

Development and evidence of validity for the Children's Hand-use Experience Questionnaire (CHEQ)

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ABBREVIATIONS

CHEQ Children's Hand-use Experience Questionnaire

AIM To describe the development of the Children's Hand-use Experience Questionnaire (CHEQ), and investigate the evidence of its validity based on test content and internal structure of the three scales in it.

METHOD The selection of items and questions was based on a literature review, expert opinion, and interviews with families. Data on the final questionnaire were collected from 86 children and adolescents (42 males, 44 females) aged 6 to 18 years (mean 12y, SD 3y), with unilateral cerebral palsy, upper limb reduction deficiency, or obstetric brachial plexus palsy.

RESULTS After item reduction and evaluation, CHEQ was designed to include 29 bimanual activities, each rated on three scales of perceived efficacy of the grasp, time taken to perform the activity, and degree of feeling bothered. The appropriateness of the included activities was confirmed by their reported relevance and bimanual nature. The internal structure of the scales was confirmed by Rasch analysis.

INTERPRETATION CHEQ can be used to assess children and adolescents with a unilateral hand dysfunction on their experiences of using the affected hand to perform bimanual tasks. In clinical work, CHEQ has the potential to become a useful tool for treatment planning and follow-up.

Daily life comprises a range of activities that more or less demand the use of two hands.^{1,2} Children and adolescents with unilateral hand dysfunction, such as unilateral cerebral palsy (CP), obstetric brachial plexus palsy, or upper limb reduction deficiency are generally able to take part in the same activities as their peers but, when skilful collaborative use of two hands is needed, they commonly have difficulties.³⁻⁵ There is broad variation between individuals in how much hand dysfunction influences the performance of daily life activities. Many children and adolescents find they are less efficient at performing the activities and need more time than their peers. They also avoid certain activities when their hand function bothers them a lot. Other activities are performed using only the non-involved hand, even if they typically require use of both hands.^{3,5} It has been acknowledged that assessments specifically developed for children and adolescents with unilateral deficiency are needed to capture their specific problems.⁵⁻⁸

Assessments asking for the person's own experience are an important complement to observation-based tests of hand function to yield a broadened perspective of the hand use in daily life. Standardized tests have a long tradition in health care for measuring outcome of intervention and describing personal characteristics. There is, however, no straight relationship between the person's capacity in test situations and

their use of the hand in manual activities of daily life.⁹ Activity performance is formed by the person's own abilities and previous experiences, but also by the demands of the task and the environment in which it should be performed. Therefore, in addition to standardized tests, there is a need to assess the person's experience of day-to-day satisfaction in an activity perspective. Some existing questionnaires assessing activity performance can be used for children and adolescents with unilateral hand dysfunction but none of these specifically focus on activities demanding the use of both hands. The ABIL-HAND-Kids questionnaire was developed for children with CP and has shown good evidence for validity. However, three-quarters of the activities could be performed using only one hand.¹⁰ The Paediatric Motor Activity Log¹¹ was developed for children with unilateral CP but also comprises a mixture of uni- and bimanual activities. The only questionnaire with a clear focus on bimanual activities is the Prosthetic Upper Extremity Functional Index. However, this scale is only applicable to children who use upper limb prostheses.⁷ Thus there is a need for a new assessment that specifically assesses individual experiences of different aspects of problems arising when bimanual activities are to be solved using a dysfunctional hand.

The aims of this study were to describe the development of the Children's Hand-use Experience Questionnaire (CHEQ),

including the rationale for item selection of bimanual activities, and to investigate the evidence of validity based on test content and internal structure of the scales for measuring experience of hand use in the performed activities.

METHOD

Part I: development of the CHEQ

Item generation initially focused on identifying usual activities of young people from 6 years of age upwards that typically require both hands. The item generation started with a study of literature and previously existing instruments, reasoning from clinical experience and interviews with children/adolescents and parents with any of the three diagnoses of unilateral CP, obstetric brachial plexus palsy, or upper limb reduction deficiency.¹² A total of 373 activities were examined against the following criteria: (1) requiring the use of two hands; (2) being frequently performed by many people; (3) possible for a wide age range to do; (4) not seasonal; (5) not too sex- or culture-specific; and (6) not strongly dependent on other functions, such as balance, gross motor function, or cognitive functions. Activities were reduced by a stepwise procedure using field testing and additional reasoning between authors. This resulted in a field version comprising 37 activities.

Because CHEQ aims to capture a young person's experience of problems with bimanual activities, different quality aspects of hand use were of interest. Based on study of the literature, reasoning from clinical experience, and discussion groups with parents and adolescents, three aspects of hand use appeared to be most interesting: (1) perceived efficacy of the grasp; (2) time taken to perform the activity; and (3) experience of feeling bothered by impaired hand function in the activity. Thus questions relating to these aspects were used in CHEQ.

Pilot testing of the field version of the questionnaire was done by interviews with 18 families. These interviews added valuable information about the relevance of the activities and the questions. A final version with 29 activities was established, based on this information and additional reasoning between the authors.

Structure of the questionnaire

In the CHEQ questionnaire, each activity serves as a heading followed by several questions (Appendix S1, published online). The first question reads, 'Is this something you usually do independently?', and has the response options (1) yes, (2) no, I get help/avoid doing it, or (3) not applicable. The following questions are only asked for activities that are

What this paper adds

- Description of the development of the Children's Hand-use Experience Questionnaire (CHEQ), including the rationale for item selection of bimanual activities.
- The CHEQ provides valid estimations of children's and adolescent's experiences of hand use on three scales when used for individuals aged 6 to 18 years with unilateral hand dysfunction.

reported as performed independently. The second question is then, 'Do you use one hand or both hands together?', and has the response options (1) one hand, (2) both hands, with the involved hand supporting without holding, and (3) both hands, with the involved hand holding the object. After these opening questions, which serve to describe whether and how the activity is performed, the respondents' experience of the performance is rated on three separate scales. In this early version of CHEQ, the ratings were done on a 10-category scale with adjectives only in the anchors. In the first scale, grasp efficacy, the question reads, 'How effective is the grasp/support?', and the anchors are 'ineffective' (category 1) and 'effective' (category 10). The efficacy of the grasp/support refers to how well objects are secured in the hand or stabilized during the activity performance, regardless of whether it looks awkward or not. In the second scale, time taken, the question reads, 'How much time do you need to do the whole task, compared to peers?', and the anchors are 'considerably longer' (category 1) and 'equally long' (category 10). In the third scale, feeling bothered, the question reads, 'Does your hand function bother you in this activity/situation?', and the anchors are 'it bothers me a lot' (category 1) and 'it does not bother me at all' (category 10). Feeling bothered may include feeling irritated, sad, or embarrassed owing to the dysfunction of the arm or hand when performing the activity.

Part II: evidence of validity based on test content and internal structure

Participants

Inclusion criteria for the study were diagnosis of unilateral CP, obstetric brachial plexus palsy, or upper limb reduction deficiency (not using prosthesis) and age 6 to 18 years. A convenience sample of 96 families from Stockholm and Örebro was recruited by an information letter through occupational therapists in paediatric rehabilitation settings. Ten questionnaires were incompletely or incorrectly filled out. Thus the analysis was based on data from 86 respondents.

The demographics of the participants are presented in Table I. The families could choose whether the child or a

Table I: Demographic data of participants

Characteristic	Male/female	Right/left hand affected	Mean age, y (SD)	n
Unilateral cerebral palsy	16/15	16/15	11 (3)	31
Obstetric brachial plexus palsy	14/12	13/12 ^a	13 (4)	26
Upper limb reduction deficiency	12/17	12/17	11 (3)	29
Total	42/44	41/44 ^a	12 (3)	86

^aOne missing.

parent should be the respondent. However, a recommendation was given that children below the age of 13 years should be assisted. This was based on experience from the field testing. In 32 families, the questionnaires were answered by the child alone (three of them were aged 11–12y, the rest above the age of 13y).

Ethical approval was given by the Ethics Research Committee of Karolinska Hospital in Stockholm. All participants gave informed consent to the research and to publication of the results.

Statistics

For the first two questions, asking for (1) independency, assistance, or applicability, and (2) if one or two hands were used, descriptive statistics were reported for evidence of test content. The following three questions, constituting the CHEQ scales, were analysed by Rasch analysis. These analyses were conducted using Winsteps 3.65.0 software (Winsteps.com, Chicago, IL, USA)¹³ according to a rating scale model. This model was used because the rating scale was not expected to function differently between items. We separately analysed each of the three scales of grasp efficacy, time taken, and feeling bothered.

Validity was analysed through an accumulation of evidence based on internal structure.¹⁴ We optimized the effectiveness of rating scale category according to the essential guidelines described by Linacre:¹⁵ the number of observations in each category exceeding 10; the measure advancing monotonically by category; and an outfit mean-square of <2. The impact on the validity and reliability of various alternatives of collapsing rating scale categories was also examined according to the recommendations of Bond and Fox.¹⁶ The goodness of fit was examined for each item in each scale. Criteria for misfit were set to infit MnSq >1.4 in combination with a *z*-value of >2.0, which identifies items that show underfit to the expected hierarchy of item difficulty.¹⁷ The data were considered to fit the model when 95% of the items showed acceptable fit.¹⁸ Targeting of these three scales, namely how well the items cover the intended measure, was examined by comparing the mean person ability measures to the mean item difficulty measure as well as the spread of persons and items. Mean person measure above 0 indicates disagreement between item mean difficulty and person mean ability. Reliability was examined through internal consistency coefficients and separation. Person and item reliability ≥ 0.80 is a minimum for comparisons on a group level. The separation ratio was transformed into a strata index describing the number of significantly different levels of measures existing in the CHEQ scales.¹⁹ Person and item strata should be a minimum of two to differentiate between high and low performers. The precision of the sample mean was evaluated by the standard error value. A standard error below 0.385 yields a 99% confidence that the estimate lies within an interval of 1 logit.²⁰ Dimensionality was examined by principal component analysis. A 'tentative guideline' by Linacre¹³ for principal component analysis is that unidimensionality is supported if the measures explain more than 50% of the variance and the first contrast no more than 5%.

RESULTS

Evidence based on test content

According to the responses to the CHEQ questions, the activities were found to be relevant to a high degree, commonly performed independently, and involved the use of both hands (Table II). 'Fasten a necklace' was only performed independently by 43%. For the other activities, more than 67% of the respondents performed them independently. At most 11 (out of 86) persons found some activities not applicable; this was the case for 'Peel an orange' and 'Fasten a necklace'. The activities were performed using both hands by 70.7 to 97.5% of the respondents (Table II). These response patterns indicate that CHEQ included questions that were by nature bimanual, found relevant to the age group of respondents, and typically performed independently.

Evidence based on internal structure

Analysis of the function of the 10 category rating scales showed an inconsistent order of thresholds between the 10 categories in all three scales. Various alternatives for collapsing rating scale categories were examined. The use of a four-category rating scale fulfilled the essential recommendations by Linacre.¹⁵ In all scales, the old category 10 formed the new category 4. Categories 1 to 9 were distributed with two to four categories in each new category, varying according to what gave the best result for each scale. With four categories, each one exclusively covered a certain proportion of the person's ability and the item's difficulty. The average measure advanced monotonically for each category and the highest outfit MnSq was 1.42. The number of ratings in each rating scale category varied between 26 (for category 1 in the time taken scale) and 765 (for category 3 in time taken). The four-category scale, compared with the 10-category scale, also improved reliability and separation values. We conducted further analyses using the four-category scale.

The Rasch analysis showed misfit for some items in two of the three scales: grasp efficacy, four items (14%); time taken, two items (7%). Hence item reduction was done separately for each scale, removing one item at a time, until at least 95% of the items in each scale showed good fit. This meant that one item showing under-fit remained in these two scales. The list of items is presented in Table II, with the removed items marked as omitted. There were 8%, 6%, and 10% of the persons showing misfit to each scale respectively. We investigated the response pattern and did not find any explanatory pattern for the misfits. All persons were therefore included in further analyses.

Analysis of the targeting of the three scales showed a fairly good distribution even though the mean ability measure of the persons was higher (3.03, 3.35, and 2.90 respectively) than the mean difficulty of the items (by default set to 0), indicating that the average person's ability was greater than the difficulty of the items (Table III). This was also shown by the number of persons scoring a maximum on the scales: 15 persons on the grasp efficacy scale, 13 persons on the time taken scale, and 18 persons on the feeling bothered scale. However, considering the spread of

Table II: Children's Hand-use Experience Questionnaire item responses for 86 respondents. Descriptive data and Rasch analysis for item measurements in the unit logits. Items that will be excluded from the calculation of a person's measures for the respective scales are marked 'omitted'. The table is sorted by the degree of independent performance of the activities

Item	Independently performed (%)	With two hands (%)	Not applicable (n/86)	Grasp efficacy				Time taken				Feeling bothered			
				Measure	SE	INFIT	INFIT ZSTD	Measure	SE	INFIT	INFIT ZSTD	Measure	SE	INFIT	INFIT ZSTD
Pull up track suit trousers	100.0	77.1	2	-0.20	0.31	1.27	1.2	0.28	0.80	-1.0	-0.65	0.24	1.01	0.1	
Put on socks	98.8	75.6	2	Omitted							-0.33	0.24	1.33	1.6	
Butter a slice of soft bread	98.8	94.0	1	0.29	0.26	1.10	0.6	0.26	1.13	0.7	0.18	0.23	0.98	0.0	
Cut out a picture using scissors	97.6	91.4	2	-0.24	0.27	1.10	0.6	0.27	1.10	0.5	0.08	0.23	1.26	1.4	
Remove a straw from the front of a juice box and insert it	98.8	92.4	3	-0.90	0.28	0.69	-1.6	0.28	0.98	0.0	-1.09	0.26	0.79	-1.1	
Eat out of a small container of yoghurt	97.5	86.1	4	-1.18	0.30	0.96	-0.1	0.30	1.25	1.3	-0.94	0.25	0.76	-1.3	
Spread out glue on paper using a glue stick	98.8	85.9	5	-0.49	0.29	0.75	-1.2	0.29	0.78	-1.1	-0.27	0.24	1.22	1.1	
Put toothpaste on a toothbrush	96.4	70.7	2	0.75	0.27	1.10	0.6	0.27	1.02	0.2	-0.92	0.25	1.29	1.5	
Cut up a pancake (or other food that is easy to cut) on a plate	96.4	72.8	1	0.36	0.31	1.77	2.8	0.28	1.46	2.0	0.56	0.23	1.38	1.9	
Remove the wrapping from a piece of candy	95.3	88.8	1	-0.36	0.29	0.72	-1.4	0.28	0.74	-1.3	-0.32	0.24	0.64	-2.1	
Handle playing cards	95.1	89.5	3	0.46	0.28	1.10	0.5	0.27	0.86	-0.7	0.80	0.23	1.39	2.0	
Open a small box (e.g. box of mints)	95.1	90.8	3	-0.95	0.31	0.67	-1.6	0.30	0.91	-0.4	-0.55	0.26	0.61	-2.2	
Open the zipper on a small bag (e.g. pencil case or purse)	96.3	94.9	4	-0.92	0.29	0.57	-2.4	0.29	0.85	-0.7	-0.76	0.25	0.81	-1.0	
Pick money out of a purse or wallet	93.9	88.5	2	-0.24	0.29	0.97	-0.1	0.28	0.91	-0.4	-0.09	0.24	0.90	-0.5	
Carry a tray (e.g. in the canteen)	92.5	93.2	5	-0.60	0.29	1.09	0.5	0.30	1.20	1.0	0.44	0.24	1.25	1.2	
Pull up the zipper of a jacket	91.8	97.5	0	0.08	0.27	1.34	1.6	0.28	0.99	0.0	-0.17	0.24	1.05	0.3	
Button up a pair of trousers	91.8	79.2	1	0.81	0.31	1.12	0.6	0.27	1.12	0.7	0.51	0.24	0.75	-1.4	
Unscrew the cap of a small, unopened soft drink bottle	88.1	93.2	2	-0.19	0.29	0.91	-0.4	0.29	0.69	-1.5	-0.17	0.25	0.89	-0.5	
Open a plastic box with a lid (e.g. an ice-cream box)	88.9	97.2	3	0.13	0.28	1.23	1.1	0.31	1.04	0.2	-0.11	0.25	1.12	0.7	
Remove the wrapper from an ice-cream	85.7	93.1	1	-0.32	0.30	0.57	-2.2	0.29	0.56	-2.3	-0.28	0.26	0.55	-2.5	
Fasten a helmet (e.g. bike helmet)	82.5	84.8	5	-0.31	0.34	0.86	-0.4	0.33	0.96	-0.1	-0.37	0.28	1.02	0.2	
Cut on a chopping board (e.g. fruit, vegetables, bread)	81.3	92.1	10	1.12	0.30	0.84	-0.7	0.32	0.72	-1.3	0.92	0.26	0.68	-1.6	
Peel an orange	75.7	92.9	11	0.82	0.33	0.66	-1.5	0.33	0.58	-2.1	0.22	0.30	0.60	-1.9	
Open a bag (e.g. bag of crisps)	74.1	93.2	5	-0.13	0.35	0.97	0.0	0.33	0.56	-2.1	-0.51	0.31	1.08	0.4	
Take off the plastic backing of a plaster	70.4	94.6	4	-0.37	0.36	0.75	-1.0	0.35	1.01	0.1	-0.26	0.30	0.720	-1.3	
Cut meat (or other food that is hard to cut) on a plate	70.0	94.6	3	Omitted				0.30	1.97	3.9	1.65	0.27	1.28	1.3	
Tie shoelaces	67.9	94.2	8	Omitted				0.31	1.44	2.0	0.59	0.30	1.31	1.3	
Open up a carton of milk or juice	67.1	88.5	5	0.20	0.37	1.46	1.5	0.36	1.21	0.8	0.08	0.30	1.12	0.5	
Fasten a necklace (whilst around the neck)	43.7	90.3	11	2.39	0.51	1.66	1.9	0.47	1.15	0.6	1.78	0.42	0.91	-0.2	

Independently performed, percentage of persons performing the activity independently. With two hands, percentage of persons performing the activity with two hands. Not applicable, number of persons out of 86 rating the activity as not applicable. Measure, logit values. SE, standard error; INFIT MNSQ, Infit mean square (ideal value 1); INFIT ZSTD, Infit: t standardized (ideal value 0).

Table III: Rasch results for each of the three Children's Hand-use Experience Questionnaire scales

	Grasp efficacy	Time taken	Feeling bothered
Principal component analysis, variance explained by measures	61.3%	64.1%	57.4%
First contrast	3.9%	3.9%	5.6%
Eigenvalue	2.6	3.0	3.8
Items included in each scale (<i>n</i>)	26	28	29
Person separation	3.42	3.81	3.04
Item separation	2.17	2.95	2.38
Person reliability	0.92	0.94	0.90
Item reliability	0.82	0.90	0.85
Person strata	4.89	5.41	4.39
Item strata	3.22	4.26	3.51
Mean standard error of items	0.31	0.30	0.26
Mean person measure	3.03	3.35	2.90

the four rating scale categories, the Rasch maps showed a correlation between the distribution of item difficulty and person ability (Fig. 1a–c). The person separation demonstrated that people can be separated into four or five groups with a reliability of 0.90 to 0.94, varying between scales (Table III). The range of standard error was from 0.26 to 0.31 (Table III). The principal component analysis supported unidimensionality for all three scales (Table III).

DISCUSSION

The results of this study demonstrated that CHEQ provides valid estimations of children's and adolescents' experiences of hand use on three scales when used for individuals aged 6 to 18 years with a unilateral hand dysfunction.

Even though there are other instruments where similar bimanual activities are included, the unique feature of CHEQ concerns the combination of different quality aspects of hand function addressed. Quality of performance has been rated in other questionnaires^{10,11,21,22} but not from the same perspective as CHEQ. In CHEQ, we ask about three different aspects of hand use, selected because they are known to be problematical to children with unilateral deficiency.^{3,4} Efficacy of grasp is important for effective hand use. The time it takes to perform bimanual activities and whether the person feels bothered or not when doing them are socially important aspects for children. Our assumption that these aspects were important and described separate qualities of hand use was confirmed by the result showing that each of them formed a unique dimension with high internal consistency. Moreover, each scale demonstrated a high degree of ratings, indicating that the participants regarded all three aspects as valid. This supports the three-scale construct in CHEQ.

Rasch analysis has the advantage of providing detailed information on several quality aspects of a test such as item fit, unidimensionality, and structure of the rating scale. A 10-category rating scale was initially used, based on the assumption that respondents prefer this when it comes to expressing feelings.²³

However, the Rasch analysis revealed that respondents did not use the 10-category scales consistently. We therefore revised the scales, resulting in improved precision. Another benefit of Rasch analysis is that it provides valid measures for tests with missing data. This is done by calculating expected responses and thereby estimating scores for missing data.¹³ Responses for different activities may be missing for individual respondents because ratings in CHEQ are only done for independently performed activities. In other types of analysis, this could create a problem of low precision in the item estimates. However, in this study the results of item standard error (Table III) demonstrate that all item estimates for standard errors are below 0.385 (0.26–0.31), indicating a precision within a 1 logit interval.

Answering questions about perceived experience requires some insights of the respondents. During pilot testing, we recognized that smaller children tended to give the same answer for all questions, not really admitting any problems. CHEQ is therefore recommended for self-rating in children over 12 years. For younger ages, it is suggested that parents support the child or act as proxy raters. It is known that small children require a different test design compared with parents and adolescents, one that takes into consideration children's ways of thinking and communicating.²⁴ However, it is important to consider that ratings of children and parents represent two different views, and that differences between the two are to be expected.^{25–27} In this study, we decided to use data both from parents and adolescents, because no comparison between respondents was investigated. When using the CHEQ for follow-up purposes, it is important that the same person has given the responses.

The CHEQ activities were found relevant for inclusion in the scales because they were commonly performed using two hands. This characteristic was seen as a prerequisite for appraising experiences of bimanual performance. Nevertheless, some participants managed to use only one hand for some common bimanual tasks, for example picking money out of their purse or buttoning up trousers (see Table II). This highlights the fact that the actual use of one or two hands differs among persons with one dysfunctional hand. According to our results (Table II), using one hand only may not have an impact on independence but it may make a person perform slowly or feel bothered when performing a particular task. One advantage of CHEQ is that the experiences of the activities are reported for each activity in relation to the use of one or two hands (Appendix S1). We believe this makes CHEQ a useful tool in discussing activity performance with a person as well as defining whether or not performance of an activity is a problem so as to target intervention.

This is the first study describing the CHEQ and further investigation is needed. To strengthen validity, data generated using the new 1 to 4 scale need to be evaluated as well as the stability of repeated measurements and sensitivity to change. The construct of the three scales in CHEQ was based on the assumption that there is a conceptual difference between them. This needs confirmation in a future study. Evidence

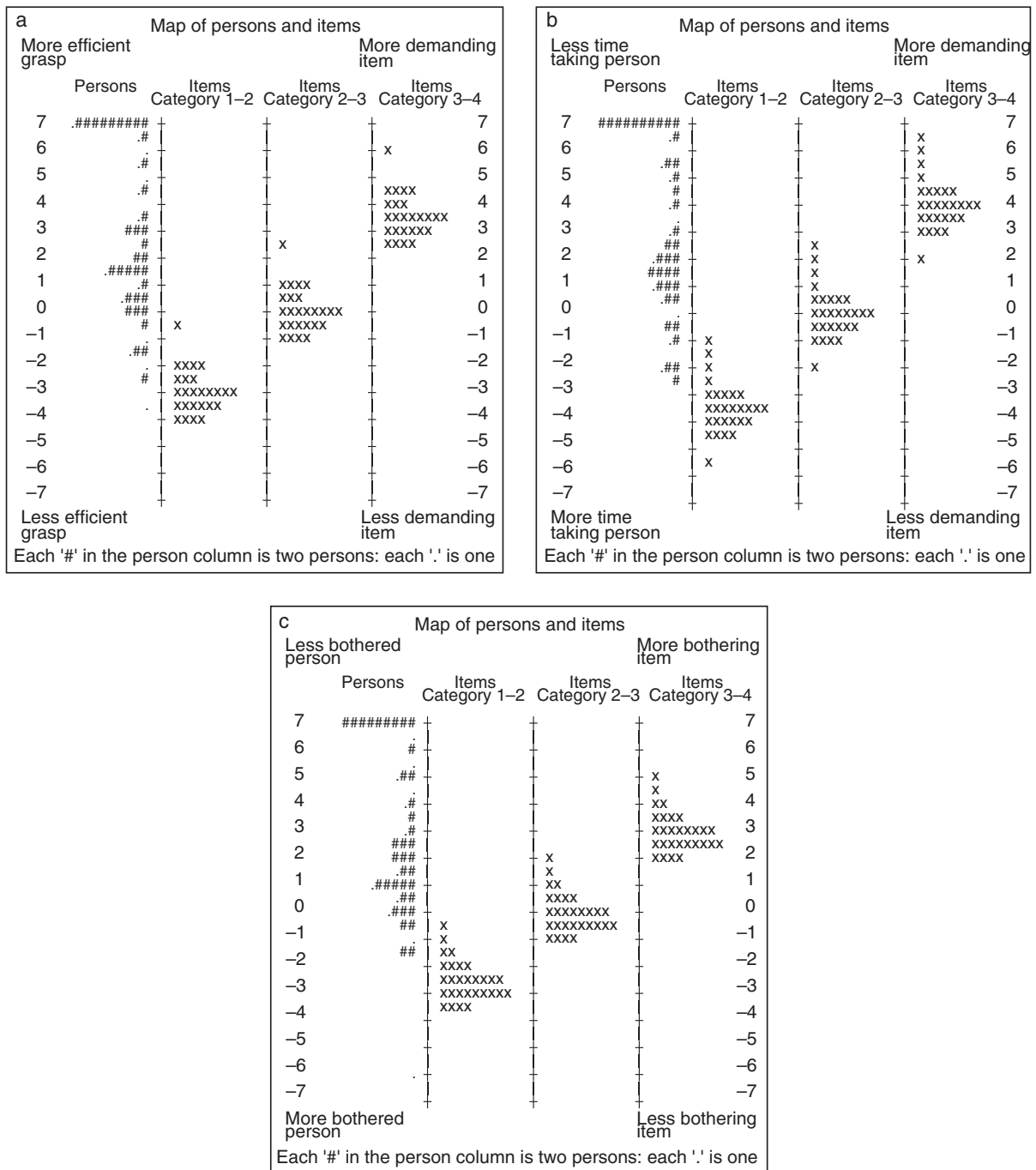


Figure 1: (a–c) Map of persons and items in each scale. In the column labelled 'persons', individuals are located at their estimated ability measure on the equal-interval logit scale. Each '#' in the person column represents two persons: each '.' represents one person. The next three columns present the level where the probability of an item being rated in either of two categories is 50%. Each 'x' is one item.

based on response processes using analysis of differential item functioning requires more participants but can give valuable future information as to whether the items function differently according to sex or diagnosis.

CHEQ is now available as an easily accessible and free web-based questionnaire (<http://www.cheq.se>). Hopefully, it will be useful in planning treatments, setting goals, evaluating treatment outcomes, and in longitudinal follow-up.

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ONLINE MATERIAL

Additional material and supporting information may be found in the online version of this article.

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