

Novel Activity and Participation Scales for Children, Adolescents, and Young Adults with Post-Acute Infection and Vaccination Syndromes and/or ME/CFS

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A) Development of MCFC Activity and MCFC Participation Score

First, factor scores for each of the two CFA models were computed using the Thomson regression method. This method accounts for both factor loadings and measurement error, yielding an unbiased estimate of the latent variable. For each person i , the score f_i is obtained as a weighted linear combination of the centered item values $(x_i - \mu)$, with the weights reflecting the item's factor loading Λ , its error variance Θ , and the factor variance Φ , i.e.

$$f_i = W(x_i - \mu) \text{ with } W = \Phi\Lambda'(\Lambda\Phi\Lambda' + \Theta)^{-1}.$$

To enable interpretability, the scores f_i were min-max normalized, yielding a scale ranging from 0 to 100. For this, the minimum f_{min} and maximum scores f_{max} were determined for each scale by systematically combining all possible combinations of item responses. The normalized scores of the i -th individual are thus calculated by

$$normalized\ score_i = \frac{(f_i - f_{min})}{(f_{max} - f_{min})} \times 100$$

where $f_{min} = -4.046622$ and $f_{max} = 1.875503$ for the Activity Score, and $f_{min} = -1.939712$ and $f_{max} = 2.555794$ for the Participation Score.

B) Full Model Report for MCFC Activity Scale CFA-Model

Standardized Factor Loadings:

	est.std
Self-care	0.772
Physical activity	0.814
Mental activity	0.699
Social contacts	0.765
School/training/studies/work	0.663

Latent Variables:

	Estimate	Std.Err	z-value	P(> z)	Std.lv	Std.all
Activity =~						
Self-care	0.680	0.086	7.946	0.000	0.680	0.772
Physical activity	0.608	0.061	9.973	0.000	0.608	0.814
Mental activity	1.027	0.119	8.604	0.000	1.027	0.699
Social contacts	0.720	0.077	9.355	0.000	0.720	0.765
School/training/studies/work	1.126	0.150	7.489	0.000	1.126	0.663

Variances:

	Estimate	Std.Err	z-value	P(> z)	Std.lv	Std.all
Self-care	0.313	0.064	4.906	0.000	0.313	0.403
Physical activity	0.188	0.047	4.023	0.000	0.188	0.337
Mental activity	1.027	0.199	5.546	0.000	1.027	0.699
Social contacts	0.720	0.066	5.541	0.000	0.720	0.765
School/training/studies/work	1.616	0.257	6.278	0.000	1.616	0.560
Activity	1.000				1.000	1.000

C) Full Model Report for MCFC Participation Scale CFA-Model

Standardized Factor Loadings:

	est.std
Participation at home	0.791
Participation outside the home	0.839
Access to education/work	0.644
Participation in school/work	0.741
Self-care	0.555
Independence in daily life	0.684

Latent Variables:

	Estimate	Std.Err	z-value	P(> z)	Std.lv	Std.all
Participation =~						
Participation at home	0.809	0.095	8.541	0.000	0.809	0.791
Participation outside the home	0.766	0.102	7.476	0.000	0.766	0.839
Access to education/work	0.699	0.153	4.563	0.000	0.699	0.644
Participation in school/work	0.974	0.150	6.483	0.000	0.974	0.741
Self-care	0.525	0.083	6.355	0.000	0.525	0.555
Independence in daily life	0.841	0.098	8.557	0.000	0.841	0.684

Variances:

	Estimate	Std.Err	z-value	P(> z)	Std.lv	Std.all
Participation at home	0.392	0.095	4.138	0.000	0.392	0.375
Participation outside the home	0.247	0.077	3.231	0.000	0.247	0.296
Access to education/work	0.688	0.166	4.143	0.000	0.688	0.585
Participation in school/work	0.777	0.195	3.984	0.000	0.777	0.450
Self-care	0.619	0.105	5.900	0.000	0.619	0.692
Independence in daily life	0.803	0.143	5.615	0.000	0.803	0.532
Participation	1.000				1.000	1.000

D) Calculation of MCFC Activity and MCFC Participation Scores

Parameters for the Calculation

Activity Scale:

	item mean μ_j	weights w_j
Self-care	$\mu_1 = 5.165$	$w_1 = 0.286165$
Physical activity	$\mu_2 = 4.527$	$w_2 = 0.425722$
Mental activity	$\mu_3 = 3.341$	$w_3 = 0.122514$
Social contacts	$\mu_4 = 4.538$	$w_4 = 0.258364$
School/training/studies/work	$\mu_5 = 2.659$	$w_5 = 0.091660$

Participation Scale:

	item mean μ_j	weights w_j
Participation at home	$\mu_1 = 3.146$	$w_1 = 0.248668$
Participation outside the home	$\mu_2 = 2.348$	$w_2 = 0.373398$
Access to education/work	$\mu_3 = 2.056$	$w_3 = 0.122333$
Participation in school/work	$\mu_4 = 2.270$	$w_4 = 0.151111$
Self-care	$\mu_5 = 4.124$	$w_5 = 0.102240$
Independence in daily life	$\mu_6 = 3.079$	$w_6 = 0.126128$

Let x_{ij} be the answer to the j -th item on the Activity or Participation Scale of the i -th individual. The Activity or Participation Score f_i is then calculated by:

$$f_i = \sum_{j=1}^n w_j (x_{ij} - \mu_j)$$

where μ are the items' means, w the items' weights, and n the number of items in the Activity ($n = 5$) and Participation Scale ($n = 6$), respectively. The min-max normalization, yielding a scale ranging from 0 to 100, is calculated by

$$\text{normalized score}_i = \frac{(f_i - f_{\min})}{(f_{\max} - f_{\min})} \times 100$$

where $f_{\min} = -4.046622$ and $f_{\max} = 1.875503$ for the Activity Score, and $f_{\min} = -1.939712$ and $f_{\max} = 2.555794$ for the Participation Score.

For example, if $x_i = (6, 5, 5, 6, 5)$ the f_i for the Activity Score is calculated as

$$\begin{aligned}
 f_i &= \sum_{j=1}^5 w_j (x_{ij} - \mu_j) \\
 &= 0.286165(6 - 5.165) + 0.425722(5 - 4.527) + 0.122514(5 - 3.341) \\
 &\quad + 0.258364(6 - 4.538) + 0.091660(5 - 2.659) \\
 &= 1.23586924,
 \end{aligned}$$

whereas the

$$\begin{aligned} \text{normalized score}_i &= \frac{(f_i - f_{\min})}{(f_{\max} - f_{\min})} \times 100 \\ &= \frac{(1.23586924 - (-4.046622))}{(1.875503 - (-4.046622))} \times 100 \\ &= 89.1992526. \end{aligned}$$

Thus, the Activity Score is 89.2. The Participation Score can be calculated analogously using the above values.