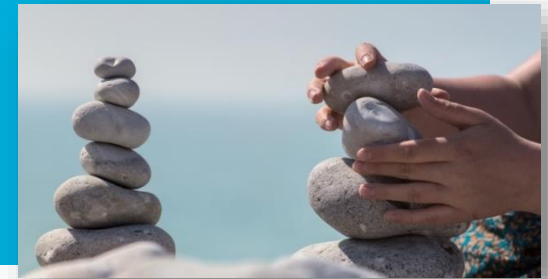


Activity balance: An important outcome measure for fatigue management in neuromuscular diseases.

WFOT Capetown, 23th of May 2018



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De Hoogstraat
Revalidatie



ergotherapienederland

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Life balance study

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

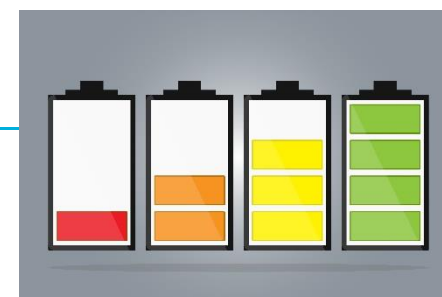
Individualized 'managing fatigue' program, a RCT
Study B-Intervention study



Activity calculator: Example



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



www.activiteitenweger.nl

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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:

Relaxation	Relaxing, restfull	-1 point
Light	Easy, minor, simple	1 point
Medium	Average, moderate	2 points
Strenuous	Heavy, demanding	3 points



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

Hak, T., et al. (2004)

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



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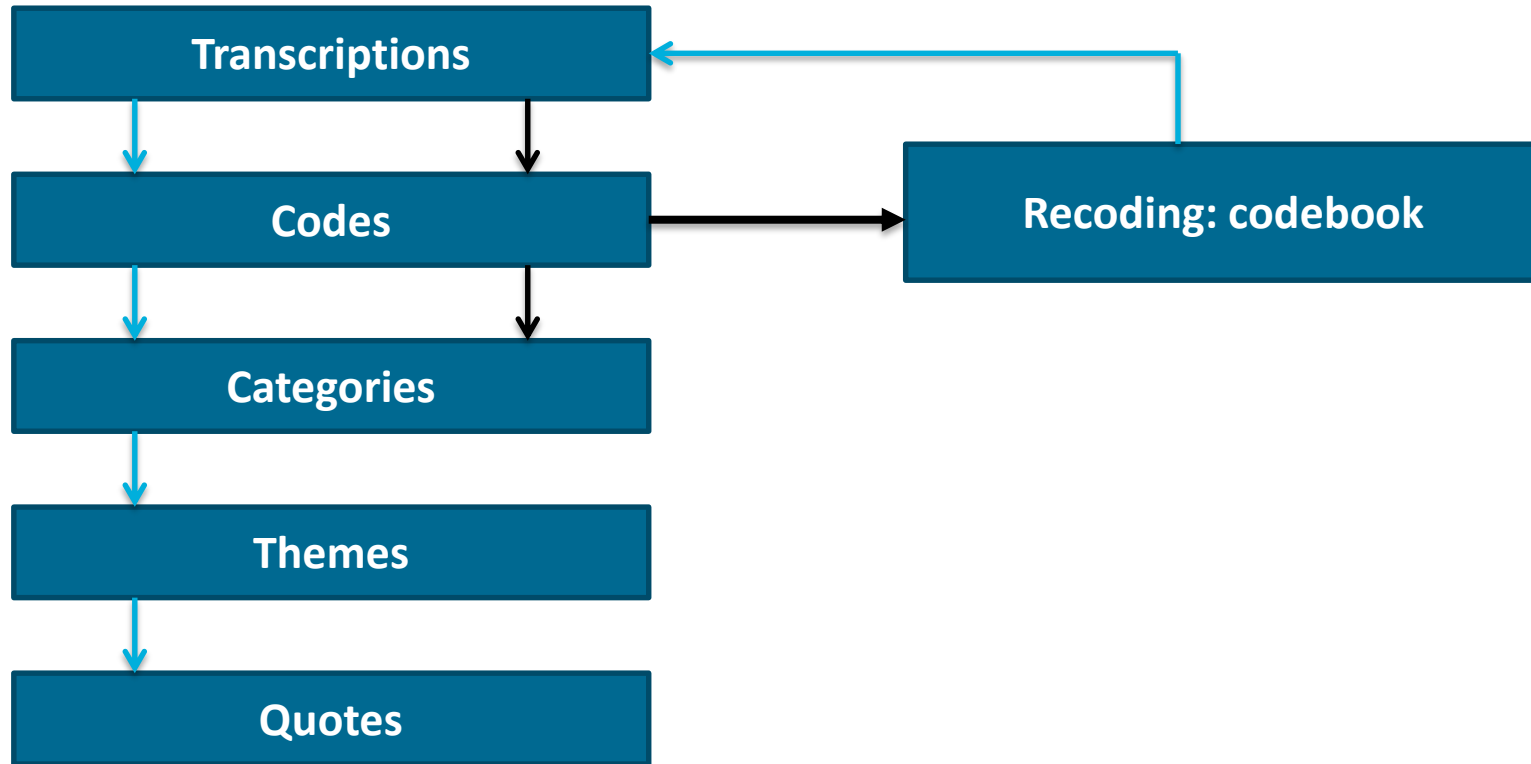
Participants

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

Participant	Age	Gender	Diagnose
A	21	F	MM
B	22	F	MM
C	43	M	MM
D	54	M	MM
E	58	M	MM
F	52	F	FSHD
G	53	F	FSHD
H	61	M	FSHD
I	66	F	FSHD
J	71	M	FSHD



Data analyses



Results: themes

Basic rules

Definitions

Time

Physical and mental

Environment



Results: themes

Basic rules

Definition

Physical
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)



Results: 5

Basic rules

Definitions

Time

Physical and
mental

Environment

“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)



Results: #1

Basic rules

Definitions

Time

Physical and
mental

Environment

“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.”
(partcipant E)



- **Future plan**

- Test-retest reliability
- Construct validity
- Responsiveness:

(floor-ceiling effects and longitudinal responsiveness)



Acknowledgements



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Leenders, Edith Cup, Sander Geurts



Activity Calculator

Greke Hulstein, Karin ten Hove



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Information

www.meandermc.nl/activity-calculator



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References

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

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