Health related quality of life in myasthenia gravis patients

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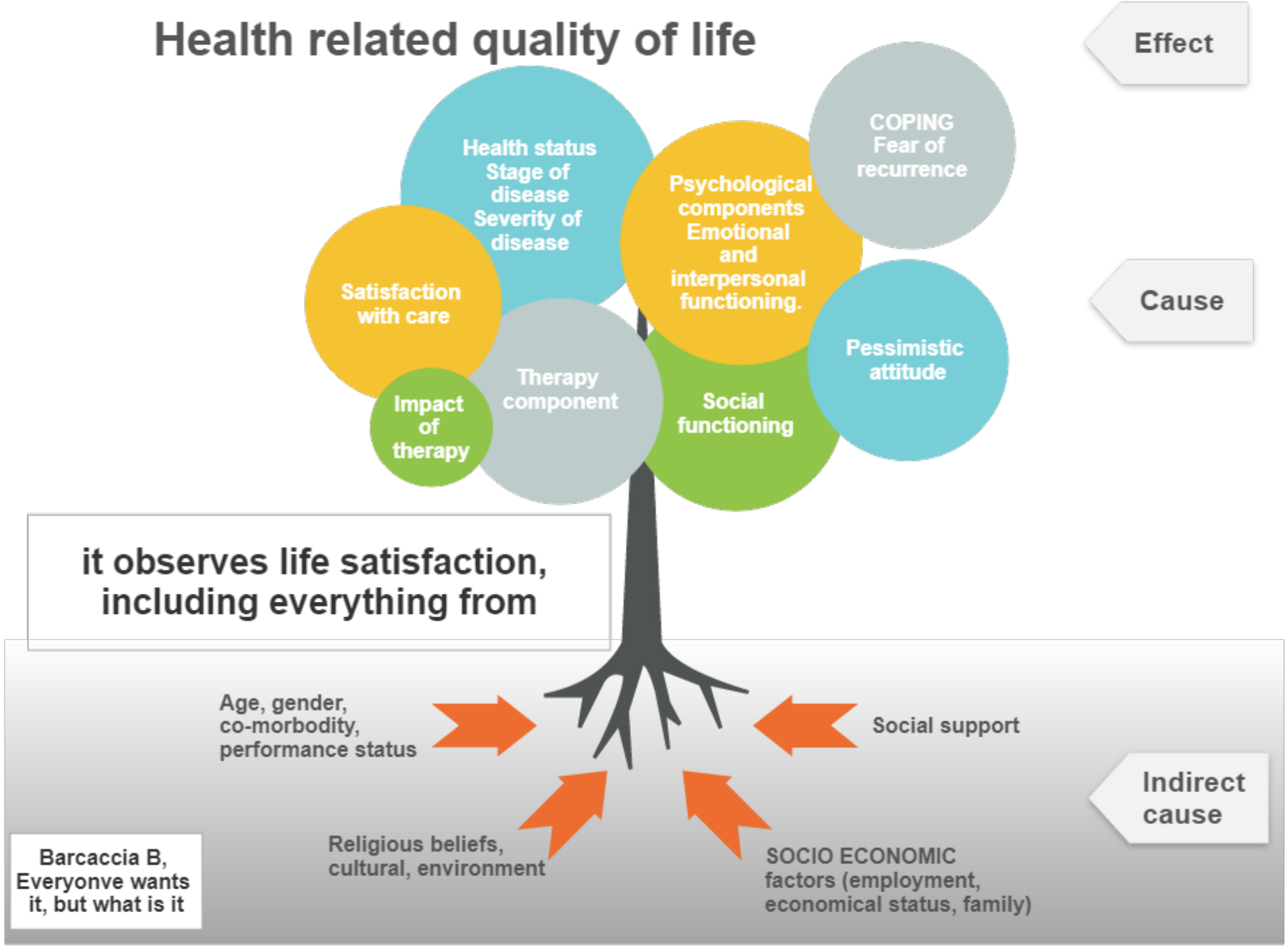
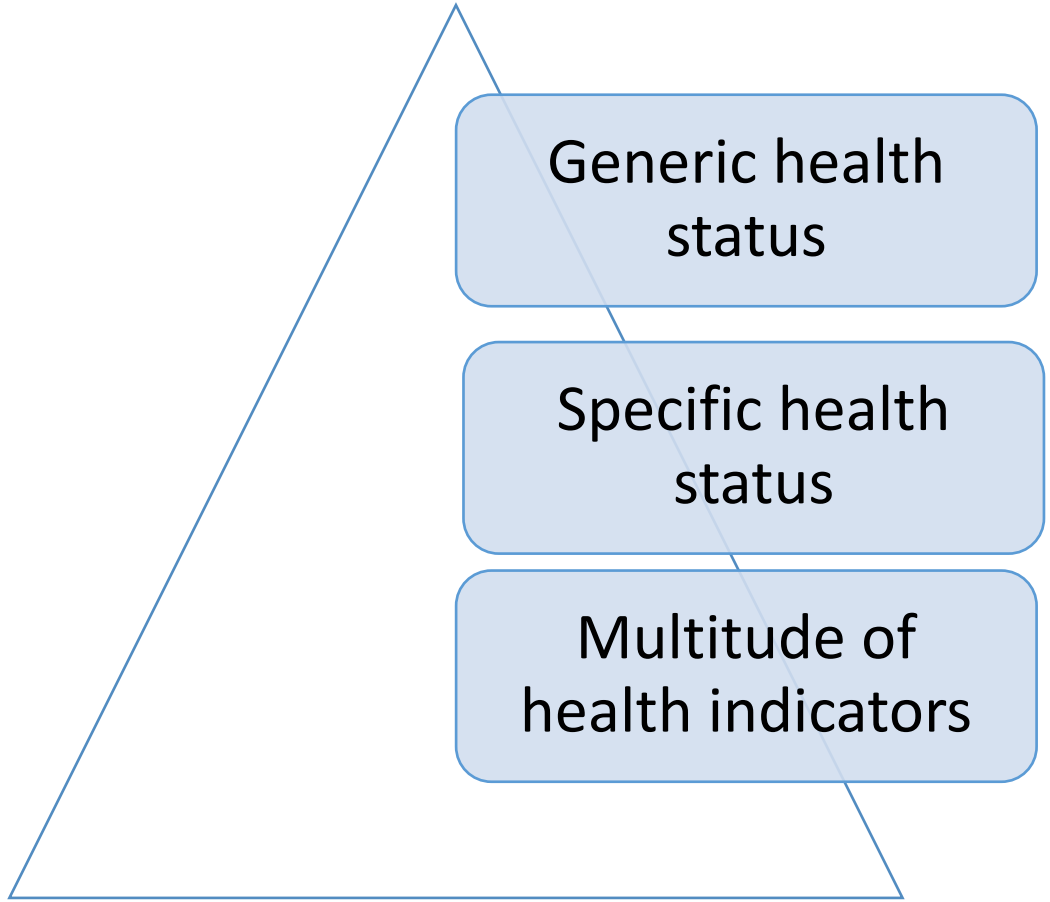
Health related quality of life



How do we measure it?



SF-36
EQ-5D

MG-QOL15
MG-ADL
QMG

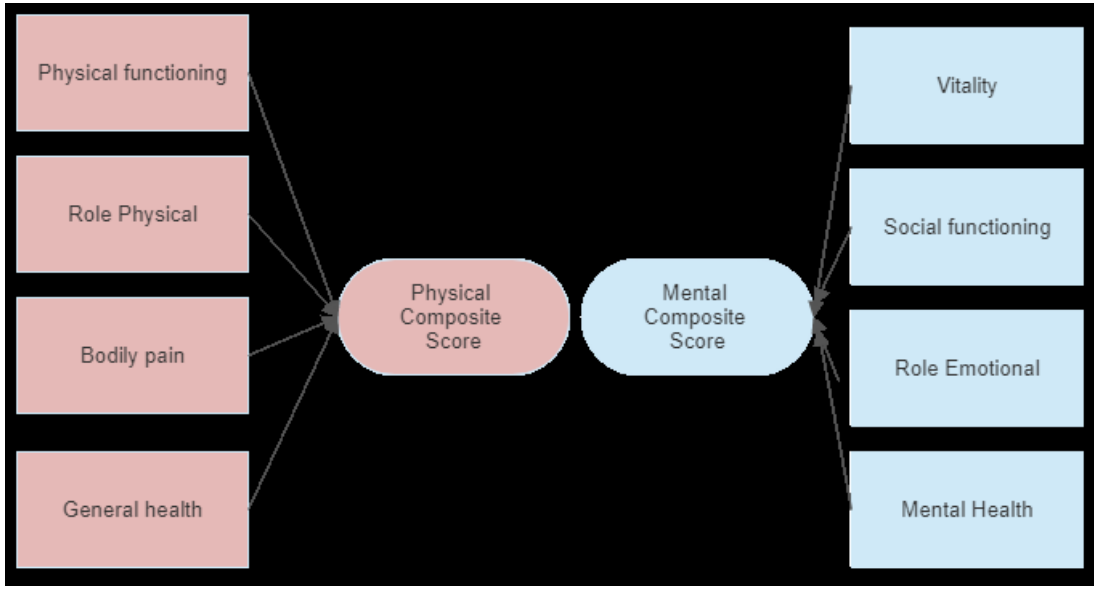
Psychosocial outcomes, Work, depression, sleep, disabilities etc.

Rand SF-36

Measures general health perceptions

36 questions, which are sorted into two summary scores physical and mental composite scale (0-100)

Translated into multiple languages and has norm-based scoring so that comparison across countries is possible



Myasthenia gravis quality of life MG-QOL15 and MGQ

Simple, easy to administer, user-friendly, and quick.

Relevant to MG

Quick look is enough

Practical in the office

Used as secondary outcome in studies

Please indicate how true each statement has been (over the past four weeks).

	Not at all	A little bit	Some-what	Quite a bit	Very much
	0	1	2	3	4
1. I am frustrated by my condition					
2. I have trouble using my eyes					
3. I have trouble eating					
4. I have limited my social activity because of my condition					
5. My condition limits my ability to enjoy hobbies and fun activities					
6. I have trouble meeting the needs of my family					
7. I have to make plans around my condition					
8. My occupational skills and job status have been negatively affected					
9. I have difficulty speaking					
10. I have trouble driving					
11. I am depressed about my condition					
12. I have trouble walking					
13. I have trouble getting around public places					
14. I feel overwhelmed by my condition					
15. I have trouble performing my personal grooming needs					

Myasthenia Gravis Quality-of-Life "MG-QOL15"
Burns TM, et al., *Muscle and Nerve* 2008

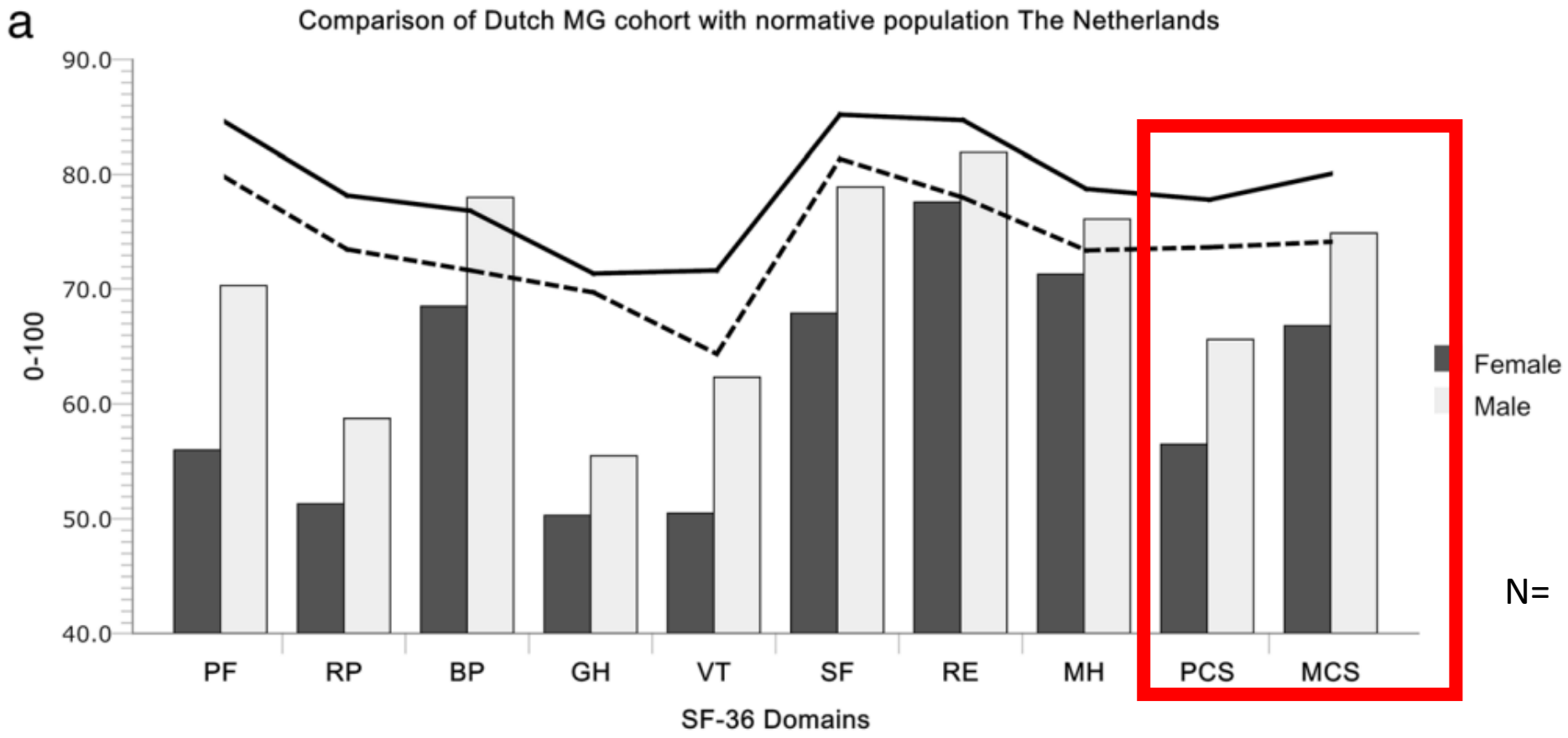
Total MG-QOL15 score

FIGURE 2. The 15-item MG-specific QOL instrument (i.e., MG-QOL15).

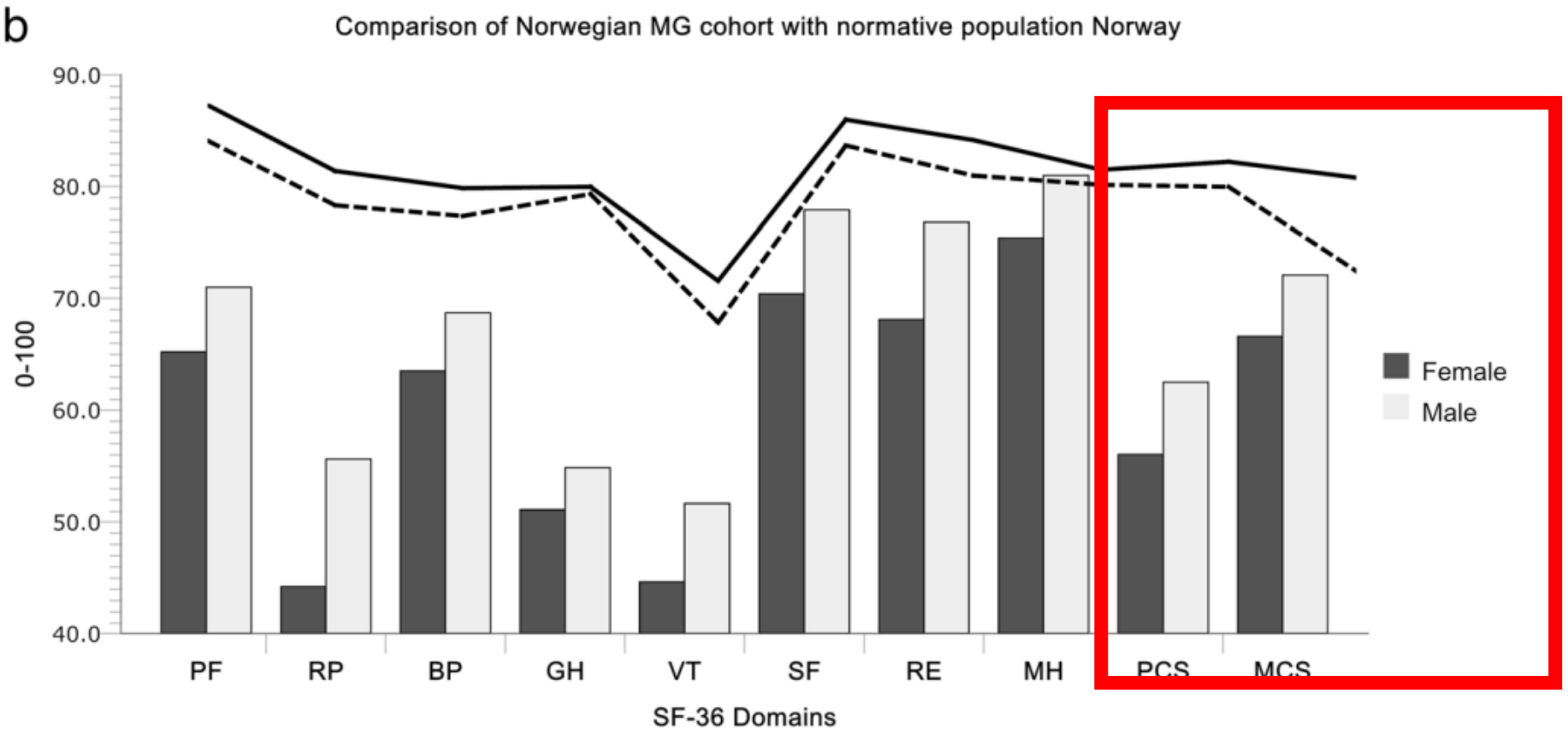
SF-36 studies in MG patients (n=11 in 2019)

Author	Type of Cohort	Patients (N)	Country	Compared to country controls
Paul et al, 2001	Cohort from patient organization	27	US	reduced
Padua et al, 2002	Clinical cohort	46	Italy	reduced
Rostedt et al, 2005-2006	Clinical cohort	42-48	Sweden	Not stated
Leonardi et al 2010	Clinical cohort	102	Italy	Reduced when symptoms
Winter et al, 2010	Multicenter cohort	43	Germany	reduced
Twork et al, 2010	Cohort from patient organization	1518	Germany	reduced
Kalkantrakorn et al, 2010	Clinical cohort	71	Thailand	Reduced
Boldingh et al, 2012	Population based cohorts	858	Norway / The Netherlands	Reduced
Szczudlik et al, 2020	Clinical cohort	339	Poland	Not stated

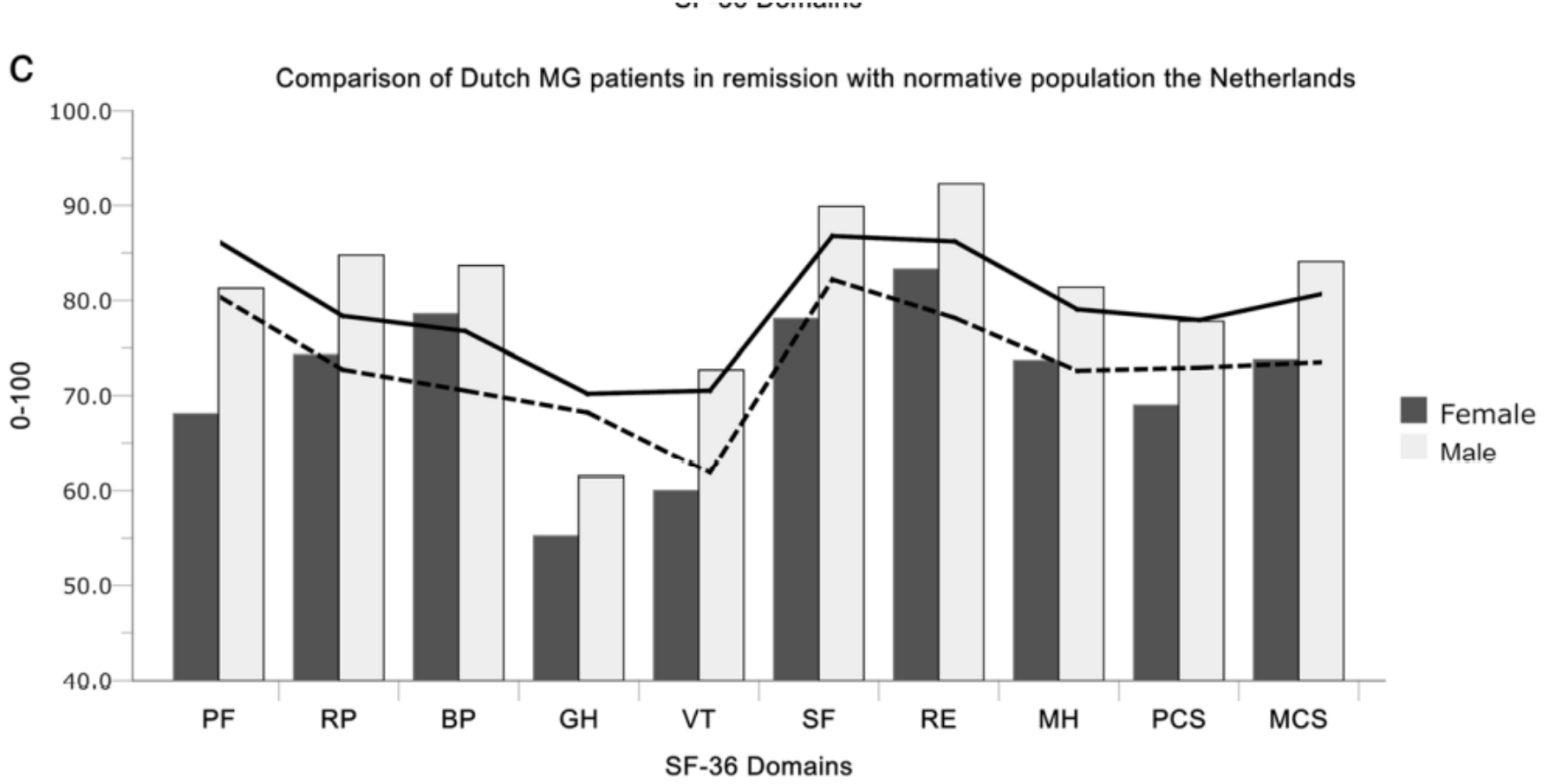
Lower quality of life compared to normative population



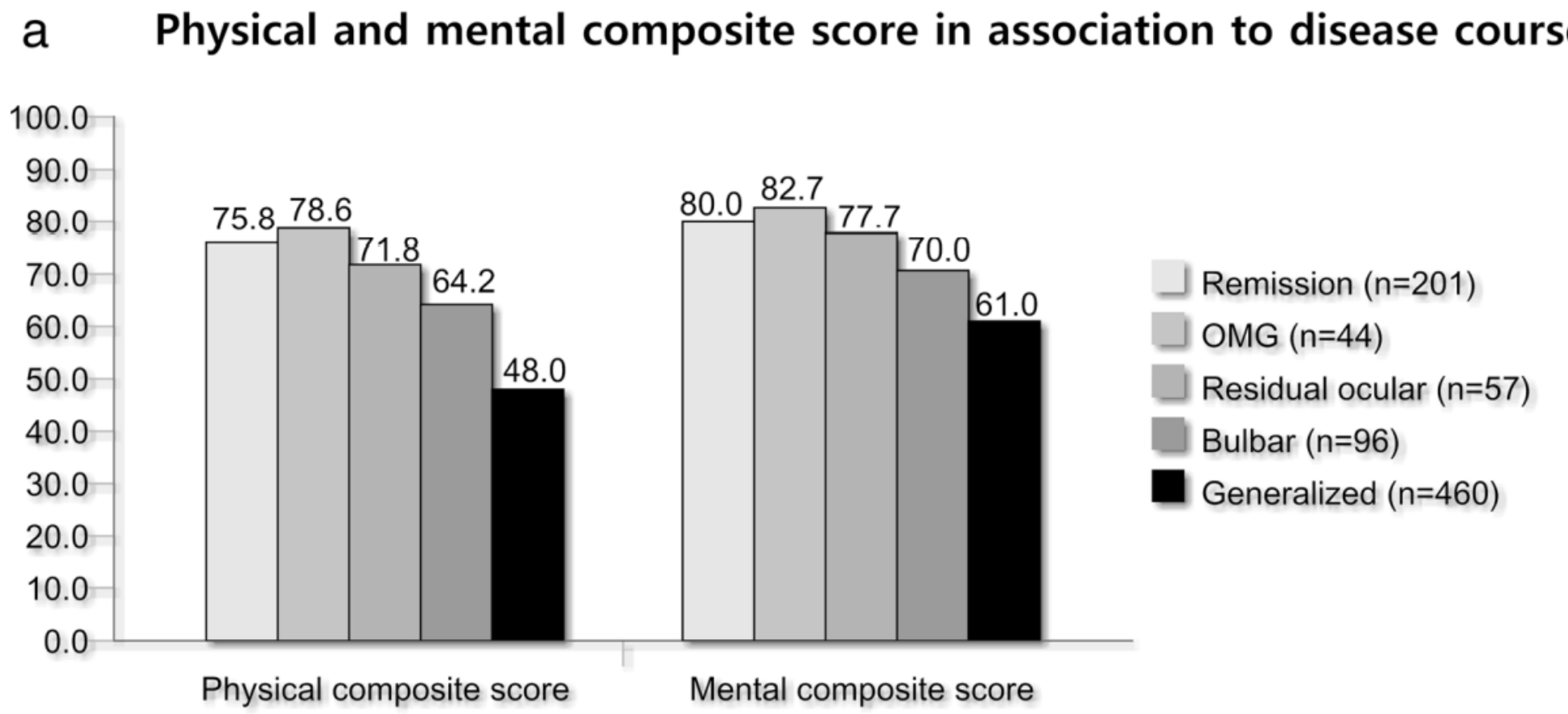
Also the Norwegian MG patients scored lower than the normative population



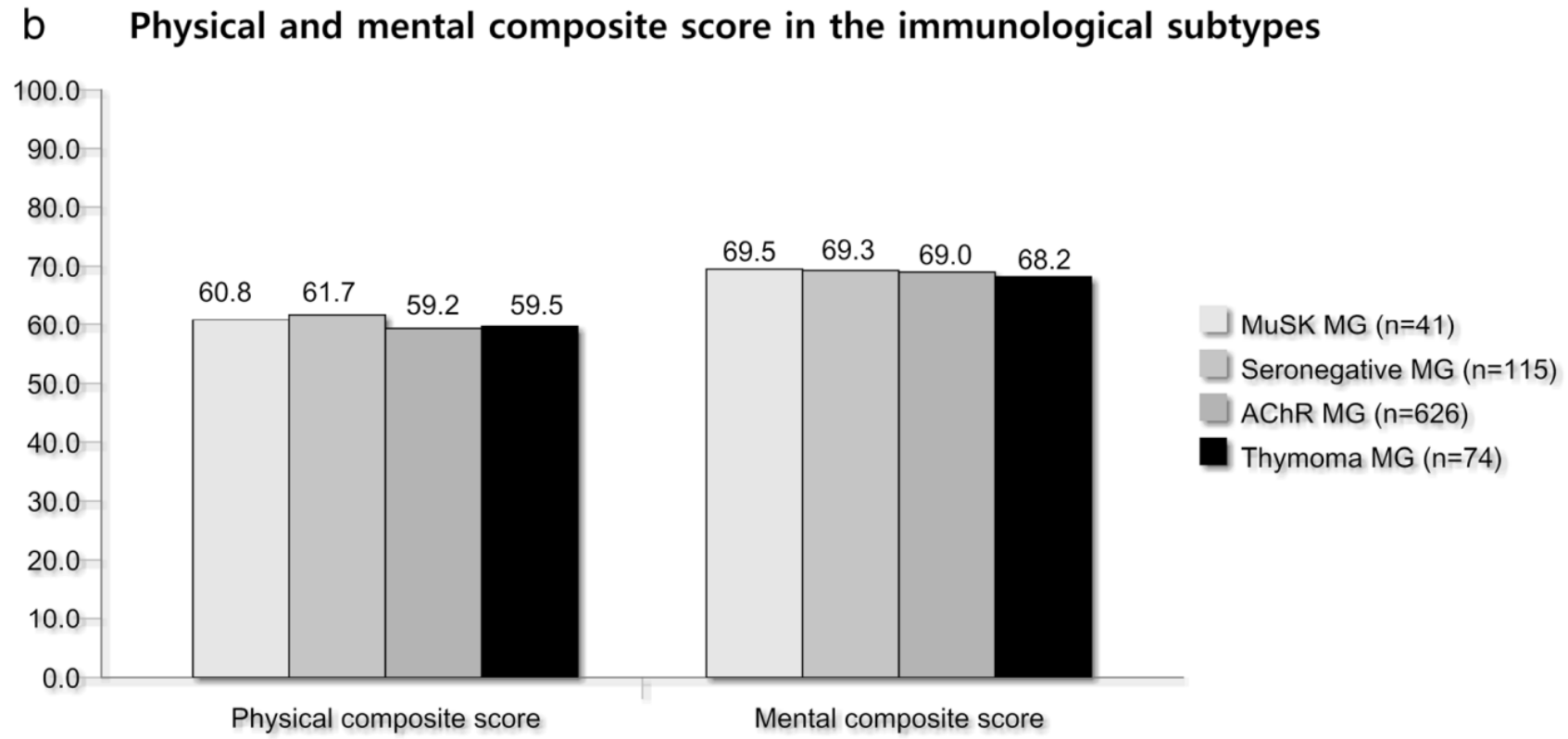
When in remission the HRQOL is not reduced



Mainly generalized and bulbar symptoms had reduced HRQOL



Antibody profile was not important



Compared to other chronic diseases

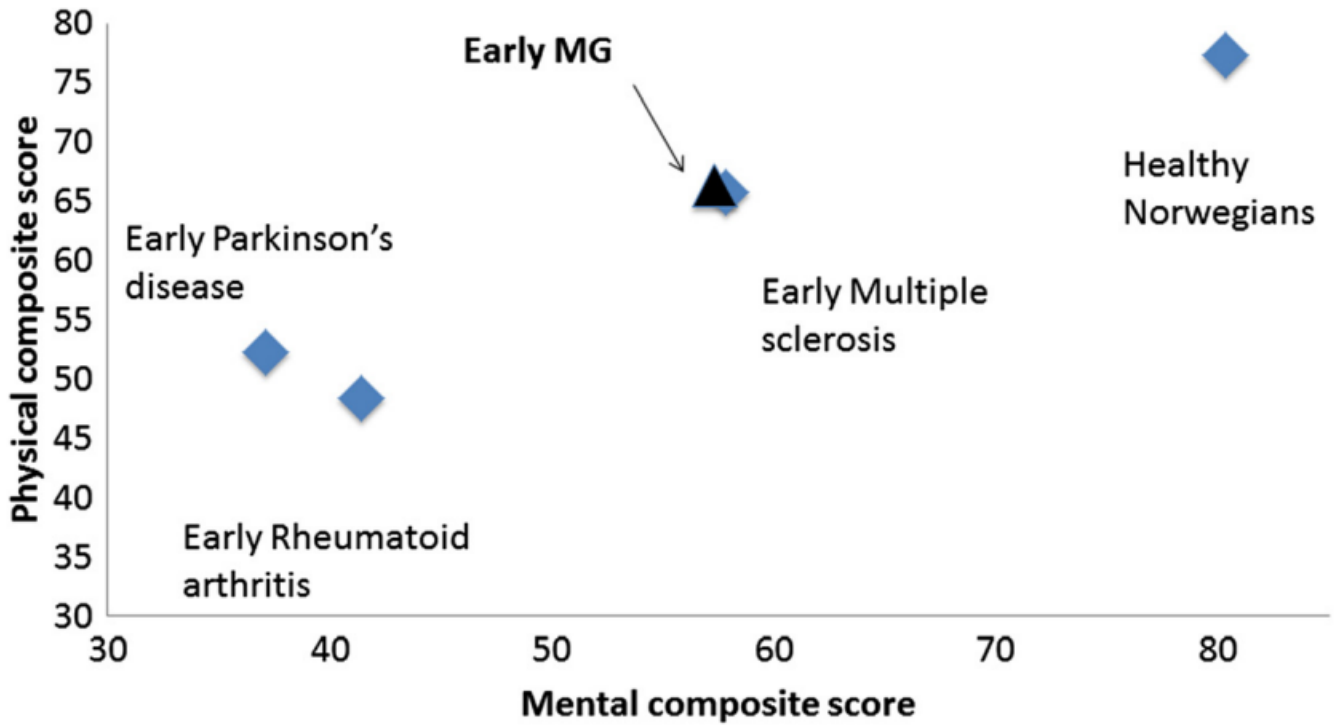


Fig. 4 HRQOL in early MG patients compared to other chronic diseases. Early Norwegian Myasthenia Gravis patients from 0-3 years after onset scored similar to MS patients [25], but better than Parkinson's patients [26] and Rheumatoid Arthritis patients with a similar disease duration [37]

Not large change between 2001 and 2010

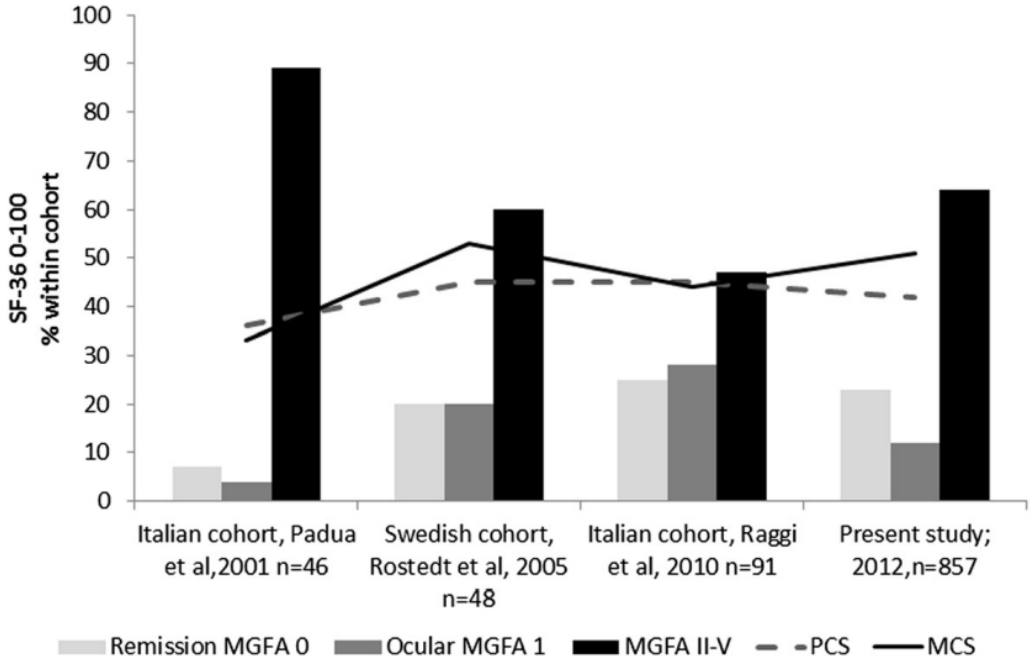


Fig. 5 Overview over HRQOL measured by SF-36 from 2001-2012. Studies providing norm-based scoring are shown. Bars illustrate the distribution of MGFA score within the cohorts, lines illustrate the PCS and MCS. Vertical axis shows SF-36 score 0-100 for lines and distribution of MGFA class within the cohort. Padua et al. reported lower scores in 2002 than we did ($p < 0.001$), however the cohort consisted of fewer patients in remission (7 %) and 89 % in MGFA class II-IV [1]. Paul et al. 2001 [2], provided not norm-based scoring, but PCS 57.6 (27) and 65.5 (24.8) were not significant different from our study

SF-36 2008-2018

- Factors associated with worse SF-36 were depression, poor acceptance and older age

Table 1 (continued)

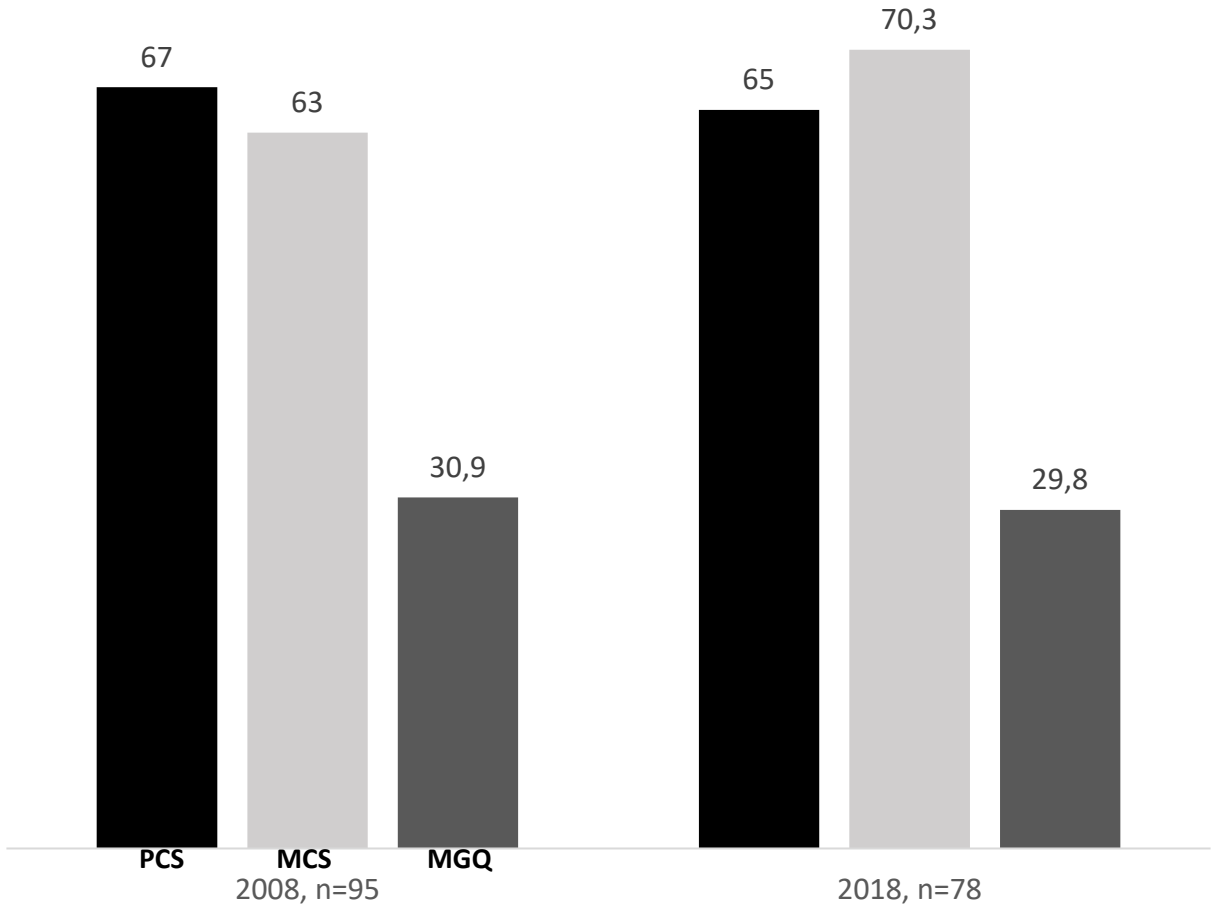
Feature	At initial testing	At retesting
Therapy (*n*)		
Pyridostigmine	78 (100%)	49 (62.8%)
Corticosteroids	76 (97.4%)	33 (42.3%)
Azathioprine	35 (44.9%)	19 (24.3%)
Cyclosporin A	8 (10.2%)	1 (1.3%)
IVIg	4 (5.2%)	0 (0%)
PLEx	5 (6.4%)	0 (0%)
None	0 (0%)	25 (32.0%)

AChR acetylcholine receptor, *IVIg* intravenous immunoglobulins, *MGFA* Myasthenia Gravis Foundation of America, *MuSK* muscle-specific kinase, *PLEx* plasma exchange

$^{*}p=0.005$; $^{**}p=0.003$

Long-term outcome in patients with myasthenia gravis: one decade longitudinal study

Ivo Bozovic[1] · Jelena Ilic Zivojinovic[2] · Stojan Peric[1] · Marko Kostic[3] · Vukan Ivanovic[1] · Dragana Lavrnic[1] · Ivana Basta[1]



Which factors influences HRQOL in MG patients

Positive factors

- Being male
- Employment
- Higher education
- Active lifestyle
- Good mental health

Negative factors

- Being women (Boldingh, 2015)
- Treatment factors (Boldingh, 2015)
- Generalized disease/ functional impairment(Boldingh, 2015 and several others)
- BMI (Szczudlik, 2020).
- Type of work, education status and physical activity (Szczudlik, 2020).
- Depression, anxiety, older age, poor acceptance (Bosovic, 2020)

Take home message

- More longitudinal studies are needed
- Optimize treatment factors
- Little change in QOL over the decades indicates need for more multidiciplinary support / courses / rehabilitation
  - Mental health factors
  - Disease acceptance and coping issues
  - Paid work and mapping of which jobs are suitable
  - Guidance into active life style
- **A lot of other factors are studied**
  - **Effect of MG on familiy planning, fatigue, sleep problems, effect of presence of co-morbidity**