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The ambiguity of the concept of participation in measurement instruments: operationalization of participation influences research outcomes

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Abstract

Objective: This study explores, based on the International Classification of Functioning, Disability and Health, the consequences of different operationalizations of participation in regression models predicting participation in one sample of patients.

Design: Cross-sectional, comparative study.

Setting: Department of Neurology of a University Hospital.

Subjects: A total of 677 patients with a Neuromuscular Disease.

Measures: Participation was measured using the Neuromuscular Disease Impact Profile questionnaire, the RAND-36 Item Health Survey (social functioning, role limitations-physical, role limitations-emotional) and the Impact on Participation and Autonomy questionnaire (autonomy outdoors, social relations). Potential predictors of participation included type of neuromuscular disease, body functions (measured with Neuromuscular Disease Impact Profile), activities (measured with Neuromuscular Disease Impact Profile), environmental factors (measured with Neuromuscular Disease Impact Profile), and personal factors (measured with the 13-item Sense of Coherence questionnaire). The results were controlled for patient characteristics.

Results: Participation was statistically predicted by different determinants depending on the operationalization used for participation. Additionally, the regression coefficients differed significantly. Body functions and activities were predictors in five out of six operationalizations of participation. Sense of coherence predicted participation in all of the operationalizations. The explained variance of the different models ranged from 25% (RAND-36 role limitations- emotional) to 65% (Neuromuscular Disease Impact Profile).

Conclusions: Different operationalizations of participation result in different prediction models. Lack of conceptual consensus makes participation an ambiguous concept in research, and this ambiguity makes evidence-based decisions directed at enhancing participation difficult. Participation needs to be operationalized in an unambiguous and standard way in order to improve the comparability of outcomes.
3.1 Introduction

Disease affects patients' functioning.\(^1\),\(^2\) The International Classification of Functioning, Disability and Health (ICF) can be used to describe functioning and the factors that influence functioning. The ICF describes functioning as an umbrella term encompassing the components body functions and structures, activities, and participation.\(^3\) Participation is defined in the ICF as an individual's involvement in life situations. Participation is related to health conditions (i.e. disease), to the components body functions and structures and activities, and to the environmental factors and personal factors (Figure 3.1).\(^3\)

![ICF framework](image_url)

**Figure 3.1** ICF framework representing the interactions between the components.\(^3\)

Note: ICF categories and chapters are not shown in this figure.

Participation is often the main target of interventions aimed at improving the health of chronically ill patients.\(^4\) Because the number of people with a chronic disease is rapidly increasing, participation has become essential to clinical practice as an outcome of health care.\(^5\) As a result, the need for valid and reliable instruments that measure participation has also increased.\(^6\) Several such instruments have been developed in the last decades,\(^6\),\(^8\) including generic measurement instruments such as the Keele Assessment of Participation,\(^3\) the Social Role Participation Questionnaire,\(^10\) the Assessment of Life Habits\(^11\) as well as disease-specific measurement instruments such as the Juvenile Arthritis Foot Disability Index.\(^12\)

However, measurement instruments differ in their operationalization of participation.\(^13\) For instance, the Keele Assessment of Participation operationalizes participation in restrictions in mobility, self-care, domestic life, interpersonal interaction, major life areas, community, and social life. In contrast, the Social Role Participation Questionnaire operationalizes
participation in role relevance and satisfaction in community, social events, physical leisure, hobbies, casual contact, travel, employment, education, and relationships. The instruments differ in the content of the items included and in the aspects measured, (e.g. restrictions, satisfaction). In the current study we focused on the content of items.

Participation has proven to be difficult to operationalize, which is partly caused by the multidimensionality of the concept itself and by the fact that there is no consensus on its conceptualization. To date, a clear definition of participation is lacking. In the current study we used the definition of participation listed in the ICF.

The ICF is a universal conceptual framework and classification system based on the biopsychosocial model. The ICF describes all components, with the exception of personal factors, and subdivides these components into chapters and categories. As such, the ICF can be used as a reference terminology. Participation is differentiated as a separate component in the framework, but in the classification system it is combined with the activity component in a single list divided into nine chapters (d1-d9). The ICF offers four options for distinguishing between activities and participation, one of which involves using a distinct set of activities and participation. We chose this option and have operationalized participation using the ICF category d660 ‘assisting others’ and the ICF chapters d7, ‘interpersonal interactions and relationships’, d8, ‘major life areas’, and d9, ‘community and social life’. This distinct set is in accordance with literature measuring participation, which emphasizes the performance of roles in a social context.

Previous studies have found associations between participation and the effect of interventions and between participation and the impact of the disease, activities, environmental factors, and personal factors. However, outcomes are difficult to compare because the measurement instruments employed used different operationalization of participation. Additionally, differences in sample characteristics also hinder a comparison between the results of different studies.

The main objective of this study was to explore, based on the ICF, the consequences of differences in operationalizations of participation in regression models to predict participation in one sample of patients.
3.2 Method

Patients diagnosed with a neuromuscular disease and treated at the Neurological Center of a University Hospital in the North of the Netherlands were selected for this cross-sectional study. The neuromuscular disorder was diagnosed by a neurologist and registered in the patient’s medical record.

Inclusion criteria for this study were: having been diagnosed with one of the following four neuromuscular disorders\textsuperscript{25} (described along with their corresponding code of the International Classification of Diseases, 10th Revision):\textsuperscript{26} motor neuron disorder G70-G73 (e.g. amyotrophic lateral sclerosis), muscle disorder G10-G13 (e.g. Duchenne muscular dystrophy), junction disorder G70-G73 (e.g. myasthenia gravis), and peripheral nerve disorder G60-G64 (e.g. polyneuropathy); living independently in the community; $\geq$ 18 years; Dutch speaking; and being able to give informed consent. Eligible patients ($n = 978$) were selected from the hospital's records. They received information about the purpose of the study and were invited to take part in the study by means of a letter. The study was approved by the Institutional Review Board (METc2009.310).

After giving informed consent, patients received the following questionnaires: the Neuromuscular Disease Impact Profile questionnaire,\textsuperscript{27} the RAND-36 item Health Survey\textsuperscript{28} (quite similar to the Short-Form-36-item Health Survey), the Impact on Participation and Autonomy questionnaire,\textsuperscript{29} and the 13-item Sense of Coherence questionnaire.\textsuperscript{30}

3.2.1 Measurement instruments

The measurement instruments used in the present study were grouped according to the components of the ICF framework (Figure 3.1). Health condition (disorder or disease), body functions and structures, activities, environmental factors, and personal factors were used as predictor variables, and participation was used as an outcome variable.

Body functions, activities, and environmental factors were measured with the corresponding components of the Neuromuscular Disease Impact Profile questionnaire. Personal factors are not included in the Neuromuscular Disease Impact Profile questionnaire; these were measured with the 13-item Sense of Coherence questionnaire.\textsuperscript{31}
Participation was measured with six subscales covered by three measurement instruments: the Neuromuscular Disease Impact Profile questionnaire; the RAND-36 Item Health Survey, and the Impact on Participation and Autonomy questionnaire. All data used in this study are patient self-reported, except for the type of neuromuscular disorder which was obtained from the medical record.

3.2.2 Disorder or disease
Disease characteristics included the type of neuromuscular disorder diagnosed by the neurologist and obtained from the medical record. Data on duration of symptoms and disease in years were retrieved from the patient self-reported questionnaire.

3.2.3 Body functions and structures, activities and environmental factors
*The Neuromuscular Disease Impact Profile questionnaire.*

The Neuromuscular Disease Impact Profile is a validated patient self-reported questionnaire that measures the severity of disability related to neuromuscular disease with a set of 45 relevant ICF categories divided into the components body functions (16 items related to the ICF chapters b1 ‘mental functions’; b2 ‘pain’; b3 ‘speech functions’; b4 ‘exercise tolerance functions’; b5 ‘functions related to the digestive system’; b6 urination functions, sexual functions’ and b7 ‘neuromusculoskeletal and movement functions’), activities (16 items related to the ICF chapters d3 ‘communication’; d4 ‘mobility’; d5 ‘self-care’ and d6 ‘domestic life’), participation (nine items, described below under the header participation), and environmental factors (four items related to the ICF chapters e3 ‘support and relationships’ and e5 ‘services, systems and policies’).

In the current study, the items of the Neuromuscular Disease Impact Profile questionnaire related to body functions, activities, and environmental factors were used as predictors. Scoring options of the Neuromuscular Disease Impact Profile questionnaire range from 0 (no disability) to 4 (complete disability) and from 0 ((strong) facilitator) to 2 (not a facilitator). The mean component scores are calculated by dividing the sum score by the number of completed items. Each component must be answered for at least 75% of the items. In cases where less than 75% of the items are answered,
the total score was not calculated. Internal consistency of the scales ranges from 0.69 to 0.93.27

3.2.4 Participation
We included participation measurement instruments based on items in the ICF category d660 and the ICF chapters d7, d8 and d9 by employing established linking rules.23 By using the ICF as a reference terminology and by linking the items of the measurement instruments to the corresponding ICF codes, we were able to compare measurement instruments.

Three measurement instruments representing six different scales related to participation were included in the current study. The scales are described below including their linked ICF code.

*The Neuromuscular Disease Impact Profile questionnaire.*27
The items of the Neuromuscular Disease Impact Profile questionnaire, indicated as participation, were used as outcome variables. It included eight questions about restrictions in performing specific actions caused by barriers in the environment using communication devices and techniques (d360); moving around in different locations (d460); using transportation (d470); performing daily self-care (d510-d540); preparing meals (d630); entering into informal social relationships and family relationships (d750-d760); engaging in remunerative employment (d850); and engaging in community life, recreation and leisure (d910/d920).

*The RAND-36 item Health Survey.*34 35
The RAND-36 item Health Survey measures perceived health status. It is a short version of the RAND Health Insurance Study Questionnaire, consisting of 36 items quite similar to the Medical Outcome Studies (MOS) Short-Form -36 item Health Survey.36 The RAND-36 item Health Survey is divided into eight scales.37 In the current study, the subscales role limitations-physical, including four questions about the extent and frequency of problems related to work or other regular daily activities (d8, d9) caused by physical health; role limitations-emotional, including three questions about the extent and frequency of problems related to work or other regular daily activities (d8, d9) caused by emotional health; and social functioning, including two questions about the extent and the frequency of restrictions in performing social
activities (d7), were used as operationalizations of participation.

Scales ranges from 0 to 100, higher scores reflect higher level of perceived health or well-being. Internal consistency of the RAND-36 scales ranges from 0.71 to 0.93.\textsuperscript{35} If a respondent missed one of the items, the total score was not calculated.

\textit{The Impact on Participation and Autonomy questionnaire.}\textsuperscript{30} The Impact on Participation and Autonomy questionnaire assesses the perceived personal impact of illness on participation.\textsuperscript{29,38} It consists of 31 items divided into five scales. In the current study, the scale autonomy outdoors, including four questions about the frequency and the degree to which one can determine where and when actions are undertaken with regard to visiting neighbors and friends (d730-d750), and making trips and spending free time (d910-d920); and the scale social life and relationships, including six questions about the experiences of social relations (d710-d720), were used as operationalizations of participation. Scoring options of the Impact on Participation and Autonomy questionnaire range from 0 (no impact) to 4 (most negative impact). The mean scores are calculated by dividing the sum score by the number of completed items. Each scale must be answered for at least 75\% of the items, otherwise the total score was not calculated. Internal consistency of these scales ranges from 0.81 to 0.91.\textsuperscript{29}

### 3.2.5 Personal Factors

Information about gender, age, education level, marital status (yes/no) and having children (yes/no) was obtained by a patient self-reported questionnaire. Education level was categorized as low, middle or high. Marital status included cohabitation.

\textit{The 13-item Sense of Coherence questionnaire.}\textsuperscript{30} The 13-item Sense of Coherence questionnaire includes 13 questions that measure an individual’s sense of coherence, meaning the degree to which an individual views the world as comprehensible, manageable, and meaningful.

Scoring options range from 1 (lowest) to 7 (highest). A total score is calculated by adding up item scores. The total score ranges from 13 to 91. Individuals who score high on the 13-item Sense of Coherence questionnaire are more likely to stay healthy than individuals with a low score.\textsuperscript{31,39} Internal
consistency of this questionnaire is 0.48.\textsuperscript{30} If a respondent had one missing response, the missing response was replaced with the individual mean score. If more than one item was missing, the total score was not calculated.

### 3.2.6 Data analysis

The original scores of all the measurement instruments used in this study are included in Table 3.1. However, for reasons of comparability in the regression analysis, all scores were standardized by dividing the sum score of each component by the maximum score of that component and by multiplying it by a hundred to obtain a result ranging from 0 (good health) to 100 (poor health).

To make the results of the regression parameters more meaningful for clinical interpretation, age was centered to the mean age of 60 years. This means that the intercept in the regression analysis represents the participation scores of a 60-year-old person. To examine to what extent the various participation instruments measured the same concept, a Pearson product-moment correlation coefficient was computed. Correlations of > 0.80 were interpreted as high.\textsuperscript{40}

The associations of the predictor variables with the outcome variables were assessed by multivariate linear regression models (method: enter).\textsuperscript{40} Interaction terms between the predictor variables were explored. The regression analyses were controlled for age, gender, education, marital status (including cohabitation) yes or no, having children or not, level of education, duration of disease in years (since medical diagnosis), and duration of the symptoms of the disease in years. Associations with \( p \)-values \( \leq 0.05 \) were considered statistically significant. The analyses were performed using SPSS for Windows version 20 (SPSS Inc., Chicago, IL, USA).
### Table 3.1 Baseline characteristics of the responders (total $N = 677$) and non-responders (total $N = 301$).

<table>
<thead>
<tr>
<th>Variable</th>
<th>Responders $n$ (%)</th>
<th>Non-responders $n$ (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Health condition</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>NMD diagnosis</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Motor neuron disorder</td>
<td>33 (4.9%)</td>
<td>13 (4.3%)</td>
</tr>
<tr>
<td>Muscle disorder</td>
<td>154 (22.7%)</td>
<td>63 (20.9%)</td>
</tr>
<tr>
<td>Junction disorder</td>
<td>234 (34.6%)</td>
<td>86 (28.6%)</td>
</tr>
<tr>
<td>Peripheral nerve disorder</td>
<td>256 (37.8%)</td>
<td>137 (45.5%)</td>
</tr>
<tr>
<td>Years since NMD symptoms (mean (SD))</td>
<td>15.2 (12.6)</td>
<td></td>
</tr>
<tr>
<td>Years since NMD diagnosis (mean (SD))</td>
<td>11.6 (10.8)</td>
<td></td>
</tr>
<tr>
<td><strong>Body functions</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>NMDIP body functions (mean (SD)) (range 0-100)</td>
<td>21.4 (12.3)</td>
<td></td>
</tr>
<tr>
<td><strong>Activities</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>NMDIP activities (mean (SD)) (range 0-100)</td>
<td>21.6 (22.3)</td>
<td></td>
</tr>
<tr>
<td><strong>Environmental factors</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>NMDIP environmental factors (mean (SD)) (range 0-100)</td>
<td>30.8 (28.9)</td>
<td></td>
</tr>
<tr>
<td><strong>Participation</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>NMDIP participation (mean (SD)) (range 0-100)</td>
<td>9.9 (14.5)</td>
<td></td>
</tr>
<tr>
<td>RAND-36 (mean (SD)) (range 0-100)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social functioning</td>
<td>73.5 (23.3)</td>
<td></td>
</tr>
<tr>
<td>Role limitations-physical</td>
<td>49.2 (42.4)</td>
<td></td>
</tr>
<tr>
<td>Role limitations-emotional</td>
<td>72.7 (39.6)</td>
<td></td>
</tr>
<tr>
<td>IPA (mean (SD))</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Autonomy outdoor (range 0-16)</td>
<td>5.8 (3.8)</td>
<td></td>
</tr>
<tr>
<td>Social relations (range 0-24)</td>
<td>5.7 (3.7)</td>
<td></td>
</tr>
<tr>
<td><strong>Personal factors</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age years (Mean (SD))</td>
<td>59.1 (15.7)</td>
<td>53.4 (18.8)</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>344 (50.8%)</td>
<td>163 (54.0%)</td>
</tr>
<tr>
<td>Education level</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Low</td>
<td>229 (33.8%)</td>
<td></td>
</tr>
<tr>
<td>Middle</td>
<td>261 (38.6%)</td>
<td></td>
</tr>
<tr>
<td>High</td>
<td>180 (26.6%)</td>
<td></td>
</tr>
<tr>
<td>Cohabitation/married</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>480 (70.9%)</td>
<td></td>
</tr>
<tr>
<td>Children</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>540 (79.8%)</td>
<td></td>
</tr>
<tr>
<td>SOC-13* (mean (SD)) (range 13-91)</td>
<td>68.6 (12.6)</td>
<td></td>
</tr>
</tbody>
</table>

NMD: Neuromuscular Disease; NMDIP: Neuromuscular Disease Impact Profile\(^{27}\); higher scores indicate a worse health or not a facilitating environment; RAND-36: RAND36-item Health Survey\(^{34}\); higher scores indicate a better health; IPA: Impact on Participation and Autonomy questionnaire\(^{38}\); higher scores indicate a worse health; SOC-13: Sense of Coherence questionnaire 13-item version\(^{30}\); higher scores indicate a better health. *$n = 625$
3.3 Results

A total of 677 patients (response rate of 69%) returned the questionnaire. Mean age of responders was significantly higher (59.3; SD 15.8) (Table 3.1) than that of non-responders (53.4; SD 18.8; n = 301) ($p < 0.001$). No significant differences in gender ($p = 0.42$) were found. There was a difference between the number of responders and non-responders with respect to the neuromuscular disease diagnoses junction disorder (34.6% versus 28.6%) and peripheral nerve disorder (37.8% versus 45.5%). The difference was not statistically significant ($p = 0.07$).

The results of the Pearson product-moment correlation coefficient between the participation measurement instruments (Table 3.2) ranged from 0.26 to 0.69.

Table 3.2: Pearson correlations between participation measurement instruments.

<table>
<thead>
<tr>
<th></th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>NMDIP participation</td>
<td>.54**</td>
<td>.26**</td>
<td>.36**</td>
<td>.65**</td>
</tr>
<tr>
<td>2</td>
<td>RAND-36 social functioning</td>
<td>-</td>
<td>.47**</td>
<td>.58**</td>
<td>.68**</td>
</tr>
<tr>
<td>3</td>
<td>RAND-36 role limitations-emotional</td>
<td>-</td>
<td>.49**</td>
<td>.37**</td>
<td>.37**</td>
</tr>
<tr>
<td>4</td>
<td>RAND-36 role limitations-physical</td>
<td>-</td>
<td>.58**</td>
<td>.44**</td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>IPA autonomy outdoor</td>
<td>-</td>
<td></td>
<td>.69**</td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>IPA social relations</td>
<td>-</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**$p < .01$**

---

*RNeuromuscular Disease Impact Profile component participation.*

**RAND36-item Health Survey, subscales: social functioning, role limitations-emotional, role limitations-physical.*

**Impact on participation and autonomy subscales: autonomy outdoor and social relations.*

**$p < .01$**
Table 3.3 Comparison of six multiple regression analyses for predicted participation (operationalized in six different ways) as dependent variable and kind of diagnosis (motorneuron disorder- peripheral nerve disorder-muscle versus junction disorder), body functions, activities, interaction term body functions*activities, environmental factors and personal factors as independent variables.

<table>
<thead>
<tr>
<th></th>
<th>NMDIP participation&lt;sup&gt;a&lt;/sup&gt;</th>
<th>RAND-36 social functioning&lt;sup&gt;b&lt;/sup&gt;</th>
<th>RAND-36 role limitations-emotional&lt;sup&gt;b&lt;/sup&gt;</th>
<th>RAND-36 role limitations-physical&lt;sup&gt;b&lt;/sup&gt;</th>
<th>IPA autonomy outdoor&lt;sup&gt;c&lt;/sup&gt;</th>
<th>IPA social relations&lt;sup&gt;c&lt;/sup&gt;</th>
</tr>
</thead>
<tbody>
<tr>
<td>R² control</td>
<td>0.04**</td>
<td>0.04**</td>
<td>0.06**</td>
<td>0.04**</td>
<td>0.07**</td>
<td>0.07**</td>
</tr>
<tr>
<td>R² total</td>
<td>0.65**</td>
<td>0.50**</td>
<td>0.25**</td>
<td>0.36**</td>
<td>0.60**</td>
<td>0.44**</td>
</tr>
<tr>
<td>B (95% CI)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Reference</td>
<td>8.63** (2.87 to 14.39)</td>
<td>40.53** (29.44 to 51.63)</td>
<td>69.09** (45.9 to 92.29)</td>
<td>29.12** (6.17 to 52.08)</td>
<td>25.55** (15.41 to 35.68)</td>
<td>36.04** (28.20 to 43.88)</td>
</tr>
<tr>
<td>Motorneuron disorder</td>
<td>2.43 (-1.28 to 6.14)</td>
<td>-7.37* (-14.51 to -0.22)</td>
<td>0.27 (-14.67 to 15.20)</td>
<td>-4.89 (-19.66 to -9.89)</td>
<td>-2.19 (-8.72 to 4.33)</td>
<td>0.04 (-5.01 to 5.09)</td>
</tr>
<tr>
<td>Peripheral nerve disorder</td>
<td>-1.13 (-2.88 to 0.62)</td>
<td>-2.82 (-6.18 to 0.55)</td>
<td>-1.23 (-8.26 to 5.81)</td>
<td>-3.06 (-10.02 to 3.90)</td>
<td>-2.49 (-5.57 to 0.58)</td>
<td>-0.96 (-3.34 to 1.42)</td>
</tr>
<tr>
<td>Muscle disorder</td>
<td>0.88 (-1.40 to 3.15)</td>
<td>-5.15* (-9.53 to -0.78)</td>
<td>4.34 (-4.80 to 13.49)</td>
<td>-0.15 (-9.21 to -8.90)</td>
<td>-2.95 (-6.95 to 1.05)</td>
<td>2.80 (-0.30 to 5.89)</td>
</tr>
<tr>
<td>Body functions&lt;sup&gt;i&lt;/sup&gt;</td>
<td>0.02 (-0.08 to 0.11)</td>
<td>0.84** (0.65 to 1.03)</td>
<td>0.89** (0.49 to 1.28)</td>
<td>2.29** (1.90 to 2.68)</td>
<td>1.03** (0.85 to 1.20)</td>
<td>0.56** (0.42 to 0.69)</td>
</tr>
<tr>
<td>Activities&lt;sup&gt;i&lt;/sup&gt;</td>
<td>0.29** (0.21 to 0.36)</td>
<td>0.18* (0.03 to 0.34)</td>
<td>0.09 (-0.23 to 0.41)</td>
<td>0.71** (0.40 to 1.02)</td>
<td>0.81** (0.67 to 0.95)</td>
<td>0.27** (0.16 to 0.37)</td>
</tr>
<tr>
<td>Body functions* activities&lt;sup&gt;i&lt;/sup&gt;</td>
<td>0.005** (0.003 to 0.007)</td>
<td>0.000 (-0.004 to 0.005)</td>
<td>-0.004 (-0.012 to -0.005)</td>
<td>-0.024* (-0.032 to -0.015)</td>
<td>-0.014* (-0.018 to -0.010)</td>
<td>-0.006* (-0.009 to -0.003)</td>
</tr>
<tr>
<td>Environment&lt;sup&gt;i&lt;/sup&gt;</td>
<td>0.03** (0.00 to 0.05)</td>
<td>-0.00 (-0.05 to 0.05)</td>
<td>-0.001 (-0.012 to 0.100)</td>
<td>-0.06 (-0.16 to -0.04)</td>
<td>0.01 (-0.03 to 0.06)</td>
<td>0.03 (-0.01 to 0.06)</td>
</tr>
<tr>
<td>Personal factors</td>
<td>SOC-13&lt;sup&gt;i&lt;/sup&gt;</td>
<td>-0.13** (-0.19 to -0.06)</td>
<td>-0.47** (-0.59 to -0.34)</td>
<td>-0.90** (-1.16 to -0.64)</td>
<td>-0.36* (-0.62 to -0.10)</td>
<td>-0.28* (-0.39 to -0.16)</td>
</tr>
</tbody>
</table>
Results

NMDIP: Neuromuscular Disease Impact Profile; RAND-36: RAND36-item Health Survey; IPA: Impact on Participation and Autonomy questionnaire; $R^2$ control: explained variance owing to control variables-age, gender, marital status, education, having children or not, duration disease in years/duration symptoms in years; $R^2$ total: explained variance due to all predictor variables together; Reference: middle-educated man of 60 years old with junction disorder, married/cohabitation, and having children or not; $b$: unstandardized regression coefficient; CI: confidence interval; SOC-13: Sense of Coherence questionnaire 13-item version.

Neuromuscular Disease Impact Profile components: participation, body functions, activities and environmental factors. RAND36-item Health Survey, Dutch version subscales: social functioning, role limitations-emotional, role limitations-physical. Impact on participation and autonomy subscales: autonomy outdoor and social relations. Sense of Coherence questionnaire 13 items version.

Note: $N = 677$; $^*p < 0.05$; $^{**}p < 0.01$; for comparison of the scales standardized scores were used ranging from 0 (good health) to 100 (worse health).
The explained variance of the different regression models ranged from 25% (RAND-36 role limitations-emotional) to 65% (Neuromuscular Disease Impact Profile Participation). The explained variance of the control variables ranged from 4% to 7% (Table 3.3).

The predictor variables that contributed significantly to the regression equation varied between the models.

If participation was operationalized with the RAND-36 social functioning, the diagnosis of a motor neuron disorder or a muscle disorder was significantly associated with a higher participation score compared with the diagnosis of a junction disorder.

Body functions (measured with the Neuromuscular Disease Impact Profile questionnaire) contributed significantly to five out of the six operationalizations of participation. The Neuromuscular Disease Impact Profile Participation was the exception here. Activities also contributed significantly to the regression equation in five out of the six operationalizations of participation. The RAND-36 role limitations-emotional proved to be the exception here. The interaction between body functions and activities was significant in four out of the six operationalizations of participation. This interaction was not significant for the RAND-36 social functioning and the RAND-36 role limitations-emotional.

Environmental factors contributed only significantly to the prediction of participation when operationalized in the Neuromuscular Disease Impact Profile questionnaire.

Personal factors, represented by the 13-item Sense of Coherence questionnaire, contributed significantly to the regression equation in the six different operationalizations of participation.

3.4 Discussion

In this study we have shown that different operationalizations of the concept of participation result in different outcomes of prediction models. Our study is the first to demonstrate the consequences of these different operationalizations on research outcomes in a single population of patients.

The differences between the percentages of explained variance (ranging from 25% for the RAND-36 role limitations-emotional to 65% for the Neuromuscular Disease Impact Profile Participation) and between the regression coefficients of the predictors can be explained by differences in
measurement instruments in which participation is operationalized, because a single population was studied, the same measurement procedure was applied for all participants, the same time frame for all participants was applicable and the same set of predictors was used. Method variance, i.e. variance in response due to measurement methods,\cite{31} may also contribute to this explained variance, but it cannot explain the large range of explained variance in the current study. The full extent of method variance is unknown.\cite{41}

The measurement instruments included in this study differ in number, content, and aspects of the items used, as was demonstrated by the linking of the items to the ICF categories and chapters. These differences show that the measurement instruments operationalized the concept of participation differently, as was confirmed by the Pearson correlation coefficient (all < 0.70). To enable a full comparison of instruments measuring participation, the content and the aspects of the items related to participation should be standardized.\cite{15}

Our results correspond to those reported in a study\cite{8} in which the content of 122 measurement instruments was compared with the ICF. The concept of participation in that study was operationalized almost similarly to our study, namely by operationalizing participation in the ICF chapters d7, d8 and d9. The result of that study showed that only 25% of the items of the measurement instruments addressed participation and that the other items failed to do so.\cite{8}

The variables personal factors, body functions, and activities contributed significantly to all (or almost all) regression equations, environmental factors contributed to only one equation. Similar findings to ours were reported in a study in stroke patients.\cite{41} That study found that body functions and activities were the most influential variables for predicting participation. The Impact on Participation and Autonomy outdoors and social relations explained 67% and 42% of the variance, respectively. A study in patients with multiple sclerosis found that higher levels of activities (exercises) were predictive for fewer restrictions in participation measured with the RAND-36 scales.\cite{42}

However, contrary to our results, a study in people with myotonic dystrophy\cite{43} and a study in people with knee pain\cite{44} found environmental factors predictive for participation measured with the Life Habits Measurement Instrument.\cite{11} Additionally, a study in spinal cord injury patients\cite{45} found that the sense of coherence measured with the 13-item Sense of Coherence

3.4 Discussion
questionnaire was not predictive for participation measured by the Reintegration to Normal Living Index. An explanation for these differences could be that the Life Habits Measurement Instrument and the Reintegration to Normal Living Index, similar to the component participation of the Neuromuscular Disease Impact Profile questionnaire, have operationalized participation by including some other items from the ICF than the category d660 and the chapters d7, d8 and d9.

Our study has some limitations. The first limitation concerns the selection of the measurement instruments included in our study. We chose instruments that used an operationalization of participation closely related to the ICF category d660 and the ICF chapters d7, d8, and d9. However, the component participation of the Neuromuscular Disease Impact Profile questionnaire also includes some items that are related to the ICF chapters d3-d6. Also, the Impact of Participation and Autonomy questionnaire lacks items related to the ICF chapter d8.

Furthermore, despite the fact that the Neuromuscular Disease Impact Profile questionnaire operationalizes the predictor variables body functions and activities properly in accordance with the ICF components, items related to the environmental factors are missing for the ICF chapters e1, e2 and e4. Additionally, personal factors are not included in the Neuromuscular Disease Impact Profile questionnaire, nor classified in the ICF. The content of these factors is not clear. We chose the 13-item Sense of Coherence questionnaire, despite the fact that this questionnaire presents personal factors in a specific perspective and that it lacked certain items.

Although our choice of measurement instruments obviously influenced the results, at the same time they confirmed the aim of our research, which was not to assess the best instrument for measuring participation, but rather to explore the consequences of different operationalizations of participation.

The second limitation of our study concerns the difference in age between responders and non-responders. It is likely that younger patients who are diagnosed with a neuromuscular disorder will want to live as normally as possible and may not want to spend time on things that confront them with their illness, such as completing a questionnaire. However, we believe that the difference in age between responders and non-responders was clinically small and therefore not very relevant for the interpretation of our results. Although age was a variable we controlled for, our study showed that personal
characteristics, including age, did not significantly contribute to the prediction of participation or to the explained variance. This finding is in keeping with results from other studies that predicted participation.\textsuperscript{41,43,48-50}

The strengths of our study include the sample size of the population, the large response rate of 69\% (677 patients), and the design, which utilized several measurement instruments related to participation at the same time and in the same population.

Our findings indicate that when selecting an instrument to measure participation, close attention should be paid to the operationalization of the concept of participation employed by that particular instrument.\textsuperscript{49} For example, if participation is measured using the Neuromuscular Disease Impact Profile questionnaire, the outcomes suggest that health professionals should focus on activities and environmental factors to enhance participation. In contrast, if participation is measured using the RAND-36 role limitations-emotional, the outcomes suggest that health professionals should focus on body functions to improve participation. Although the concept of participation itself has gained widespread acceptance, consensus on its definition and on its operational measurement instruments is still lacking.\textsuperscript{19}

In conclusion, our study shows that the outcomes of prediction models vary greatly due to the different operationalizations of participation, making participation an ambiguous concept in research. However, it is encouraging for the conceptualization and the operationalization of participation that the ICF has provided a definition, chapters and categories relating participation to the performance of roles in a social context. Future studies should consider using the ICF as reference terminology to conceptualize and operationalize participation in an unambiguous and standard way. This will enable comparisons of outcomes related to participation that address the effectiveness of interventions that can assist policy-makers in making evidence-based decisions directed at enhancing participation.
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“Artsen wilden haar een nieuwe heup geven, een kunsthartklep implanteren en haar ogen opereren. Zelf vond ze alleen dat laatste nodig: als zij gewoon haar krantje kon lezen, en haar kleinkinderen kon zien zou ze heel gelukkig zijn.”

NRC Handelsblad, 22 december 2014, Machteld Huber.