Severe, and very severe ME in Norway

Symptom burden and access to care.
An internet-based, open patient survey.

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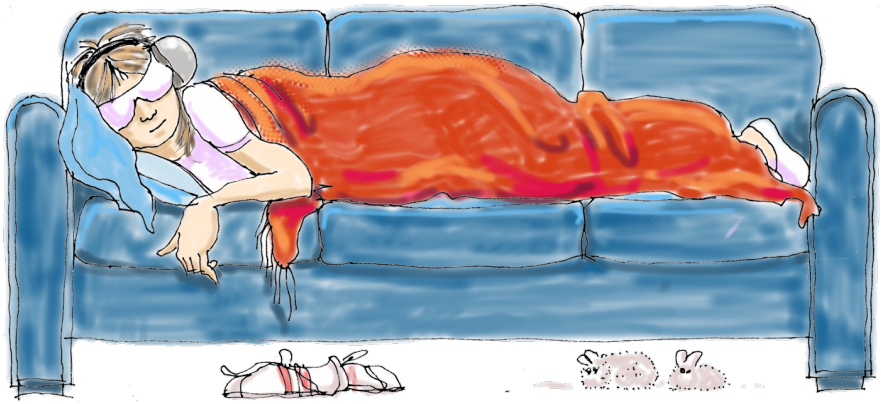


Background

- Little relevant research
- Very severe burden for patients/ families/ healthcare systems
- A previous Norwegian 2019 internet-based survey, n=5822:
  - 15 % had severe ME
  - 1 % had very severe ME

  Not population based..

Study design

- Pre-study pilot (n=80) to find important targets ++
- Main study anonymous survey open
  July – Oct 2018
- Info spread widely via social media
- Surveymonkey used. Only **One** response pr IP address allowed
- 80 - 96 questions: Multiple choice/ structured (+ some open-ended)

We made the *Activities of daily living score* (ADLS)

ADLS score calculation:

Sum of **Item Weight x Frequency** for each the **15 items**.

Max possible score 124 (= all items: daily)

Domain	Activity	Item weight (energy use)
Motor	**1. Leave the house**	**4**
	2. Go for a short walk	**5**
	3. Have visitors or visit	**3**
Communication	**4. Communicate online**	**1**
	5. Have a conversation > 5 min	**1**
	6. Say a few words	**1**
General daily activities	**7. Cook a simple meal**	**3**
	8. Eat without assistance	**1**
	9. Get out of bed, get dressed	**2**
	10. Sit up in bed	**1**
	11. Turn myself over in bed	**1**
Basic hygiene	**12. Basic personal hygiene**	**2**
	13. Shower	**3**
	14. Wash my hair	**2**
	15. Use the toilet	**1**

Item weight (energy use):
Authors estimation of energy demand for each item:
1 = Low demand ..... to ..... 5 = High demand

Frequency of undertaking the 15 activities:

0 = Never
1 = 1-2x/ year
2 = 1x/week to 1x/ 2 months
3 = Several times/ week
4 = Every day

Severity classification- ICC vs our ADSL score

- Based on ICC* severity definitions.

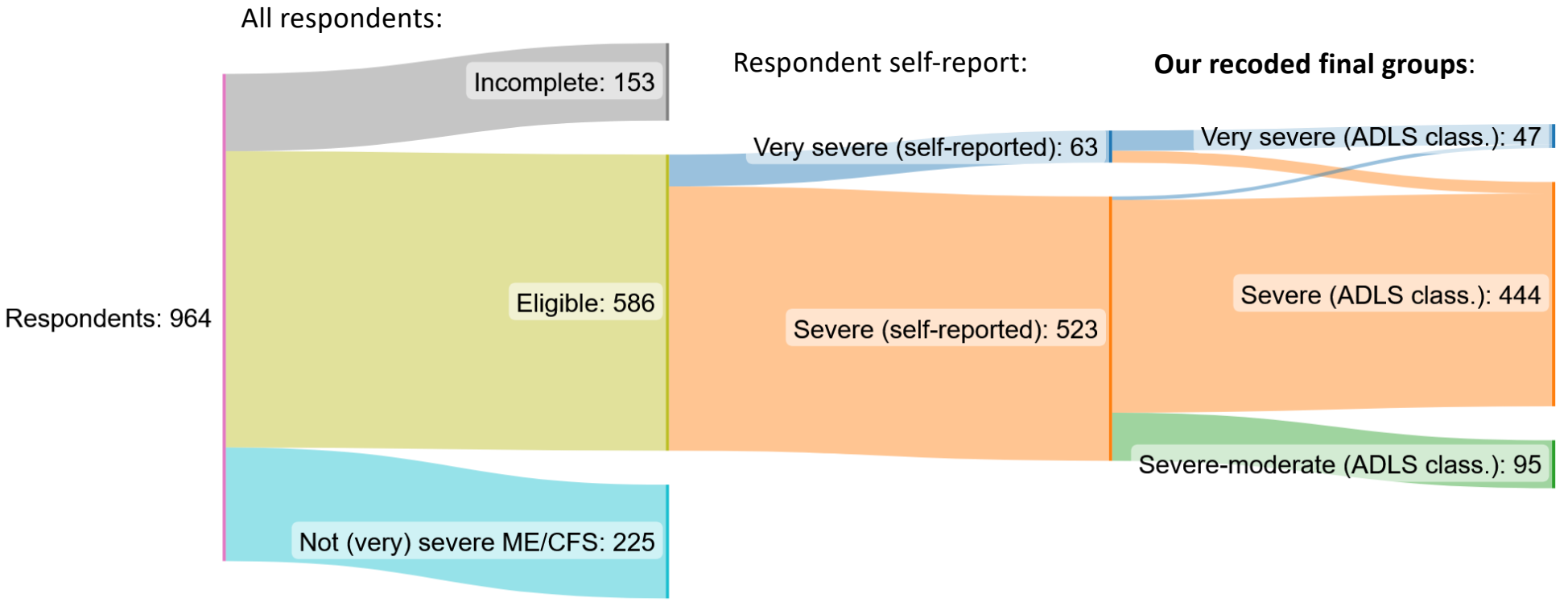
  Based on all survey question responses we (subjectively) chose ADLS cut-off scores to classify severity:

  - Very Severe ME (**VSME**): Fully bedridden, in need of care:
    - Always in bed. Help with personal hygiene and eating. Some - tube fed. Very sensitive to light/sound
    - **ADLS 0-35: VSME**
  - Severe ME (**SME**): Housebound, partly bedridden:
    - In bed/ on sofa most of the day. Can eat and f ex brush teeth
    - **ADLS 36-86: SME**
  - («Moderate» ME (**MME**)- NB **NOT** primarily targeted for this study):
    - NB! Non- representative group included in some results for comparison
    - **ADLS >87 : «moderate» ME** (when compatible with item responses)

    * ICC = 2011 International Concensus Criteria

Study population- excluded, included, severity change

Included: Very Severe (n= 47) (blue) Severe (n= 444) orange Severe-Moderate* (n= 95) green

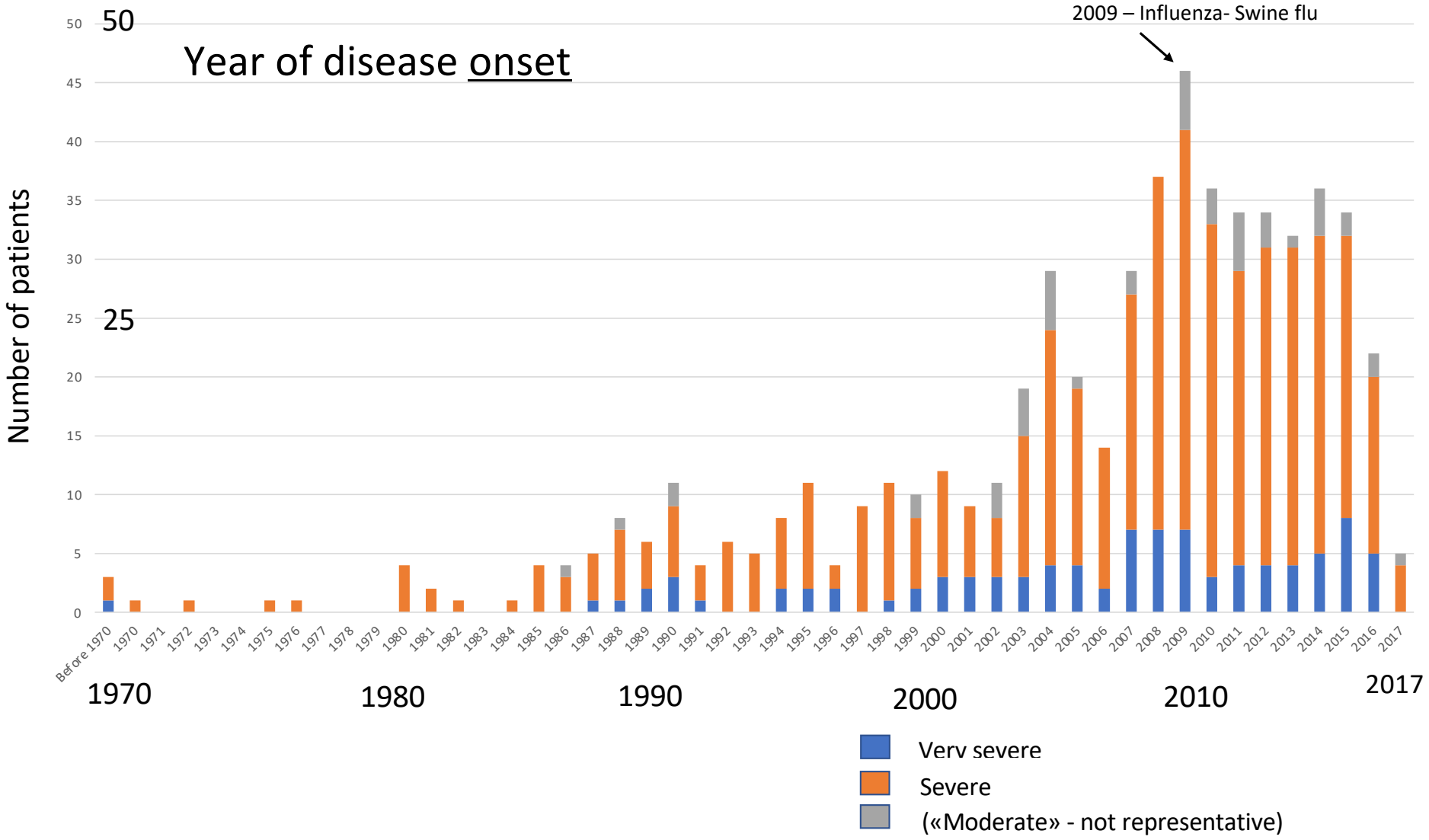


Made w ith SankeyMATIC ***Severe-Moderate***: Not representative- Recoded from Severe

Participants

- 491 eligible respondents included:
  - Severe ME (**SME**): 444.
  - Very Severe ME (**VSME**): 47 (after excluding/ reclassifying some)
  - 95 reclassified as «Moderate» (**MME**).
  - All were diagnosed by healthcare professionals (doctors)
    - 15% by their family doctor (general practitioner)
    - 85% by specialist/ in hospitals

    Norway: Almost always:
    Canada criteria for adults, and Jason (2006) criteria for children/ adolescents


Year of disease onset
2009 – Influenza- Swine flu
Number of patients
50
25
0
Before 1970
1970
1980
1990
2000
2010
2017
Very severe
Severe
(«Moderate» - not representative)

Sex, age at study time, age at onset, duration, living situation. %

Numbers are percentages	Very severe, n=47	Severe, n=444	«Moderate», n=95	Total, n=586
Female	87	88	87	88
Age 0-19 years	**19**	**12**	**5**	11
Age 20-39 years	49	42	44	43
Age 40+ years	32	46	51	46
Onset 0-15 years	**43**	**32**	**22**	31
Onset 16-29 years	26	31	32	31
Onset 30+ years	32	36	45	37
Duration 0-5 years	21	22	23	22
Duration 6-15 years	62	51	47	51
Duration 16+ years	17	28	30	27
Live alone	**17**	25	30	25
Live with parents	**45**	20	13	25
Live with partner/ spouse	17	40	47	39
Live with others/ institution	21	10	11	11

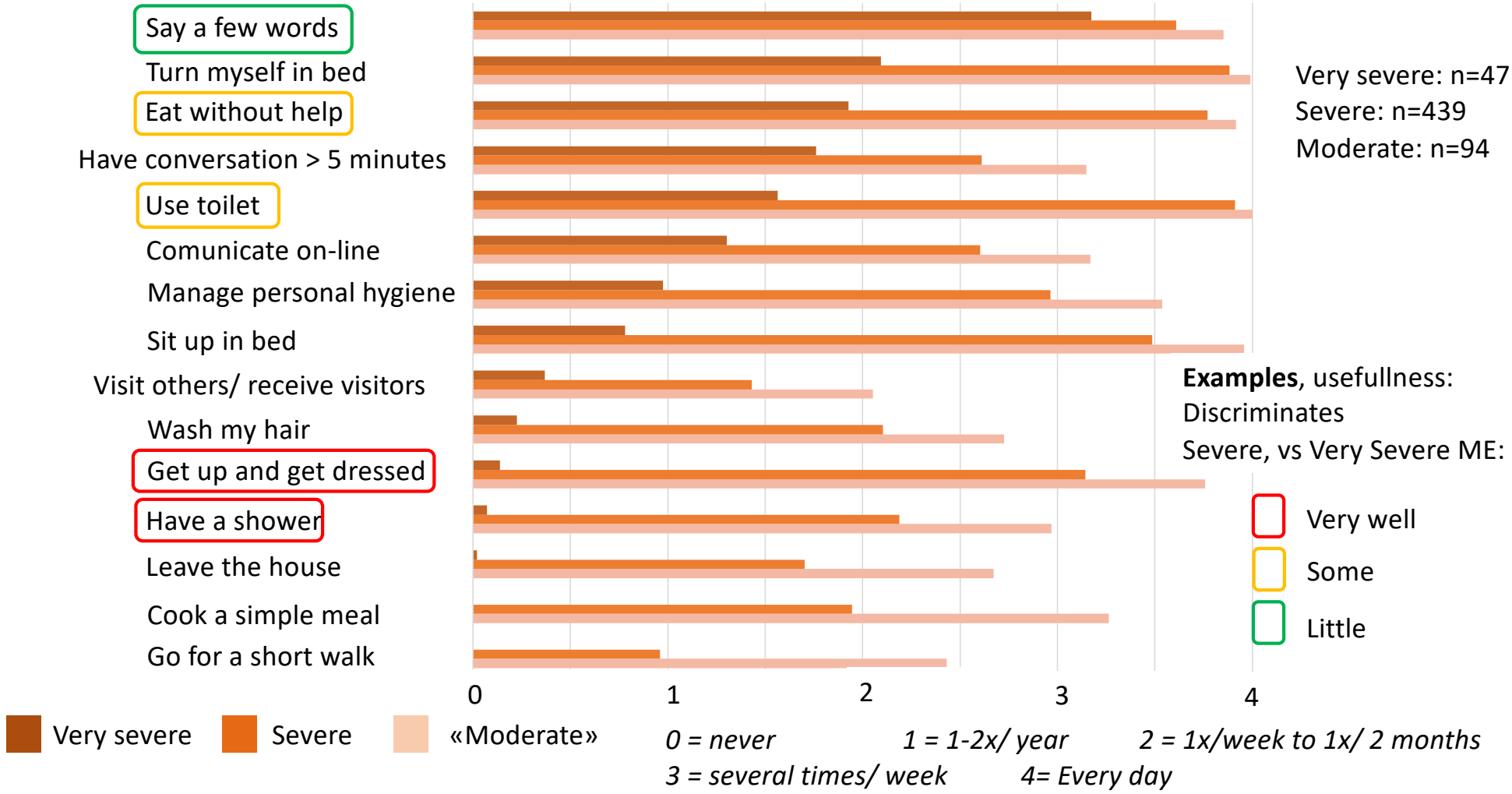
Change in severity over time

- Getting **worse**:
  Very severe = Severe 50 %

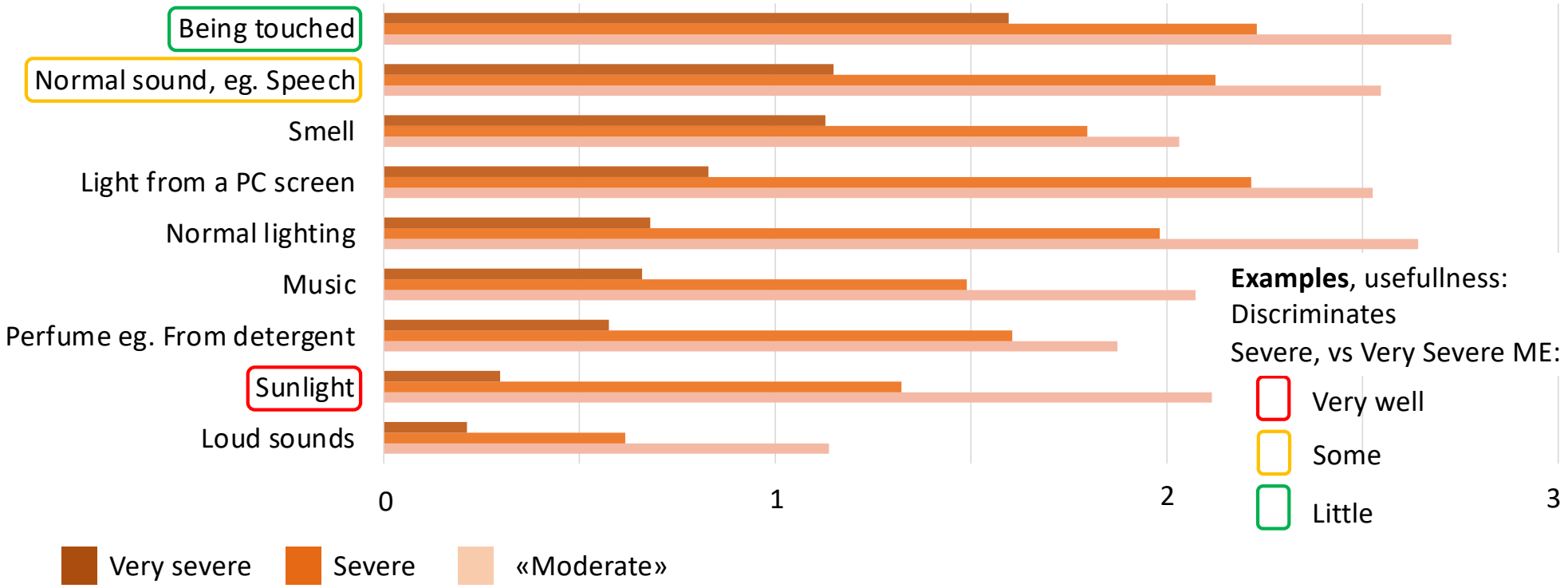
- Getting **better**:
  Very severe 0 %.
  Severe 8 %

- Fluctuating:
  Very severe 8 %
  Severe 33 %

Average capacity for various ADL items



Average tolerance score (0 - 4) for sensory stimuli



Tolerance score:

0 = does not tolerate at all
1 = seldom tolerates
2 = tolerates once in a while
3 = tolerates
4 = tolerates well

Very severe: n=47
Severe: n=439
Moderate: n=94

Most troublesome symptom
(Very severe + Severe combined)

- Based on scoring symptoms on a 0-5 scale:
  - Least severe (not mentioned- 0) –to – Most severe (5)
- Average scores:
  - **Fatigue** **3.4**
  - **Muscle/ joint pain** **2.1**
  - Brain fog 1.7
  - Sleep disturbance 1.6
  - Sensory intolerance 1.6
- Worse sensory intolerance (relative) with increased disease severity

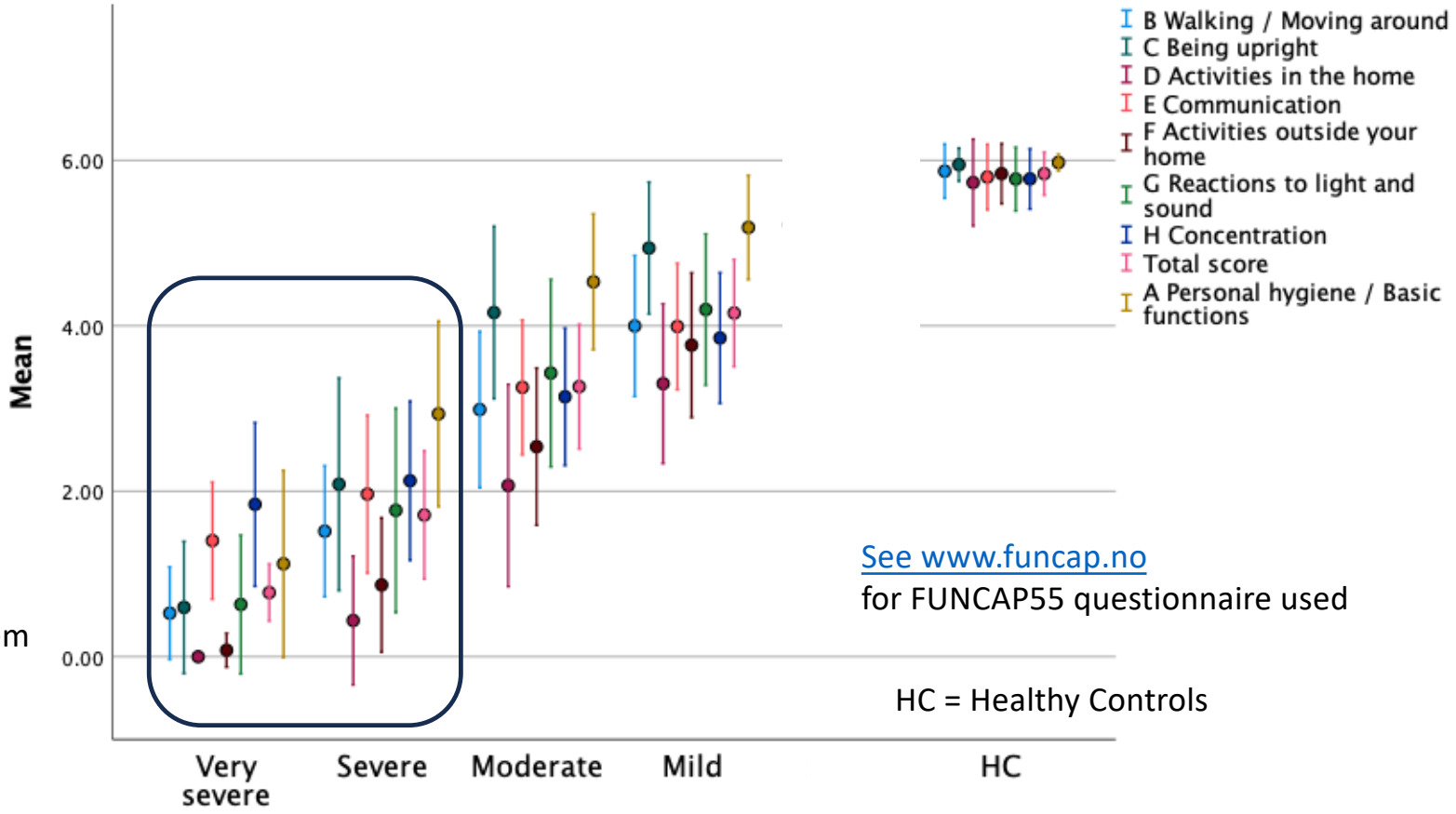
- Very severe ME: 30 % Tube-fed

FUNCAP55: Mean domain scores across ICC Severity degrees

NB: From a different study! (FUNCAP ref)

Mean FUNCAP Domain scores:

0: Unable
=< 2: PEM
.
.
.
6: No problem



n = 19 n = 136 n= 733. n = 360 n = 178

[See www.funcap.no](http://www.funcap.no)
for FUNCAP55 questionnaire used

HC = Healthy Controls

FUNCAP ref:
Sommerfelt et al. J Clin Med. 2024

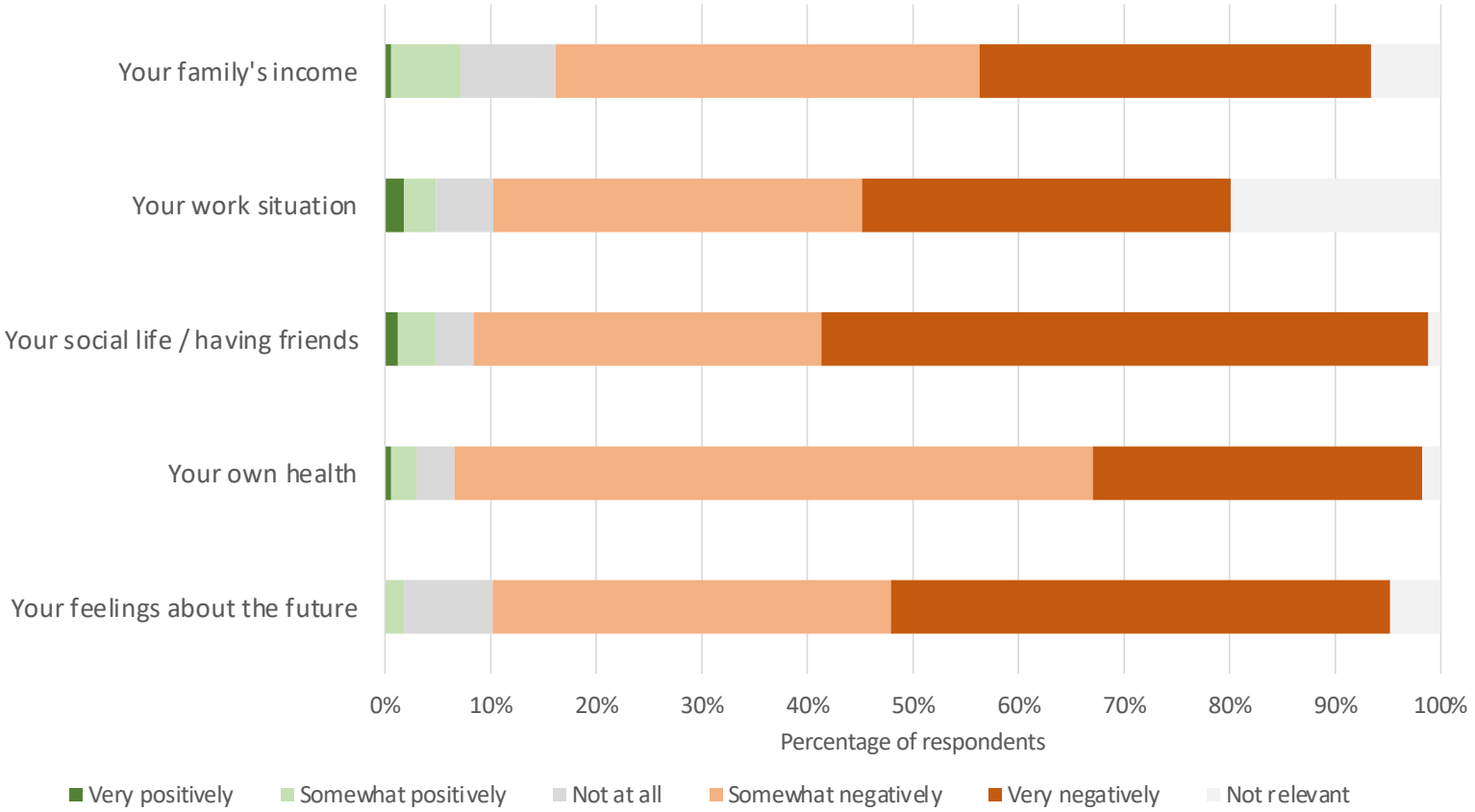
Carers situation

- Very severe and Severe ME
  - 60 % received help from health/ social care systems (Severe= Very severe). Many **did not want** such help due to negative experience
  - 40% Very severe, 20% Severe received **home nursing** - satisfied with it
  - Approx 50 % of patients/ carers satisfied with **family doctor/ physiotherapist/ occupational therapist**
  - 12-15 % satisfied with **hospital experience** (specialist services)
  - Work, social, and financial situations were severely impacted

- Very severe
  - All but one needed 24 hour care
  - Care constituted > 1 full work schedule (= «full job»)

Impact of being a carer for severe and very severe ME/CFS patients

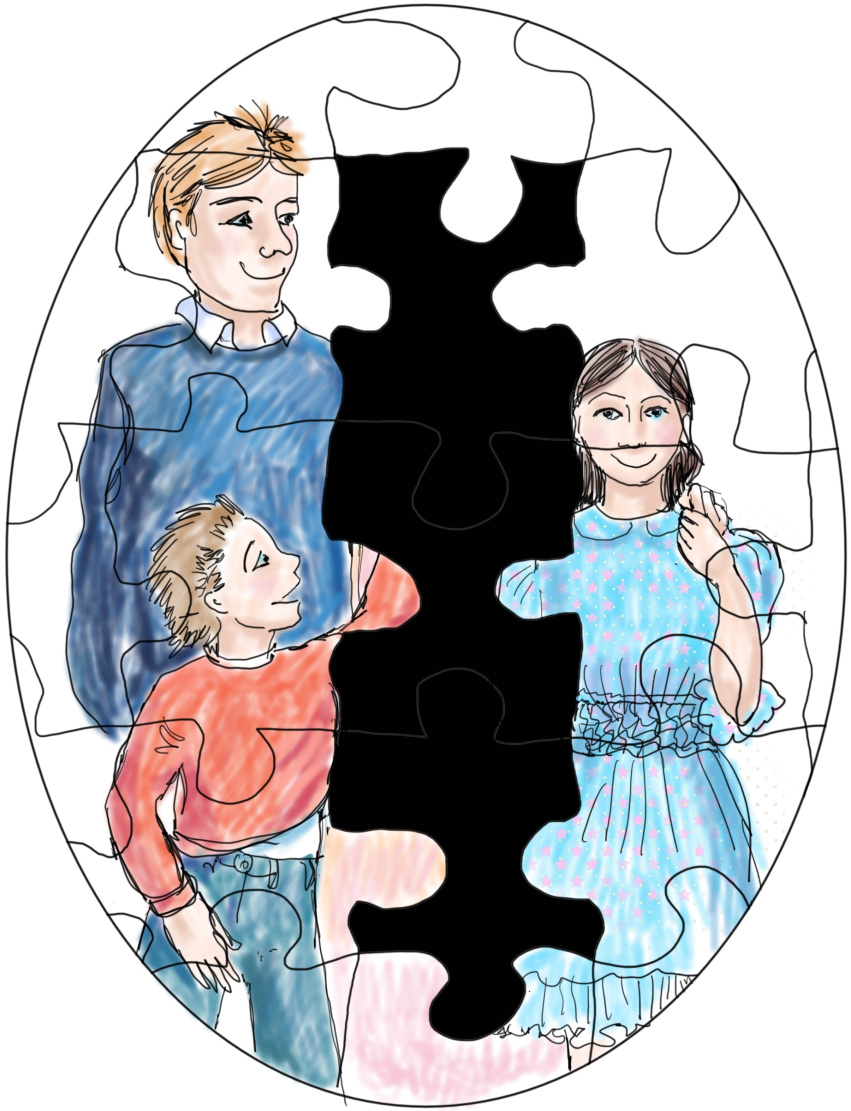
Percentage of respondents



Conclusion severe/ very severe ME

- Extreme severity of symptoms and lack of functional capacity

- Strikingly inadequate recognition of very difficult burden of care for close family



Thank you for your attention

* Our gratitude **to the patients and their carers** for responses!!

* Deepfelt thanks to the extensive work from my collaborators/ coauthors Trude Schei and Arild Angelsen from the Norwegian ME Association (patient organization- 6500 members)

And for:

NORGES MYALGISK ENCEFALOPATI FORENING

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