

Characterizing Health-Related Quality of Life in Narcolepsy: A Mixed-Methods Study

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What is Narcolepsy?

- Hypersomnolence of central origin
- Daily periods of excessive daytime sleepiness (EDS) ≥ 3 months
 - Could display as gradual or “sleep attacks”
- Cataplexy: Brief (< 2 min), sudden loss of muscle tone in response to strong emotions (e.g., laughter, surprise)
 - Narcolepsy Type I: with Cataplexy
 - Narcolepsy Type II: without Cataplexy

Associated Symptoms

- Intrusion of REM
 - Visual and Auditory Hallucinations
 - Hypnagogic: *wake* → *sleep*
 - Hypnopompic: *sleep* → *wake*
 - Sleep paralysis
 - Temporary inability to move
- Disturbed nighttime sleep



Narcolepsy

- Prevalence: 25-50 per 100,000 people
 - 0.025%- 0.05% of general population
 - Misdiagnosed or under-diagnosed
- Onset: After age 5, most often between age 15 and age 25
 - Sleepiness->Cataplexy->Other REM-related symptoms

Quality of Life

Studies have shown a decreased health-related quality of life in people with narcolepsy (PWN)

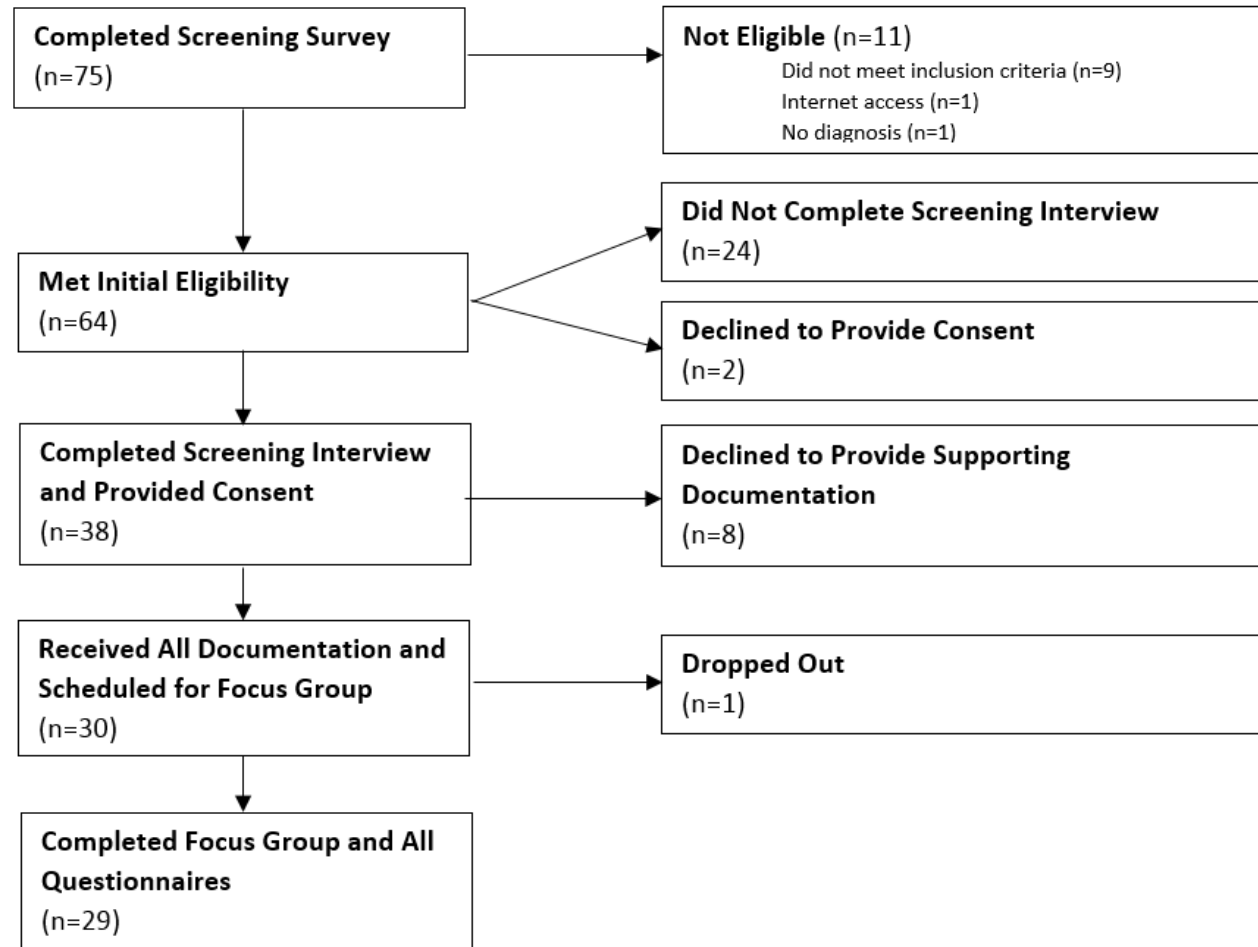
- Daniels et al. (2001)
 - Over half of subjects had depressive symptoms (BDI>10)
 - Short Form 36 (SF-36) showed PWN had deficits in all 8 domains
 - Role limitation due to physical problems
 - Energy/Vitality
 - Social functioning
- Kapella et al. (2015)
 - All domains of health-related stigma, mood, and daytime functioning were significantly worse in PWN compared to matched controls
 - Health-related stigma was associated with lower functioning and quality of life

LINC: Living with Narcolepsy

The purpose of this study:

- Use qualitative methods to identify the specific impact of narcolepsy on health-related quality of life
- Test the feasibility of PROMIS as a way to characterize the clinical population of PWN
- Treatment development study

Study Flow



Demographics

Characteristic	
Sex (n, %)	
Female	27 (93.1%)
Male	2 (6.9%)
Race (n, %)	
White	26 (89.7%)
Black	1 (3.4%)
More than one race	2 (6.9%)
Age (Mean, SD)	31.1 years (SD=7.6)
Years of Education (Mean, SD)	16.9 years (SD = 1.7)
Narcolepsy Diagnosis (n, %)	
Type I	17 (58.6%)
Type II	12 (41.4%)
Time since diagnosis (Mean, SD)	4.3 years (SD=3.6)

Mixed-Measures Study

PROMIS

- Depression
- Anxiety
- Fatigue
- Sleep Disturbance
- Sleep Impairment
- Pain Interference
- Physical Functioning

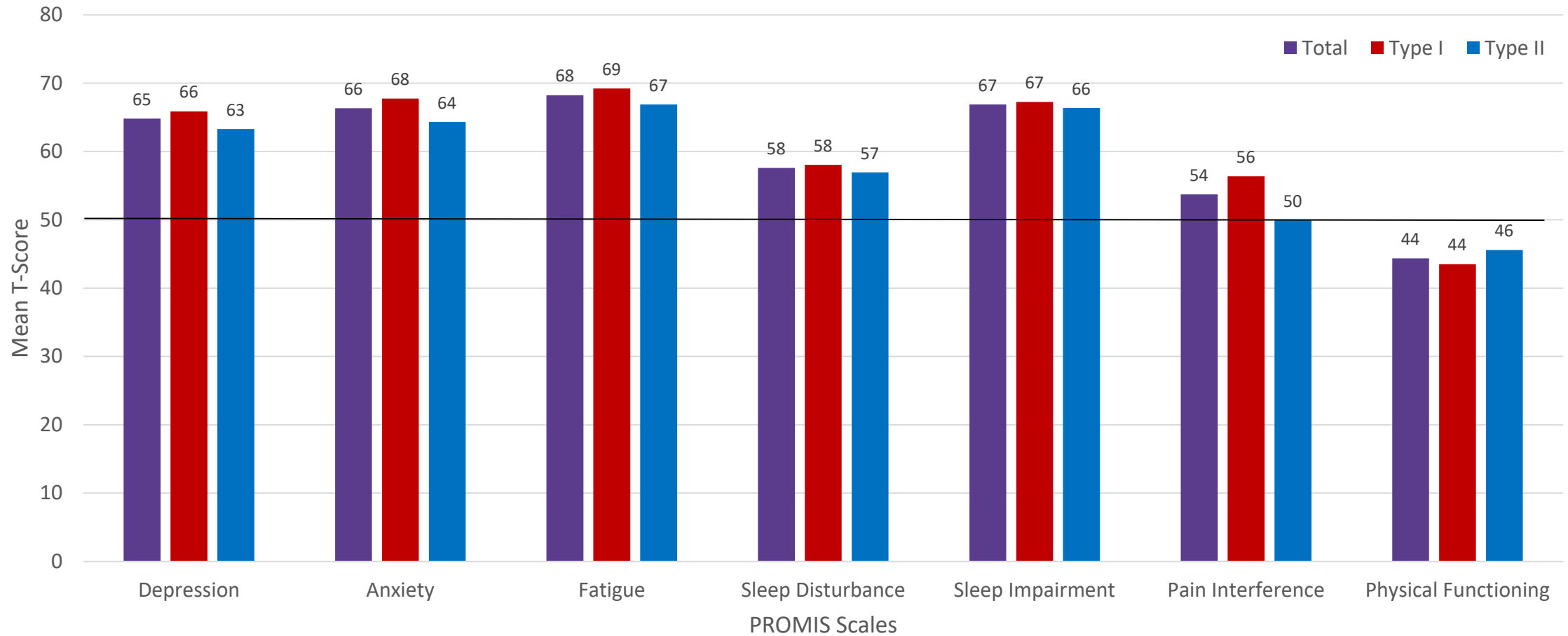
Legacy Measures

- PHQ
- ESS
- SF-36

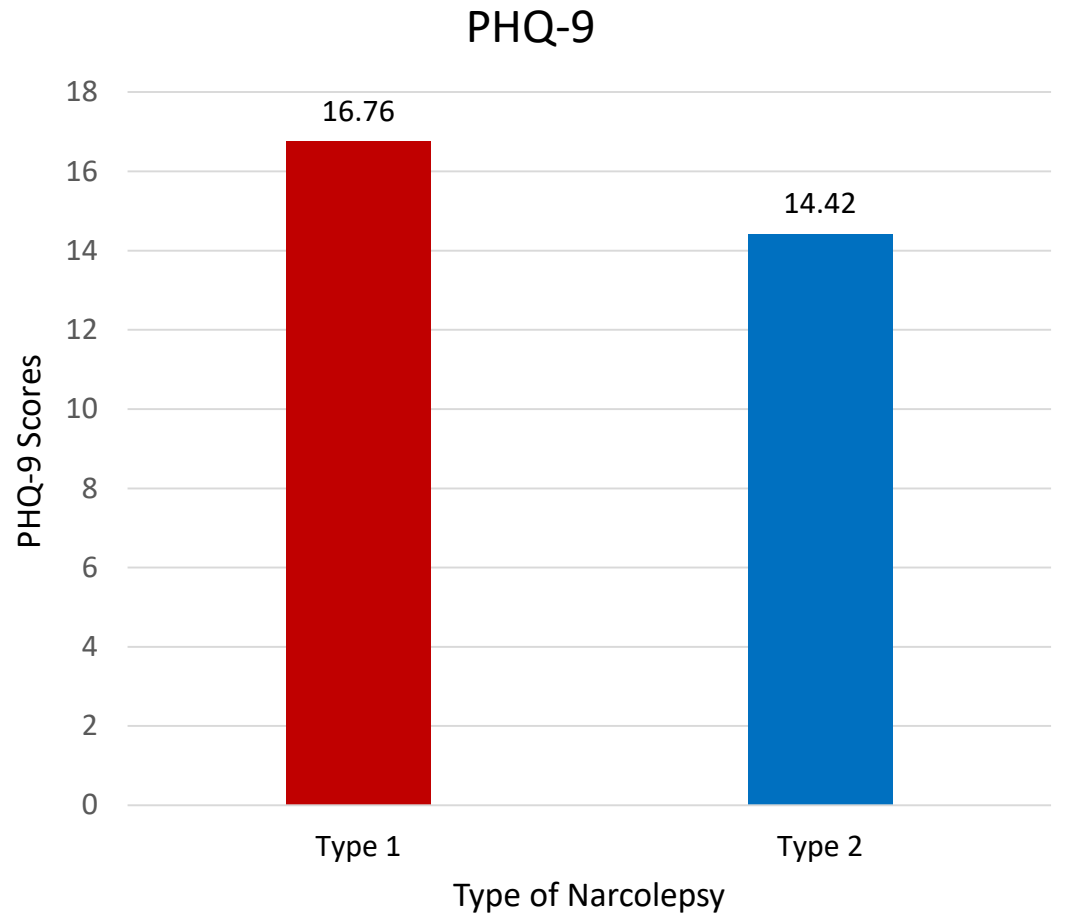
Focus Group

- Health-Related Quality of Life
- Barriers to Care
- Patient Preferences for Psychosocial Treatment

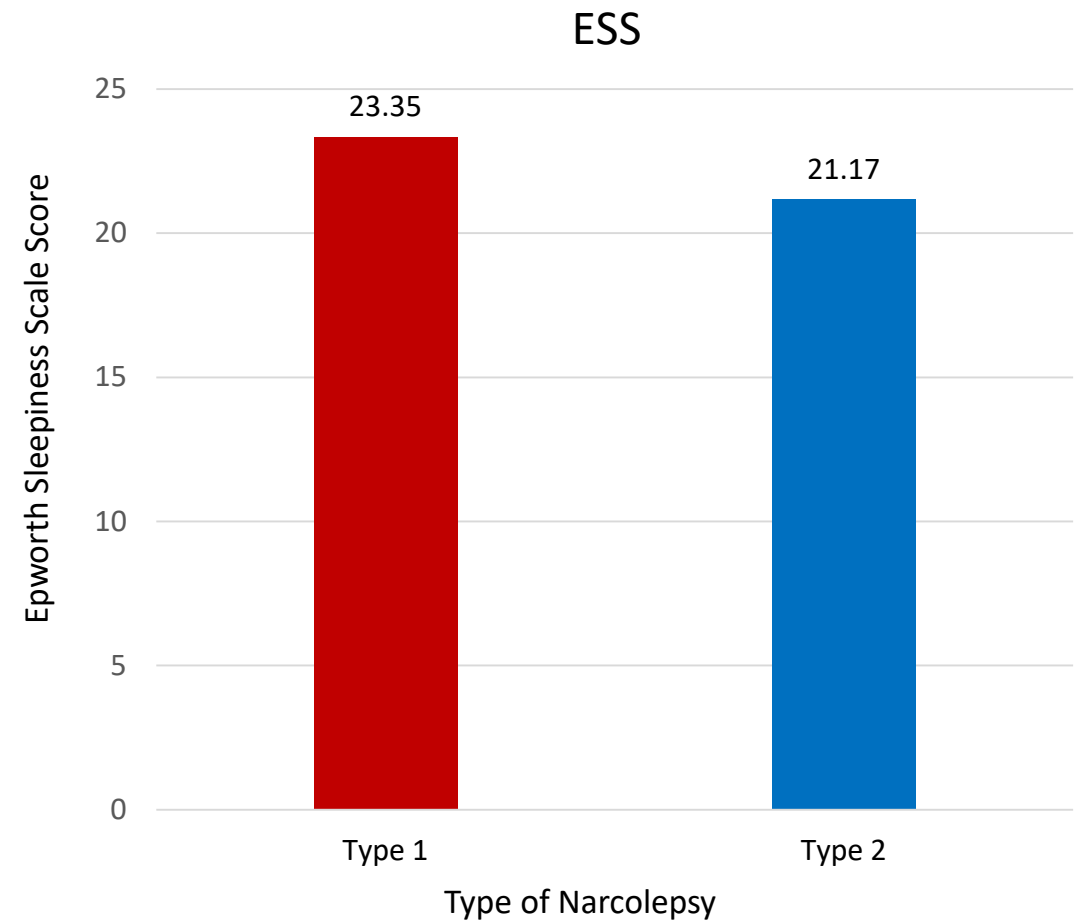
Results: PROMIS



Results: PHQ-9 and ESS

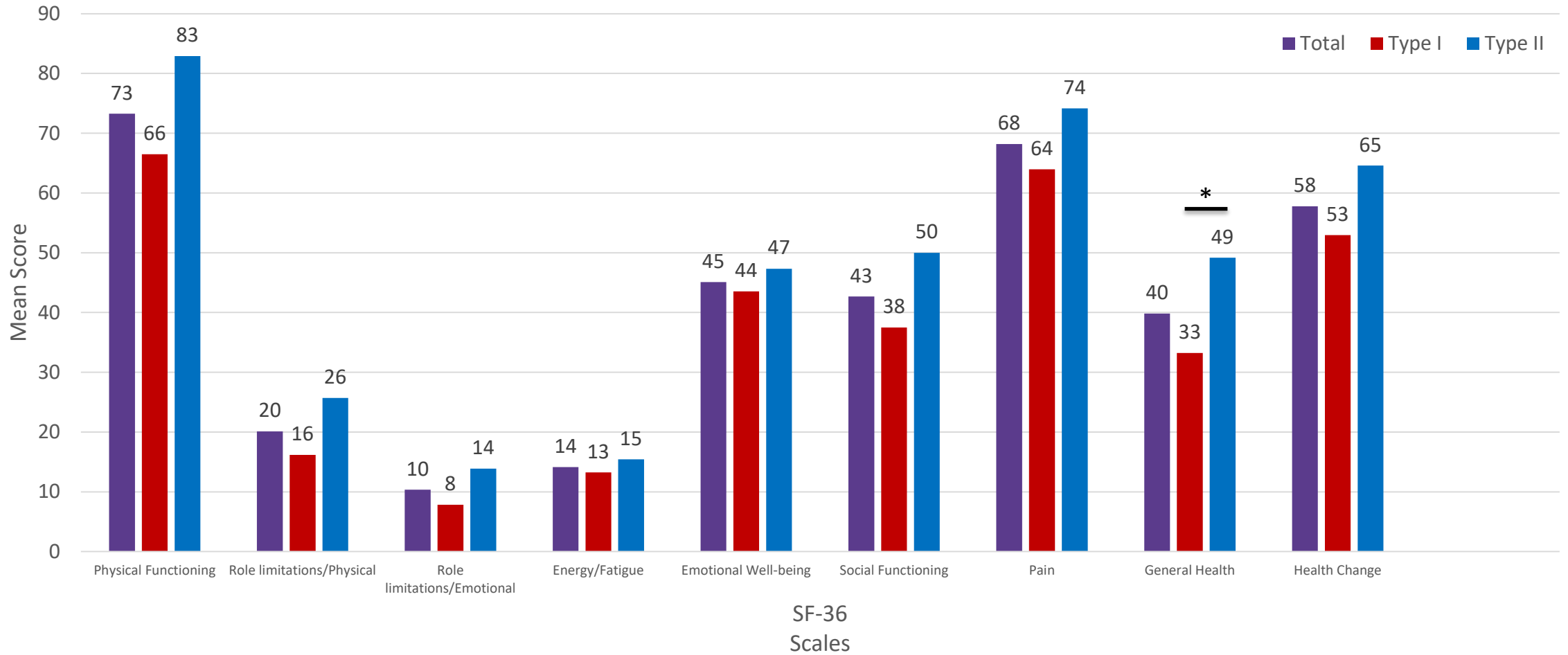


None-Minimal (0-4), Mild (5-9), Moderate (10-14), Moderately severe (15-19), Severe (20-27)



Lower Normal (0-5), Higher Normal (6-10), Mild EDS (11-12), Moderate EDS (13-15), Severe EDS (16-24)

Results: SF-36



*Denotes significant difference (p<0.05) between narcolepsy type I and narcolepsy type II

Focus Groups

- Conducted 10 focus groups
 - Used live videoconferencing (BlueJeans.com)
 - Typical group size = 3 participants
 - About 60 minutes
- Thematic Analyses
 - Preliminary review to develop code book
 - Reduced data to “themes” “nodes” “examples”
 - Iterative process to determine overarching semantic themes

Focus Groups

Narcolepsy is poorly understood by the public

- Negative social stigma (lazy, funny, skeptical)
- Shaped by media
- Dismissed as mental illness

“[People say]: I don’t think you have narcolepsy. I think you’re just tired.”

-Female, 28, Type I

“I feel like people think of it as kind of a joke...And they’re like, ‘Oh, that sounds great. I wish I slept all the time’.”

-Female, 26, Type II

“[People say:] Well it doesn’t look like anything’s wrong with you.”

-Female, 33, Type I

Focus Groups

Impact from narcolepsy symptoms

- Unpredictability of symptoms
- Anxiety and avoidance of situations due to cataplexy
- Constancy of sleepiness

“Basically, what made me go downhill was, with my cataplexy, I was walking on campus. And there was this long spot on campus that there isn’t really anything to hold onto. And I had an incident in which I went all the way down to the ground. Even to this day, I still avoid that area. And it’s really taken a lot out of me.”

-Female, 21, Type I

“It’s almost like we’re addicted to sleep...the only way to feel better and to rid of that craving is to close our eyes and actually fall asleep, but it never goes away.”

-Female, 36, Type I

Focus Groups

Low self-image and self-efficacy

- Some were ashamed of having narcolepsy
- Not having self-worth or having a negative sense of self
- Feeling incapable of functioning at their desired level

“I just don’t have any self-worth...I feel like I’m a different person than I used to be.”

-Female, 26, Type II

“I feel like I’ve gone in my head from somebody who was capable to someone who’s not capable.”

-Female, 28, Type II

Focus Groups

Negative impact on social functioning and relationships

- Limited time and energy to invest in making or maintaining friendships
- Some were hesitant to tell friends and family about diagnosis
- Invisible illness makes it hard for people to understand

“I can’t keep in touch. I can’t follow through. I can’t meet up with them. I can’t be invested. And it has ruined relationships too.”

-Female, 31, Type I

“Destroyed my social life...I was very active in traveling, doing a lot of activities...I can’t really do as much as I used to.”

-Male, 29, Type I

“I’m scared to pursue any intimate, personal relationships because of my cataplexy.”

-Female, 26, Type I

Focus Groups

Dismissed by healthcare providers

- Many providers aren't knowledgeable about narcolepsy
- If they are knowledgeable about narcolepsy, have inadequate time to address psychosocial impact

"My therapist, she doesn't know a lot about narcolepsy...I've had to really force that piece into my mental health treatment."

-Female, 28, Type II

"[The physician is] very just like facts only, like spends very little time really hearing me out. It's very, 'here's your prescription, I'll write it, go.'"

-Female, 35, Type II

Discussion

- First study to report PROMIS Data for PWN
 - Congruent with legacy measures and qualitative data
- Qualitative findings illuminate how narcolepsy symptoms affect health-related quality of life
 - Health-related stigma consistent with findings from Kapella et al. (2015)
 - Indications that cataplexy has adverse effects on psychosocial functioning
 - Avoidance of situations due to cataplexy

Limitations

- Small sample size
 - Limits ability to detect significant differences between narcolepsy type I and narcolepsy type II
- Generalizability of findings could be compromised
 - Small number of males n=2
 - Bias against individuals from lower SES
- Validity of PROMIS as a means to detect clinical change
 - PATH Study

Acknowledgements

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Thank you to all of the study participants!

Thank you!

