Activity balance: An important outcome measure for fatigue management in neuromuscular diseases.

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Fatigue

Life balance
Life balance study

Validation of instruments that measure activity balance or life balance *Study A-Clinimetric study*

Individualized ‘managing fatigue’ program, a RCT

*Study B-Intervention study*
## Activity calculator: Example

<table>
<thead>
<tr>
<th>Time</th>
<th>Activity</th>
<th>Time length</th>
<th>Relaxing</th>
<th>Light</th>
<th>Medium</th>
<th>Strenuous</th>
<th>Points</th>
</tr>
</thead>
<tbody>
<tr>
<td>8.00</td>
<td>Waking up/bathing/dressing</td>
<td>30 min.</td>
<td></td>
<td>X</td>
<td></td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>8.30</td>
<td>Preparing and eating breakfast</td>
<td>30 min.</td>
<td></td>
<td>X</td>
<td></td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>9.00</td>
<td>Walking the dog</td>
<td>45 min.</td>
<td></td>
<td></td>
<td>X</td>
<td></td>
<td>3</td>
</tr>
<tr>
<td>9.45</td>
<td>Drinking a cup of coffee</td>
<td>15 min.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>-0.5</td>
</tr>
<tr>
<td>10.00</td>
<td>Cleaning</td>
<td>30 min.</td>
<td></td>
<td></td>
<td>X</td>
<td></td>
<td>3</td>
</tr>
<tr>
<td>10.30</td>
<td>Grocery shopping</td>
<td>60 min.</td>
<td></td>
<td></td>
<td></td>
<td>X</td>
<td>6</td>
</tr>
</tbody>
</table>
Activity calculator weighing instructions

How do I experience this activity?
1. Most of the time, on average
2. Regardless of duration of the activity
3. And not related to the energy used in other activities, that same day
Activity calculator: weighing and scoring

**Per half hour:**

<table>
<thead>
<tr>
<th>Activity</th>
<th>Activity Description</th>
<th>Points</th>
</tr>
</thead>
<tbody>
<tr>
<td>Relaxation</td>
<td>Relaxing, restfull</td>
<td>-1 point</td>
</tr>
<tr>
<td>Light</td>
<td>Easy, minor, simple</td>
<td>1 point</td>
</tr>
<tr>
<td>Medium</td>
<td>Average, moderate</td>
<td>2 points</td>
</tr>
<tr>
<td>Strenuous</td>
<td>Heavy, demanding</td>
<td>3 points</td>
</tr>
</tbody>
</table>
Research questions

How do people with neuromuscular diseases and fatigue weigh activities in the Activity calculator?

Which factors influence the scoring proces?
Qualitative research: method

Interviews

Three Step Test Interview (TSTI) method:
1. Thinking aloud
2. Focussed interview
3. Semi-structured interview

Beatty and Willis (2007)
Participants

• The Dutch Association for Neuromuscular Disorders: participants with Fascioscapulohumeral dystrophy (FSHD) or Mitochondrial Myopathy (MM)

• 52 patients responded

• Interviews N=10, home visits
Participants

5 female, 5 male
5 FSHD, 5 MM
Age 21-71

<table>
<thead>
<tr>
<th>Participant</th>
<th>Age</th>
<th>Gender</th>
<th>Diagnose</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>21</td>
<td>F</td>
<td>MM</td>
</tr>
<tr>
<td>B</td>
<td>22</td>
<td>F</td>
<td>MM</td>
</tr>
<tr>
<td>C</td>
<td>43</td>
<td>M</td>
<td>MM</td>
</tr>
<tr>
<td>D</td>
<td>54</td>
<td>M</td>
<td>MM</td>
</tr>
<tr>
<td>E</td>
<td>58</td>
<td>M</td>
<td>MM</td>
</tr>
<tr>
<td>F</td>
<td>52</td>
<td>F</td>
<td>FSHD</td>
</tr>
<tr>
<td>G</td>
<td>53</td>
<td>F</td>
<td>FSHD</td>
</tr>
<tr>
<td>H</td>
<td>61</td>
<td>M</td>
<td>FSHD</td>
</tr>
<tr>
<td>I</td>
<td>66</td>
<td>F</td>
<td>FSHD</td>
</tr>
<tr>
<td>J</td>
<td>71</td>
<td>M</td>
<td>FSHD</td>
</tr>
</tbody>
</table>
Data analyses

- Transcriptions
- Codes
- Categories
- Themes
- Quotes
- Recoding: codebook
Results: themes

- Basic rules
- Definitions
- Time
- Physical and mental
- Environment
"Taking a bath is relaxation, however all the preparations before you go to bath are strenuous. Taking off your clothes, taking a towel, bath gel, clean clothes. It is quite a lot before you can take a bath."

(participant A)
Results: themes

Basic rules

Definitions

Time

Physical and mental

Environment

"With medium I have the choice to rest and with strenuous I have to rest." (participant E)
"For some activities I score them as light if I do them in the morning, but later that day I would score them as medium or strenuous. That has to do with my energy level that decreases during the day. (participant F)"
Results: themes

Basic rules

Definitions

Time

Physical and mental

Environment

“Hiking and riding a bicycle is strenuous, uhm, for my muscles. Mentally it clears my head, so it is relaxing. It shows that there is a difference in physical and mental.”

(participant D)
"I am thinking about summer time, if I do activities in summer, it is nice and warm and everything..., I can do much more. And then in autumn, I think..., oh yes, I gets worse faster. So I have to reduce my activities."
(participant E)
Future plan

- Test-retest reliability
- Construct validity
- Responsiveness:
  (floor-ceiling effects and longitudinal responsiveness)
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Activity Calculator
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Information

www.meandermc.nl/activity-calculator

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References

Activity Calculator (Activiteitenweger) ©meander2014. [www.activiteitenweger.nl]
