

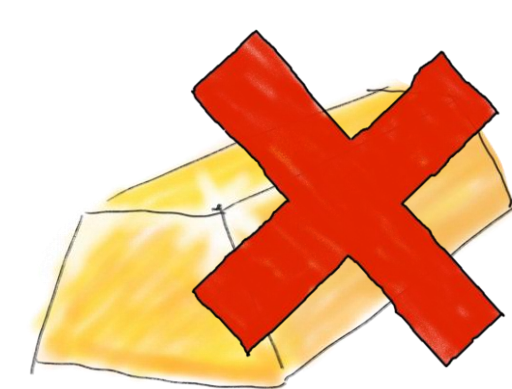
FUNCAP

Assessing FUNCTIONAL CAPACITY in Myalgic Encephalomyelitis/ Chronic fatigue syndrome: A patient informed survey

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WHY



There is a need to accurately assess functional capacity in patients with PEM – but there has been no gold standard for how to do it.

Assessing functional capacity is needed for:

- Diagnosis and follow up
- Assessment for welfare benefits
- Need for practical assistance in the community
- Outcome measure in research

CAN OR "CAN"

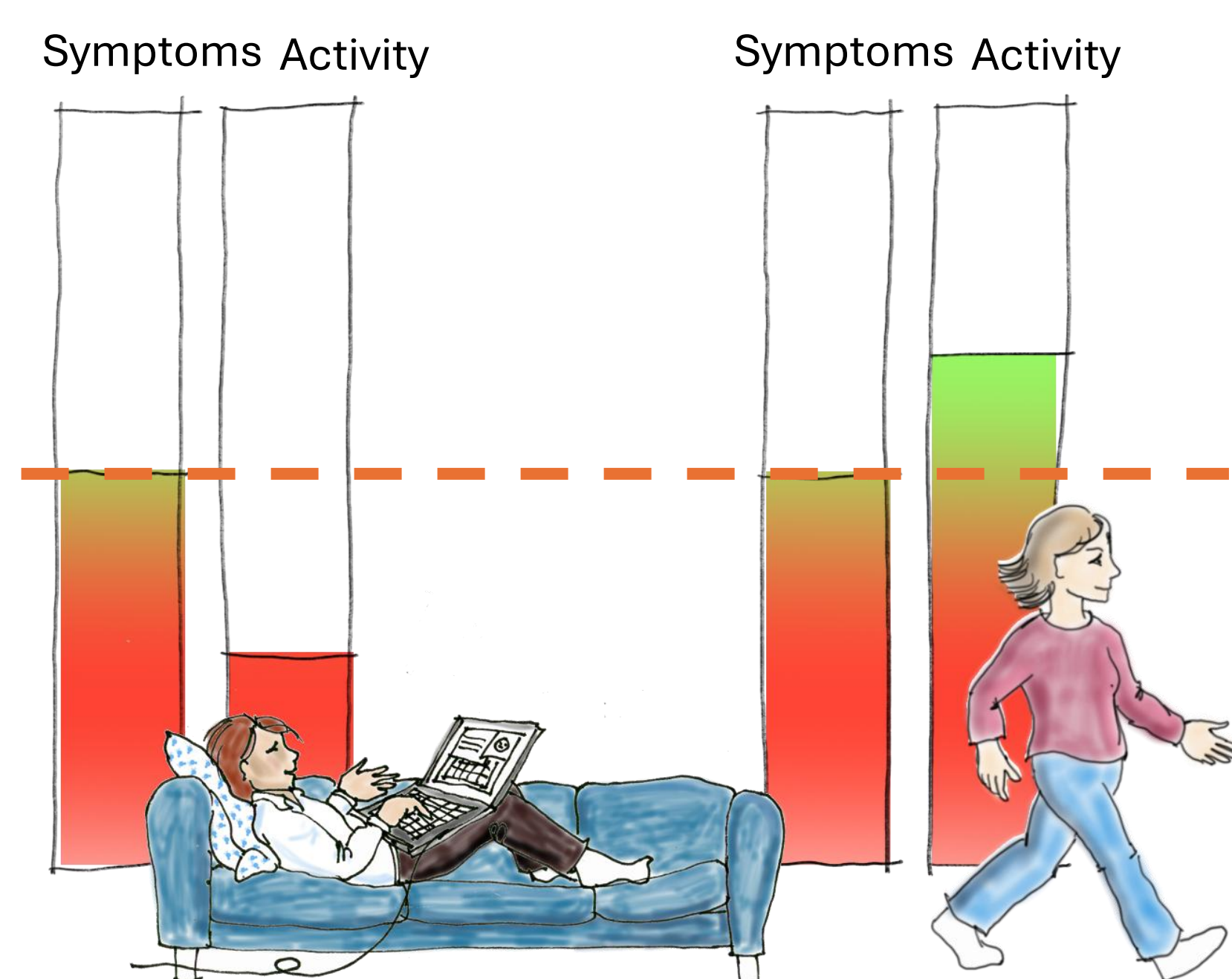
Existing questionnaires ask if you «can» do an activity. What does «can» mean?

- Can, without problems?
- Can, but crashes afterwards?

Asking what a person with ME «can» do without asking about consequences will not give good answers.

Existing questionnaires do not ask about disabilities common in ME/CFS, like light or sound hypersensitivity, «brain fog» or orthostatic intolerance.

If improving, patients typically increase activity while maintaining a manageable symptom level. Asking only about activity or symptoms may miss change. Outcome measures must take both into account.



HOW

Questions sourced from CFS-APQ (Nijs et al, 2005) and a generic Norwegian 40-item questionnaire (Brage et al, 2004) based on WHO ICF 2001. Items relevant to severe/very severe ME/CFS came from an activities of daily living score used in a previous survey of severely ill ME patients in Norway (Sommerfelt et al 2023)

Three successive rounds of anonymous surveys in Norway. Feedback from patients was the basis for changes in items and the scoring scale.

Round four in English, made available on social media, respondents from the US, the UK, Canada, Australia, as well as non-English speaking countries.

Round five; final Norwegian round, round six; test-retest.

FUNCAP domains:

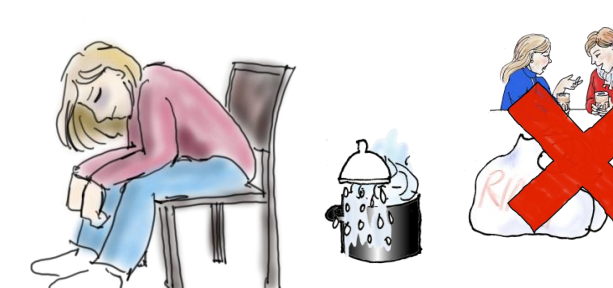
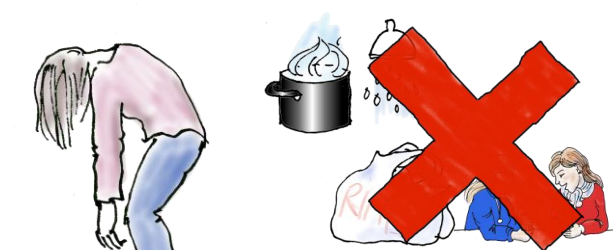
- Personal hygiene/basic functions (7/3)*
- Walking – moving about (7/3)
- Being upright (5/3)
- Activities in the home (6/2)
- Communication (7/3)
- Activities outside your home (7/4)
- Reactions to light and sound (6/3)
- Concentration (10/6)



* Items in domain in FUNCAP 55 and FUNCAP 27

FUNCAP response scale

- I cannot do this
1. My capacity will be severely reduced for at least three days
2. I can do little else on the same day and for one to two days afterwards
3. I can do little else on the same day
4. I must limit other activities on the same day
5. This rarely affects other activities
6. Unproblematic – does not affect other activities



Click to go to FUNCAP.no website for full questionnaire

Feedback from patients during first three rounds:

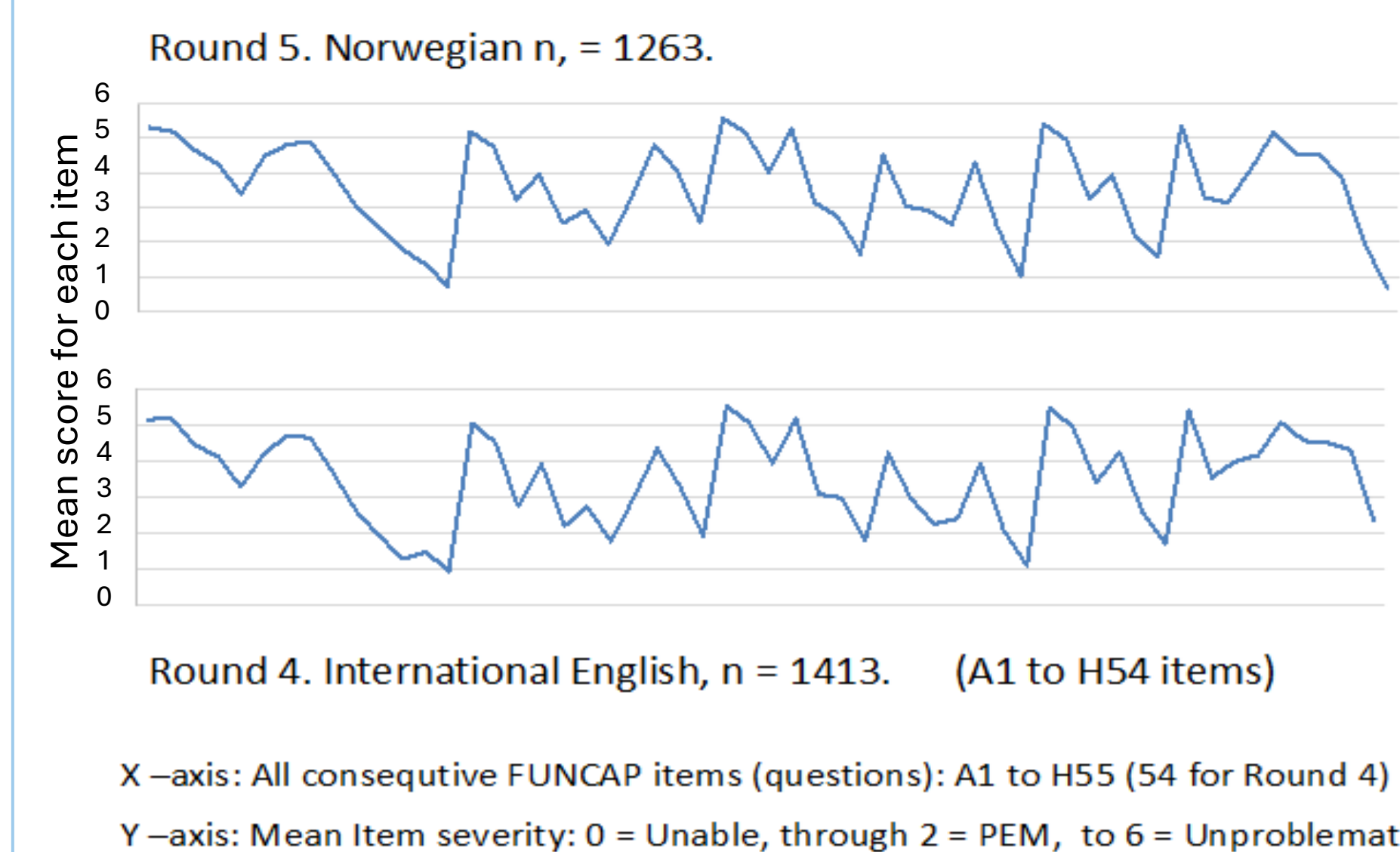
- Be exact when asking about time or distance, do not say «short walk» or «long time»
- Specify activities that will show the disability in the whole spectrum of ME patients, from mild to severely ill.
- PEM is cumulative, include complex activities that involve many sub-activities

RESULTS

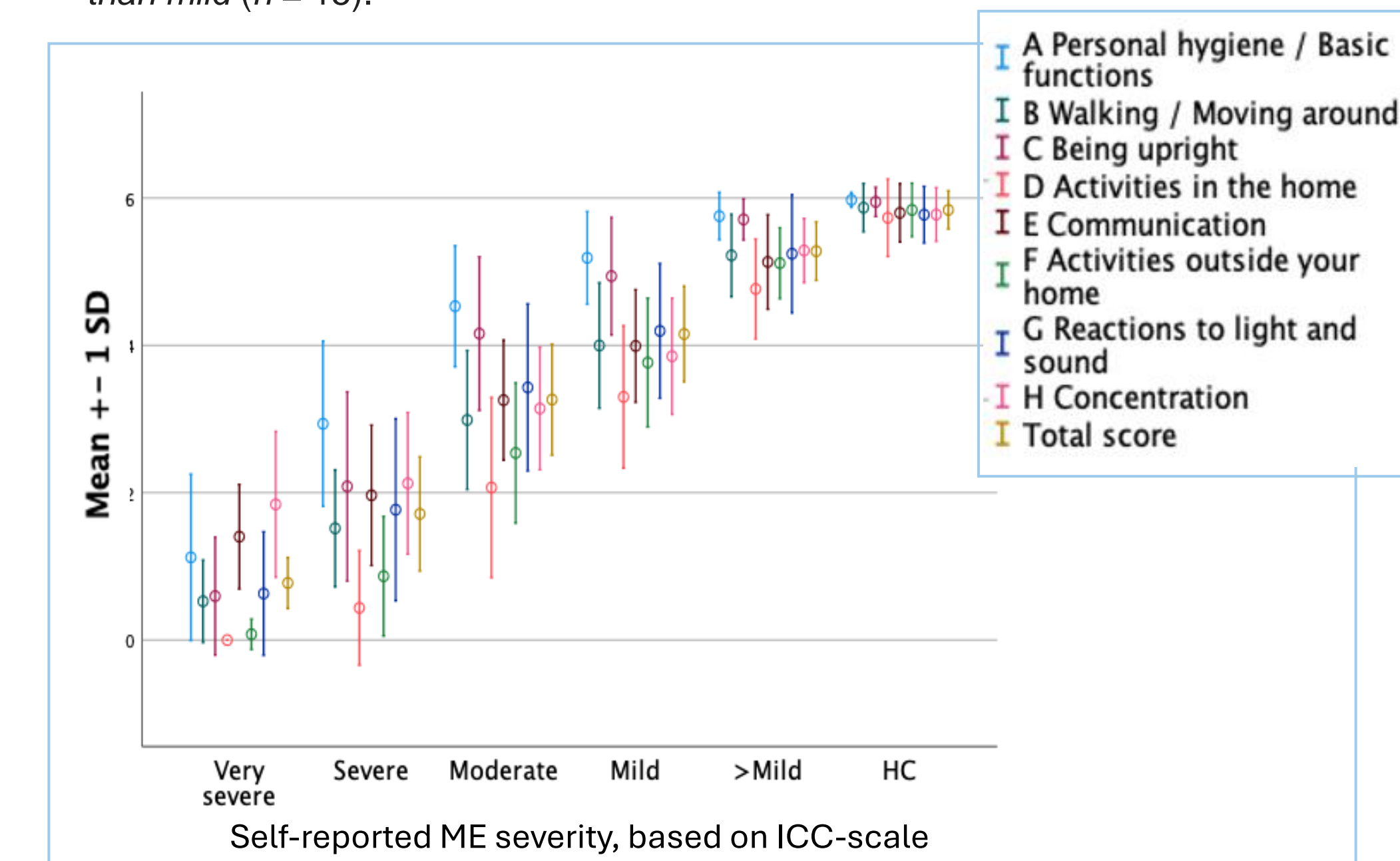
Good reliability and validity, very good internal consistency, good test-retest reliability, with negligible floor and ceiling effects were found, with comparable findings in all aspects in both a large Norwegian (n = 1263) and a separate English-language international sample (n = 1387) demonstrating the validity and reliability of FUNCAP.

Patient feedback: “I could accurately describe my level of functionality. The questionnaire was easy to use”

Round 5 & 4: Mean A1 to H55 item scores Mean items scores (and SD's) were almost identical



Round 5. Mean (+/-1 SD) A to H sub-scores and total scores on the FUNCAP55 questionnaire for ME/CFS (n = 1263) respondents and healthy controls (HC, n = 178) according to ME/CFS severity degree which was as follows: very severe (n = 19), severe (n = 136), moderate (n = 733), mild (n = 360), better than mild (n = 15).



FUNCAP has 55 questions. We have also developed a shorter version with 27 questions.

FUNCAP55 may mainly find use in diagnosing optic workup clinical of ME and assessments for social benefits. FUNCAP 27 mainly for follow-up and in research.



ARTICLE

Sommerfelt, K.; Schei, T.; Seton, K.A.; Carding, S.R. Assessing Functional Capacity in Myalgic Encephalopathy/Chronic Fatigue Syndrome: A Patient-Informed Questionnaire. *J. Clin. Med.* 2024, 13, 3486.

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FUTURE

FUNCAP 55 and FUNCAP 27 is already in use in clinical practice. We have received positive feedback from both patients and doctors.

FUNCAP 27 is used by the Visible app for monthly check-in, and is currently being used in several clinical studies

FUNCAP is available under creative commons license.



Free downloads of questionnaire in English, Norwegian, Swedish, German, Dutch and French

FUNCAP website: FUNCAP.no