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RESEARCH ARTICLE

PROPERTIES OF JOINED WHO ICF-CY BODY FUNCTIONS B CODES AND ACTIVITY AND PARTICIPATION D CODES IN CHILDHOOD DISABILITY

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ABSTRACT

Aim: To examine the possibility of joining ICF-CY body functions b codes and activity and participation d codes to create a common disability variable
Study design: Open field pilot research study
Methods: The parents of 332 children with spina bifida, spinal muscular atrophy, muscular disorders, cerebral palsy, visually impairment, hearing impairment, mental disability and disability following treatment for brain tumours were visited and 47 body functions b codes and 57 activities and participation d code qualifiers were scored. Each code had 5 qualifier levels. Following Rasch analysis, 33 b codes and 39 d codes were retrieved. Fifty four of these were selected to cover the full spectrum of disability in the best possible way. After joining them, they underwent psychometric and Rasch data analysis to create a disability variable based on both ICF-CY coding systems.
Results: The mean score of the joined b and d codes was 0.96, with SD 1.00 and range 0.28–2.15. Variance was 1.69, range 0.49–3.13 and Cronbach's alpha 0.98. Inter-code correlation was 0.67, range 0.10–0.98. Rasch analysis documented good coverage on the whole range of the disability variable. The lowest score was −4.97, and the highest was 4.86. The mean location was −1.52. The joined codes were ordered. Furthermore, the distribution of the b and d codes on the child-code map documented a better measure of disability with d codes, in children with relatively less disability.
Conclusion: Separate ICF-CY body functions b codes and activities and participation d codes underwent previous selection after Rasch analysis and then were joined to cover the whole spectrum of disability in childhood, which it did well. As such, the codes can be implemented to register and monitor the total severity range of childhood disability and can be a common disability variable for children with 8 different disabilities. It is hoped that the ICF-CY codes thus selected, when added to ICD-10 diagnosis registering, can contribute to better information on disability across health sectors for both individual children and groups of children.

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INTRODUCTION

In 2007, the World Health Organisation (WHO) released the International Classification of Functioning, Disability and Health, Children and Youth Version (ICF-CY) to provide a common framework for the assessment of disability in children, for clinical and research use (World Health Organization, 2011; World Health Organization, 2007). The classification is based on a conceptual model encompassing the health condition of the individual with a disability, together with factors related to body function and structure, activities of daily living and participation in social activities and other relationships. These factors should be evaluated in relation to environmental and personal factors that may have a positive or negative influence on the disability's impact.

We have conducted a field research study to generate a disability variable that could be extracted from ICF-CY qualifier scorings and that could inform on the severity of disability in each child and in a population of children with disabilities. To reach that goal, we selected 47 ICF-CY body functions b codes and 57 activities and participation d codes to best cover the whole range of disabilities in children with spina

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bifida, spinal muscular atrophy, muscular disorders, cerebral palsy, visual impairment, hearing impairment, mental disability and disabilities following treatment for brain tumour. ICF-CY code qualifiers were worded and scored during interviews with parents of and caregivers to 332 participating children in their homes or institutions. The data analysis showed good psychometric properties, and a Rasch analysis documented valid results on the disability variable assigned to each child, provided the number of b codes was reduced from the 47 originally selected codes to 33 and the number of d codes was reduced from 57 to 39. We also found that both b and d codes were overrepresented in children with more severe disability, indicating that some codes could be omitted without disturbing the generation of the disability variable. Furthermore, the distribution of the codes on the continuous scale of the disability variable was uneven, with lapses in children with milder forms of disability, indicating that codes should be added here for increased precision in the generated disability variable (Illum and Gradel, 2015). Lastly, during the interviews, we got the impression that body functions and activity and participation issues are closely knit together, especially in younger children and children with major disabilities, because body functions, capabilities and limitations are lived out, as the children addressed had activity and participated to the best of their ability.

Although it was not intended by the WHO, we have analysed whether body functions b codes and activity and participation d codes could be joined to constitute one coding system in order to address disability in children. This could ease the registration of disability in daily practise and could better cover children who only have disability related to motor functions. To document such properties, we have repeated psychometric and Rasch data analysis on selected and joined codes, which previously and separately had valid psychometric properties and covered a complete spectrum of disability for the group of children mentioned.

MATERIALS AND METHODS

The children and their parents were followed clinically for some years at the Department of Child Neurology, H. C. Andersen Children's Hospital, Odense University Hospital. Parents of children with spina bifida, spinal muscular atrophy, muscular disorders, cerebral palsy, visual impairment, hearing impairment, mental disability and disabilities following treatment for brain tumour were previously introduced to the ICF-CY and the open field pilot research study by letter and later contacted for an interview in own homes. While this was conducted, we basically used the universal scoring system consisting of a 5-point Likert scale, with qualifiers worded as follows for the b codes and d codes, respectively:

Children with disabilities and qualifier-level wording:

0: No impairment No difficulty
1: Mild impairment Mild difficulty
2: Moderate impairment Moderate difficulty
3: Severe impairment Severe difficulty
4: Complete impairment Complete difficulty

But to enable a more detailed discussion of the child's needs, rather than simply focussing on the meaning of these basic definitions of level of impairment, the b and d code qualifier levels were defined as follows:

0: Child's ability is as expected for his/her age
1: Child has difficulties but functioning is still in the expected range for his/her age
2: Child needs help from another person with functions, activities and participation
3: Child needs help and care; the child has only limited ability with respect to body functions, activities and participation
4: Child is totally dependent on others for body functions, activities and participation

The data were recorded, and upon finishing all of the interviews, they were analysed for psychometric and Rasch data properties and published (Illum and Gradel, 2015).

We selected both b and d codes that fit the Rasch model and represent the whole spectrum of disability represented by the participating children, joined them and subjected the data to completely identical analysis, as previously performed. These data are presented.

Psychometric evaluation

Data targeting was estimated from the code scale's midpoint, range and observed scores, together with floor and ceiling effects. Reliability was operationalised as internal consistency and estimated with the Cronbach's alpha coefficient for average inter-item correlation. Validity was determined by non-statistical evaluation of the clinical meaning of the code scale, and was further investigated in the Rasch analysis. Within-scale factor analysis including the corrected item-total correlations and Cronbach's alpha above (alpha = $N \times \bar{c} / \bar{v} + (N - 1) \times \bar{c}$, where N = number of codes, $\bar{c}$ = average inter code covariance and $\bar{v}$ = average variance) was used to calculate a score for a general assessment childhood disability construct. The standard error of measurement, (SEM) = SD x $\sqrt{(1 - \text{alpha})}$, and 95% confidence intervals, (95% CIs) = ± 1.96 x SEM, were calculated.

Stata 12 (StataCorp, TX, USA) was used for data analysis.

Rasch modelling data

The Rasch analysis model defines an individual's probability of success (P) on a given item in terms of the difference between the individual's ability (B) and the item difficulty (D). $P = \exp(B - D) / 1 + \exp(B - D)$ or $\log P / (1 - P) = B - D$. Probability of success P can also expressed as log(odds) = B – D or logit = B – D.

Rasch analysis was applied to all five qualifiers for the joined ICF-CY b and d codes. In practise, when a child's level of disability equals a certain qualifier level, B and D are identical, and the derived log(odds) or logit value will be 0. For codes at which the child's disability level is higher or lower, the relevant logit value will be correspondingly positive or negative. A logit scale is constructed that constitutes the latent disability construct or variable (also called a measure in Rasch terminology) for the joined b and d codes and qualifiers used. This is represented by the child-code map, here called the child-joined b and d code map.

The joined b and d code response categories should be ordered in order to imply an impact continuum. In the polytomous ICF-CY scale, five qualifiers with four Rasch-Andrich thresholds (τ1, τ2, τ3 and τ4) are defined. Each threshold is indicated by the equal probability of disability between two adjacent qualifiers.

The joined b and d codes should define a single disability variable. This can be tested by calculating how well the observed responses conform to the expected responses calculated using the Rasch model (logit = B – D). Conformity with the model is denoted by fit, which is expressed as infit and outfit. Infit statistics reflect the overall performance of the codes and decrease when the data appear to be too predictive. Infit weights information (1 / variance) and is less sensitive to unexpected scores. Outfit statistics are sensitive to outlier results that are rare or have occurred in an unexpected way. Both are expressed in terms of mean-squared values (INFIT MNSQ and OUTFIT MNSQ). The values should be close to 1. Values greater than 1 are defined as underfit and indicate other sources of variance in the data that degrade the data. Values less than 1 are defined as overfit and indicate that data is predicted too well. Mean-square values are productive for measurements in the range 0.5–1.5. Values in the range 1.5–2.0 are unproductive but do not disturb measurement, but values > 2.0 may distort or degrade and thus misfit. It may be reasonable to retain a joined b or d code with misfit if it is part of a sound continuum and is clinically meaningful (Tennant and Conaghan, 2007; Pallant and Tennant, 2007; Hobart and Cano, 2009; Cano et al., 2011).

A child's location on the disability continuum should be reliable and reproducible. There should be a high probability that children who have higher logits are actually more disabled than children who have lower logits.

Winsteps 3.74.0 was used for the Rasch measurements (Linacre 2014).

Funding

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Ethical considerations

Neither the Danish Ministry of Social Affairs nor the National Board of Health influenced the study protocol, data collection, data analyses or results. All of the eligible parents in a defined geographical area were contacted by mail or telephone, or in person. The parents were known to us. Participation was voluntary for the parents and caregivers. The protocol was accepted by and registered at the Danish Data Protection Agency (DOK121763) before the start of the research. Approval for the protocol was sought from the National Board of Health (Project 7-202-05-207/8).

Collaboration

The participating parents were visited.

Discussions of statistical issues were undertaken and statistical analysis were provided by epidemiologist Kim Oren Gradel, PhD.

RESULTS

The original data set from which the presented data were generated comprised data from 332 children, of which 63 children had a discharge diagnosis of spina bifida, 8 had spinal muscular atrophy, 36 had muscular disorders, 157 had cerebral palsy, 8 were visually impaired, 13 were hearing impaired, 11 had a mental disability and 36 had been diagnosed with and treated for brain tumours. The children's ages were a mean 9.4 years, with SD 3.8 years and age range: 1.0–15.9 years.

Psychometric properties of the joined b and d code scores

Because the b and d codes had previously shown similar psychometric and Rasch properties, and the measures had a correlation coefficient of 0.89, a joint analysis could be performed. Fifty-four b and d codes were selected to maximise coverage of the spectrum of code properties whilst avoiding overlap (Table 1).

The mean of the scores was 0.96, SD 1.00 and range 0.28–2.14. Variance was 1.69, with range 0.49–3.13. The mean-corrected code -total was 0.76, with range 0.48–0.88.

Targeting showed a code-scale- score midpoint of 108 and range 0–216. The observed code scores had mean 48.00, SD 51.2 and range 0–215. Floor effect was 4.5% and ceiling effect 0.0%.

The reliability and validity showed a Cronbach's alpha of 0.98. The inter-code correlation was 0.67, with range 0.10–0.98. The standard error of the measurement was 7.24, with a 95% CI around the individual child's scores ± 5.5.

Results of the Rasch analysis

The results were generated according to the principles outlined above (3-9).

The mean location on the disability variable (measure) was −1.52, SD 1.77. The lowest score (least disabled child) was −4.97, and the highest location (representing the child with most disability) was 4.86. The coverage of codes along the disability range was good, although it could still be denser at the lower and upper parts of the range (Figure 1). Thus, joined b and d codes apply to children far below and above their mean locations. The mean τs of all 54 joined codes are illustrated in Figure 2 and Table 2. They are ordered to indicate that the code qualifiers represent increasing severity of disability and to ensure they are understood properly.

Table 1. Fifty-four ICF-CY b and d codes that had previously demonstrated fit to the Rasch model and as a joined code set still fit. The codes are not arranged according to ICF-CY code order, but for illustrative purposes are arranged according the level of disability that each code best represents, as arranged in the child b and d code map (Figure 1). Codes *b1252, d131* and *d155* are at the level of the disability variable or measure equal to 0

b2702: Sensitivity to pressure (corrects clothes, feels sand in shoes, touches vibrating objects appropriately)

b156: Perceptual functions (reacts appropriately to sounds and light)

b1564: Tactile perception (perceives touch and accepts being touched in an appropriate way)

b5102 (b5103, b51050, b51051): Chewing (chews and swallows food appropriately)

b1266: Confidence (has appropriate self-assurance, boldness and assertiveness)

b1561: Visual perception (perceives shape, size and colour appropriately)

b16702: Reception of sign language (reads and understands signs and pictures appropriately)

d3150: Communicating by receiving body gestures (comprehends facial expressions, body language)

d3152: Communicating by receiving drawings and photographs (comprehends meaning)

d710: Basic interpersonal interactions (interacts appropriately and shows consideration)

d8800: Solitary play (occupies oneself in purposeful play and games)

b1478: Psychomotor functions (has control of inappropriate activities, movements, sounds and words)

b16700: Reception of spoken language (understands what is said and explained appropriately)

d560: Drinking (indicates need, carries it out, decides on appropriate amount)

b1142: Orientation to person (has identity of self and others and reads body language)

b1408: Attention functions, other specified (concentrates and tolerates noise in an appropriate way)

b144: Memory functions (has appropriate memory for events)

d130: Copying (imitating, mimicking sound, gesture, facial expression, signs)

d3102: Comprehending complex spoken messages (understands and responds appropriately to questions)

d660: Assisting others (assists and is concerned with needs)

d750: Informal social relationships (initiates, manages and maintains play and causal relationships)

d8801: Onlooker play (purposefully observes others)

b1672: Integrative language functions (has appropriate conversations and explains appropriately)

d177: Making decisions (makes choices among options, carries them out, learns consequences)

d4153: Maintaining a sitting position (remains seated sufficiently long for eating, playing, drawing and writing)

b1252: Activity level (has appropriate energy levels in reacting to demands)

d131: Learning through actions with objects (learns from playing with toys and objects)

d155: Acquiring skills (learns to play games, keeps one’s room tidy, manipulates toys)

b163: Basic cognitive functions (understands abstract ideas and instructions and discusses them appropriately)

b2708: Sensory functions related to temperature, other specified (senses and grips objects appropriately)

b760: Control of voluntary movement functions (has appropriate hand movements)

d4451: Pushing (handles a milk bottle on a table, pushes toys and objects)

d5702: Maintaining health (cares for self and is self-aware)

d8803: Shared corporative play (joining others in sustained engagement and understanding play rules)

b1140: Orientation to time (knows and understands day and time)

d1551: Acquiring complex skills (learns to play games, understands and applies rules and appropriate sequences)

d2101: Undertaking a complex task (prepares, initiates and arranges social play activities and own birthday)

d4600: Moving around within the home (gets around, walks in home)

b1646: Problem-solving (plans, organises, explains and solves tasks appropriately)

b1720: Simple calculation (carries out simple calculations)

d4701: Using private motorised transportation (parents as drivers)

d860: Basic economic transactions (purchases, makes correct exchanges, saves)

d140: Learning to read (develops competence to read written material)

d150: Learning to calculate (develops competence to perform simple mathematical operations)

d2302: Completing the daily routine (prepares, initiates and arranges for school, manages homework)

d5101: Washing whole body (applies soap and water, washes hair, dries off)

d465: Moving around using equipment (gets around in wheelchair, walks on crutches or walker)

d530: Toilet (indicates need, plans, carries it out, eliminates waste)

d540: Dressing (puts on and takes off clothes)

d920: Recreation and leisure (engages in games, sport, hobbies and socialising)

b770: Gait pattern functions (walks and runs with appropriate patterns)

d845: Acquiring, keeping and terminating a job (leisure-time job)

d4552: Running (moves appropriately with quick steps)

d4750: Driving human-powered transportation (bicycle and tricycle)

```
Disability
variable
(measure)  child joined b and d code map

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   4             +
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   3             +
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               # |
   2           . +
               # |
               # T|  b2702
              .# |  b156
             ###  |T
               # |  b1564
   1          .## +  b5102
              .# |  b1266  b1561  b16702 d3150
              .#  |S d3152  d710   d8800
              ## |  b1478  b16700 d560
              .# |  b1142  b1408  b144   d130   d3102  d660   d750   d8801
             ### S|  b1672  d177   d4153
   0          ###  +M b1252  d131   d155
             ### |  b163   b2708  b760   d4451  d5702  d8803
           ##### |  b1140  d1551  d2101  d4600
          ###### |  b1646  b1720  d4701  d860
        .####### |S d140   d150   d2302  d5101
      .######### |  d465   d530   d540   d920
  -1       .##### +
     ########### |  b770   d845
       ######## M|T d4552
    ############ |
           ##### |  d4750
           ##### |
  -2      ####### +
        ######## |
           .#### |
           .#### |
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  -3        .#### +
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  -4           . +
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              .# |
  -5     .####### +
<less>|<frequent>
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Figure 1. The distribution of the sample of 332 children across the joint set of 54 b and d codes that fit the Rasch model.Each "X" represents 2 children. M = mean, S = 1 standard deviation and T = 2 standard deviations, Each | represents an interval of 0.2

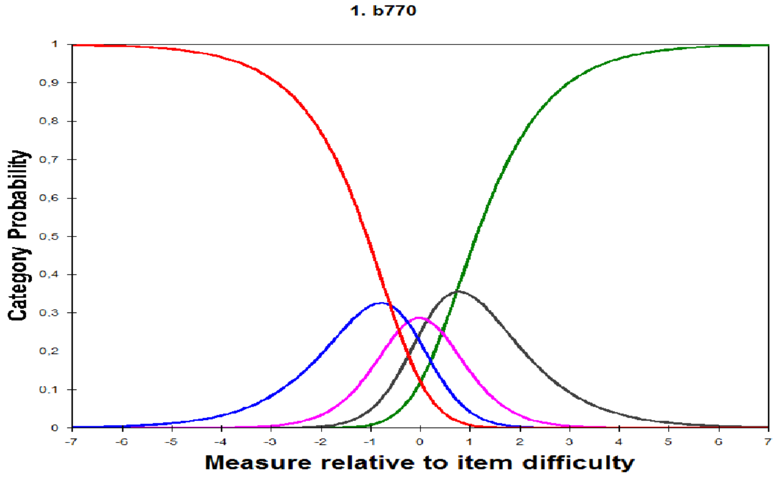


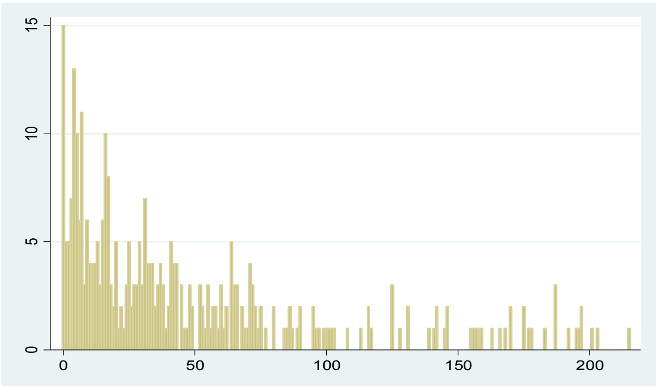
Figure 2. Qualifier (category) information function for the joined set of 54 b and d codes. Qualifier 0 = red, 1 = blue, 3 = purple and 4 = black

The τ value is given by the meeting point of two probability curves, i.e. 50% probability that each qualifier is selected. If the qualifier definitions were misunderstood and/or formulated in a problematic way, the curves would not follow qualifier order

Table 2. Structure calibration of the joined b and d codes. The values for the Andrich τ threshold are those shown in *Figure 2*.

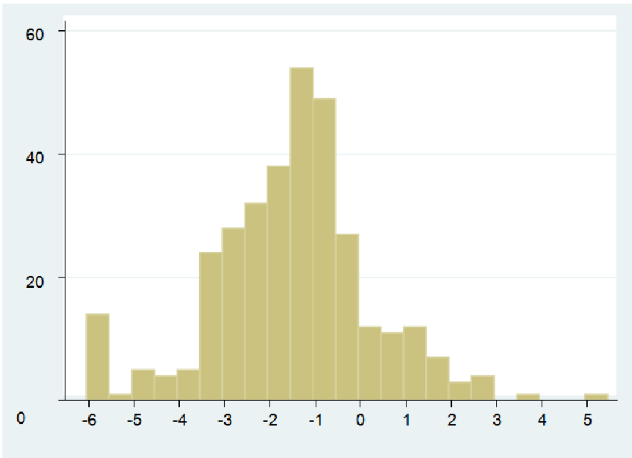
QUALIFIER	OBSERVED COUNT	OBSERVED COUNT %	OBSERVED AVERAGE	SAMPLE EXPECTED	INFIT MNSQ	OUTFIT MNSQ	τ THRES-HOLD	CATEGORY MEASURE
0	9444	57	−2.33	−2.33	1.09	1.11	-	−2.08
1	2802	17	−1.16	−1.24	1.11	.93	−.61	−.79
2	1579	9	−.55	−.45	1.05	1.15	−.26	−.02
3	1296	8	.22	.36	1.02	1.01	.14	.77
4	1524	9	1.63	1.53	.88	.88	.73	2.14

Number of children



Sum scores of joined set of b and d codes

Number of children



Rasch measure

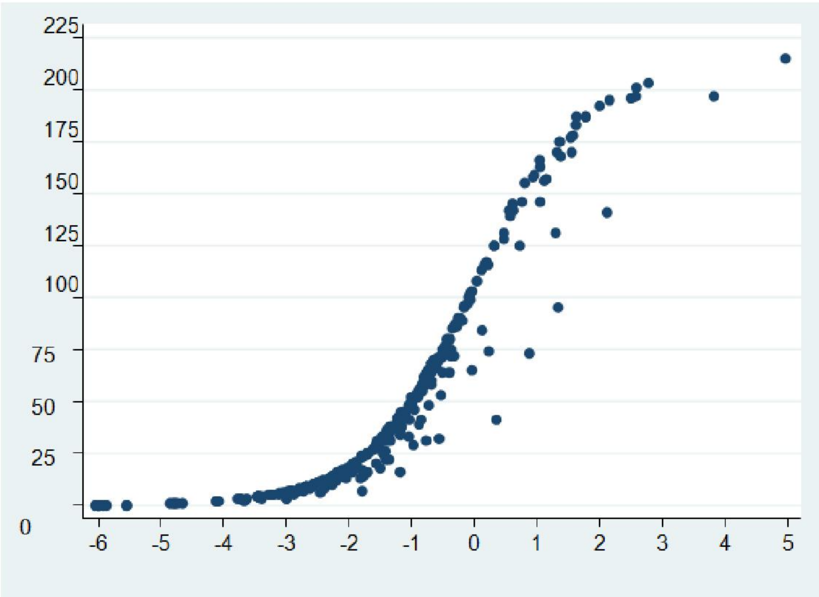
The Rasch data had an infit MNSQ > 1.5 for codes b1408, b1266, b2702 (highest with 2.22), d4701, d4153, b156, d4552 and d4600. Outfit MNSQ > 1.5 applied to b1408 (highest with 3.05), b1266, b2702, b1564, b770, d4552 and b5102. Both the infit and outfit MNSQs are underlined in Table 1 and Figure 1.

Comparison of joined b and d code scores and Rasch measures

As illustrated, the joined b and d codes were scored using a 5-point Likert scale. Such a scale provides qualitative data, which in principle should not be added; the use of summarised scores to provide a unitary measure of disability for individual children or groups of children is therefore potentially problematic. However, this study demonstrated that relatively more children are less disabled than their joined and summed b and code scores would suggest if Rasch measures are employed (Figures 3a and b).

degree of impairment or difficulty: none, mild, moderate, severe or complete. The WHO and many medical and surgical societies have decided which ICF codes should be included in the core and comprehensive data sets employed in various clinical and research settings. A similar process is now underway for the ICF-CY codes used to assess childhood disability (Nijhuis et al., 2008; Adolfsson et al., 2010; Jeglinsky et al., 2012; Martinuzzi et al., 2012; Pan et al., 2014; Meucci et al., 2014; Klassen et al., 2013). This study was undertaken to find out how ICF-CY codes might be used in clinical practise. A sample of 332 children with various diseases was analysed, encompassing the broadest possible range of disability, ranging from children with almost no symptoms to children who were totally physically dependent and children who were mentally disabled, visually impaired and hearing impaired.

Sum of scores



Rasch measure

Figure 4. Item characteristic curve showing the relationship between the joined set of 54 b and d code scores (y-axis) and Rasch measures (x-axis)

The Rasch measures cover the full range of data for the sample of 332 children and form a single item characteristic curve (Figure 4). However, the data for a small number of children fall outside and to the right of this ICC. This indicates that these relatively few children might be judged as more disabled than they really are, on the basis of the joined b and d code scores.

DISCUSSION

In 2007, the WHO released the child and youth version of the ICF to create a common language for all aspects of disability, across culture, age, gender and disease (2). The coding system encompasses around 1,400 codes organised in categories related to body function, body structure, activities and participation, and environmental factors. Each code has five qualifiers, which are used to grade functioning in terms of the

In order to facilitate the use of qualifiers by providing definitions that were as explicit as possible, the qualifiers were worded in terms of the level of help needed by the child for activities of daily life, relative to unimpaired age peers. Once explained in conversations during our visits, parents and caregivers had no difficulty judging which qualifier level was most appropriate for their child. Defining the codes explicitly, it was hoped, would ensure that the data obtained would be suitable for statistical analysis.

Also, qualifier wording, in terms of need for help universally across the disease diagnosis, was considered, but with different means for help. For the same reason, it is necessary to know the details of an individual’s condition. ICD-10 codes and ICF-CY codes are therefore considered as complementary and should be considered together in future data system implementations, clinical data handling, communications, evaluations and research.

Although the ICF-CY holds a vast number and diversity of codes, this study demonstrates that proper coverage of codes across the total range of disabilities might not be easy. This especially applies to children with milder degrees of disabilities related to motor functions, as illustrated by the disability variable child-joined b and d code map (Figure 1). In fact, although code b770 is one of very few codes that matches the difficulties of children with cerebral palsy, it does not sufficiently cover disabilities related to milder forms of motor disabilities (3). However, joined b and d codes cover this important area better, although not in a perfect way, as there still is some discontinuity in the ranging of the codes (Figure 1). This also illustrates that certain ICF-CY codes might be precious and therefore not easily discharged if they show less proper functions, as illustrated, among other ways, by the infit and outfit MNSQ values. Thus, instead of discharging such codes, the wording might be changed for better function. This is one reason why we have combined Rasch analysis with the wording of codes. We believe that this combination could become valid in future, repeated analyses, in which the ICF-CY concept could be steadily improved, rather than having a fixed composition of codes.

The joined b and d codes segregate properly and give proper meaning along the spectrum of disabilities, as they are experienced in daily living and clinical practise. The child-joined b and d code map illustrates this (Figure 1). This map, together with the corresponding list of codes (Table 1), is best understood when read from below and thus starting with the mildest disability, which is related to motor functions only. Here, bicycling (d4750) is only possible with a high motor function level, and running (d4552) is more demanding than walking (b770). A more complex picture is seen in the middle area, where cognitive functions dominate. The upper area is related to more basic functions, such as swallowing. Also, reception of spoken language (b16700) might be compromised before the ability to receive sign language (b16702).

The child-joined b and d code map (Figure 1) also shows that children with more complex disabilities are best covered with a broader range of codes. At the same time, the codes at the extremes are less precise, as illustrated by the relatively higher number of codes with infit and outfit MNSQ values out of range. These are underlined in the map and the code table. The reason for this might be that qualifiers are more difficult to apply uniformly or that it is more difficult to judge disability in the extremes. Lastly, Rasch analysis per se might not be too precise in the extreme ranges.

In joining the b and d codes, we have also demonstrated that d codes fit better among children with milder disabilities. By counting b and d codes above and below the disability variable or the measure level of 0, they are equally represented above, but two thirds of the d codes are below. Thus activity, and participation seem to represent children with less disability better.

As with both b and d codes alone, the joined disability variable or measure gives a more realistic distribution of children with disabilities that fits clinical experience better than would be the case if the qualifier codes were only summed (Figures 4a and b). If this were the case, more children would have far less disability than in reality. This is an issue of serious consideration that should be addressed, as qualitative data might not have equal steps, as illustrated by the unequal distance between the code qualifiers (Figure 2 and Table 2). The relationship between the joined b and d code scores and disability variables or measures—the item characteristic curve—does demonstrate that some assessments of disability by the joined b and d codes does not follow the curve properly and lies to the right of the curve. Thus, some children are assessed with more disability than they might have in reality (Figure 4). The reason for this is less clear. But a cleaner assessment might be obtained when codes with less fit are reworded or changed in repetitive quality improvements of codes, as having more children participate might also change this.

In conclusion, joined b and d codes do function well, as they give meaning on a continuous scale of disability. The joined set seems to cover milder disability better than either b or d codes alone. Psychometric properties have high code-total correlation and validity and reliability data. With Rasch data analysis of the ICF-CY qualifier data, the highly desired single-disability variable was measured properly, in spite of the great diversity of disability in the participating children. We hope that future and systematic applications of ICF-CY will benefit children with disabilities and join children, parents, care units and schools closer together when such a valid and common ICF-CY language is applied.

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