness of the scale in terms of percentage progress/deterioration of the  $i$ -th patient between two successive time periods by  $\frac{P_{it} - P_{i(t-1)}}{P_{i(t-1)}} \times 100$ , which also indicates effectiveness

of a treatment plan. If higher  $P$ -scores  $\Rightarrow$  higher disabilities,  $P_{it} - P_{i(t-1)} > 0$  indicates progress in  $t$ -th period over  $(t-1)$ -th

period. Reverse is true for  $P_{it} - P_{i(t-1)} < 0$ . Similarly, progress for a group of patients can be assessed where  $\bar{P}_t < \bar{P}_{(t-1)}$ . Testing of significance of progress since ratio of two normally distributed variables follows  $\chi^2$  distribution.  $H_0: Progress_{(t+1)over t} = 0$  may avoid need to find minimal important difference of a scale for comparing changes over time among the group of patients.

Plotting of progress/deterioration of one or a group of patients across time can be used to study progress pattern i.e. responses to treatments from the start.

Help to fit regression equation of DMT on HRQoL and use HRQoL scores as predictor of disabilities after adjusting demographic characteristics, after checking normality of error scores.

-  $x_0$  of test  $X$  and  $y_0$  of test  $Y$  are equivalent ( $x_0 \Leftrightarrow y_0$ ) if

$$\int_{-\infty}^{x_0} f(X) dx = \int_{-\infty}^{y_0} g(Y) dy \quad (1)$$

where  $f(X)$  and  $g(Y)$  denote pdf of  $X \sim N(\mu_1, \sigma_1)$  and  $Y \sim N(\mu_2, \sigma_2)$  i.e. area under the curve  $f(x)$  up to  $x_0 =$  area of the curve  $g(y)$  up to  $y_0$  [30]. The equation (1) can be solved using Standard Normal Table. Finding equivalent score-combinations is possible even if the scales have different number of items or dimensions.

## Reliability

Normally distributed  $P$ -scores enables estimation of item variance, scale variance and estimation of Cronbach alpha of DMT or HRQoL at population level. Reliability can better be found as per the theoretical definition from single administration [31]. This involves dichotomization of a test/dimension in two parallel  $g$ -th and  $h$ -th subtests with lengths  $\|x_g\|$  and  $\|x_h\|$  and angle between the two vectors representing the subtests ( $\cos\theta_{gh}$ ). For sample size  $N$ , error variance of a dimension is

$$S_E^2 = \frac{1}{N} [X_g^2 + X_h^2 - 2X_g X_h \cos\theta_{gh}] \quad (2)$$

And reliability of  $i$ -th dimension as per theoretical definition is

$$r_{tt(i)} = 1 - \frac{S_E^2}{S_X^2} = 1 - \frac{X_g^2 + X_h^2 - 2X_g X_h \cos\theta_{gh}}{NS_X^2} \quad (3)$$

Equation (3) helps to find battery reliability where scale/battery score is the sum of scores of the dimensions (say  $m$ ) by:

$$r_{tt(test)} = \frac{\sum_{i=1}^m r_{tt(i)} S_{D_i}^2 + \sum_{i=1, i \neq j}^m \sum_{j=1}^m 2Cov(D_i, D_j)}{\sum_{i=1}^m S_{D_i}^2 + \sum_{i=1, i \neq j}^m \sum_{j=1}^m 2Cov(D_i, D_j)} \quad (4)$$

Where  $S_{D_i}$  denotes sample SD of the  $i$ -th dimension.

If battery score is taken as weighted sum of dimensions i.e.  $I_t = \sum_{i=1}^m w_i D_i$  where  $w_i > 0$  and  $\sum_{i=1}^m w_i^2 = 1$  battery reliability of weighted scores is

$$Weighted_{r_{tt(test)}} = \frac{\sum_{i=1}^m w_i^2 S_{D_i}^2 + \sum_{i=1, i \neq j}^m \sum_{j=1}^m 2w_i w_j Cov(D_i, D_j)}{\sum_{i=1}^m w_i^2 S_{D_i}^2 + \sum_{i=1, i \neq j}^m \sum_{j=1}^m 2w_i w_j Cov(D_i, D_j)} \quad (5)$$

## Properties

- Test reliability, isomorphic to the theoretical definition is possible.

- If  $X$  follows normal, true score of an individual with observed score  $X_0$  is estimated by

$$X_0 \pm SEM, \text{ where } SEM = \text{sample } S_E,$$

- Split-half reliability as correlation between two parallel subtests  $r_{gh}$  is different from theoretical reliability ( $r_{tt}$ ) from (3).

- Normally distributed scores help to test  $H_0: r_{tt(Test)} = 1$  which

is equivalent to test  $H_0: \sigma_X^2 = \sigma_T^2$  against  $H_0: r_{tt(Test)} = 1$  using

test statistic  $F = \frac{S_X^2}{S_T^2}$  and reject  $H_0$  if  $F$  is large  $F > F_{\alpha, (N-1, N-1)}$

## Validity

A HRQoL scale may have different validity for different DMT. If  $X$  and  $Y$  are two scales and  $r_{XY} = 0.70$  (say), then 0.70 is the validity of  $X$  and also of  $Y$ . If  $r_{XY}$  is still more, two different scales are probably not needed.

The problems of selection of criterion scale with matching dimensions, score ranges, etc. can be avoided by Factorial Validity defined as ratio of the first eigenvalue to the sum of all eigenvalues i.e.  $\frac{\lambda_1}{\sum \lambda_i}$  where  $\lambda_1$  is the highest eigenvalue corresponding to

the main factor for which the scale was developed. Normally distributed  $P$ -scores satisfy assumption of PCA and enable computations of  $\lambda_i$ 's and component loadings of an item = (the eigenvector)  $\times \sqrt{\text{the eigenvalue}}$  which can be interpreted as the correlation of the item with the principal component or item validity.

## Properties

- Factorial validity is simple to comprehend
- Item validity is given in terms of component loading
- Sum of item validities  $\neq$  Scale validity.
- Eigenvalue  $\approx 0$  indicates existence of multicollinearity among the items

## Classifications

Classifications of individuals to a finite number of non-overlapping classes are often done by a recommended categorization of total scores. However, boundary points need to ensure that members within a class/cluster are similar (small within-group variance)

and members between classes/clusters are dissimilar (high between-group variance). Efficiency of classification needs to be evaluated. Quartile clustering helps in classification of individuals in four mutually exclusive quartiles  $Q_1, Q_2, Q_3, Q_4$  assigning equal probability to each quartile/class i.e.

$$\int_0^{Q_1} f(x) dx = \int_{Q_1}^{Q_2} f(x) dx = \int_{Q_2}^{Q_3} f(x) dx = \int_{Q_3}^{Q_4} f(x) dx$$

## Conclusion

The proposed method generating normally distributed scores contributes to improve scoring of instruments Relating to assessment of disabilities due to various diseases and HRQoL, avoiding limitations of summative Likert scores.  $P$ -scores facilitate better arithmetic aggregation, meaningful comparisons,

unique ranks, analysis under parametric set up for estimation of population parameters and statistical testing, classification, and integration of various scales. In addition, proposed scores also help to use HRQoL-scores as predictor of disabilities after adjusting demographic characteristic and compute reliability, battery reliability, validity, item validity, responsiveness, etc. in better fashion. Health care professionals and researchers can take advantages of the proposed method to convert ordinal discrete scores to normally distributed continuous scores with desired properties, including assessment and testing of responsiveness and evaluating psychometric parameters. Future studies with longitudinal multi-data set may be undertaken for generalization of findings along with better psychometric properties of the proposed transformation for improved patient care and clinical outcomes.

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