



Pain in FD/MAS: Preliminary data from the FD Foundation Patient Registry

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Potential Biases in Registry Data

- Uncertainties in diagnosis of FD/MAS
- Many surveys partially completed
- Responder bias—may skew data toward more severely affected patients
- Limited statistical analyses performed—additional work needed to confirm findings



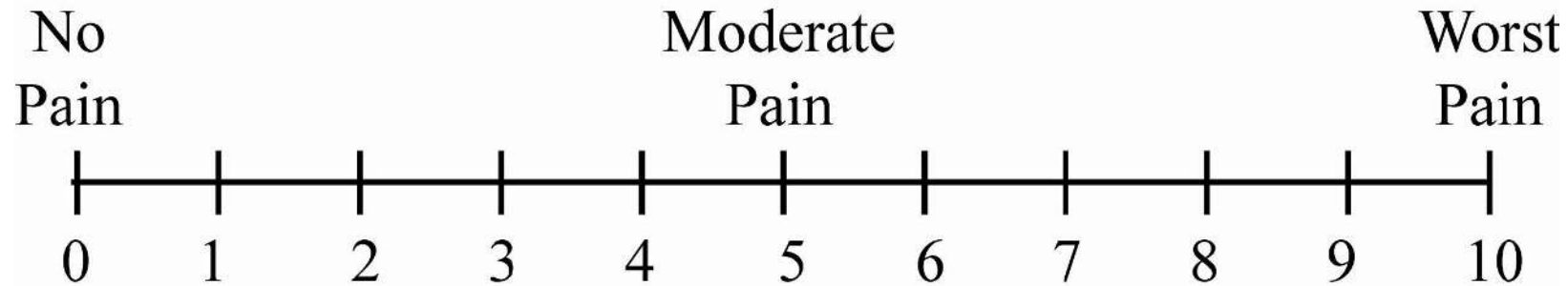
Data is very preliminary!



Brief Pain Inventory

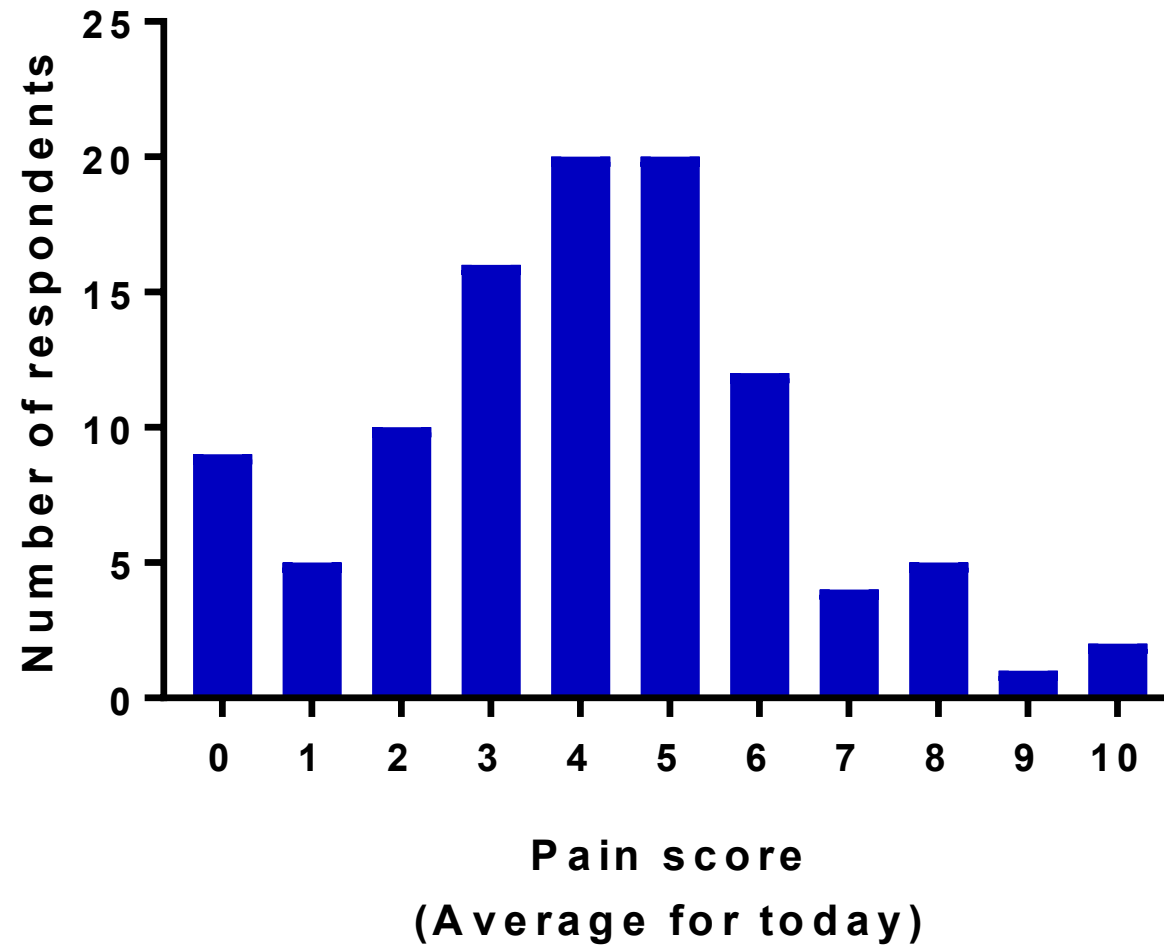
- Widely used for assessing pain
- Allows patients to rate:
 - Pain **severity**
 - Degree to which pain **interferes** with feeling and function
- 122 respondents total, mostly complete data on 104
- Average age 36 years (range 2-69)

Brief Pain Inventory: Pain Severity

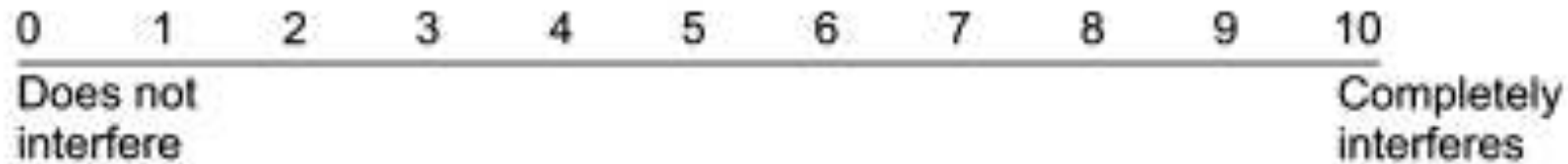


- 83% of respondents (86 of 104) reported feeling pain severity ≥ 3 in past 4 weeks
 - Average pain 4.7 (range 0-10)
 - Worst pain 8 (range 0-10)
- 91% (95 of 104) report feeling pain today
 - Average pain 4.1 (range 0-10)
 - Worst pain 6 (range 0-10)

Distribution of Pain Severity

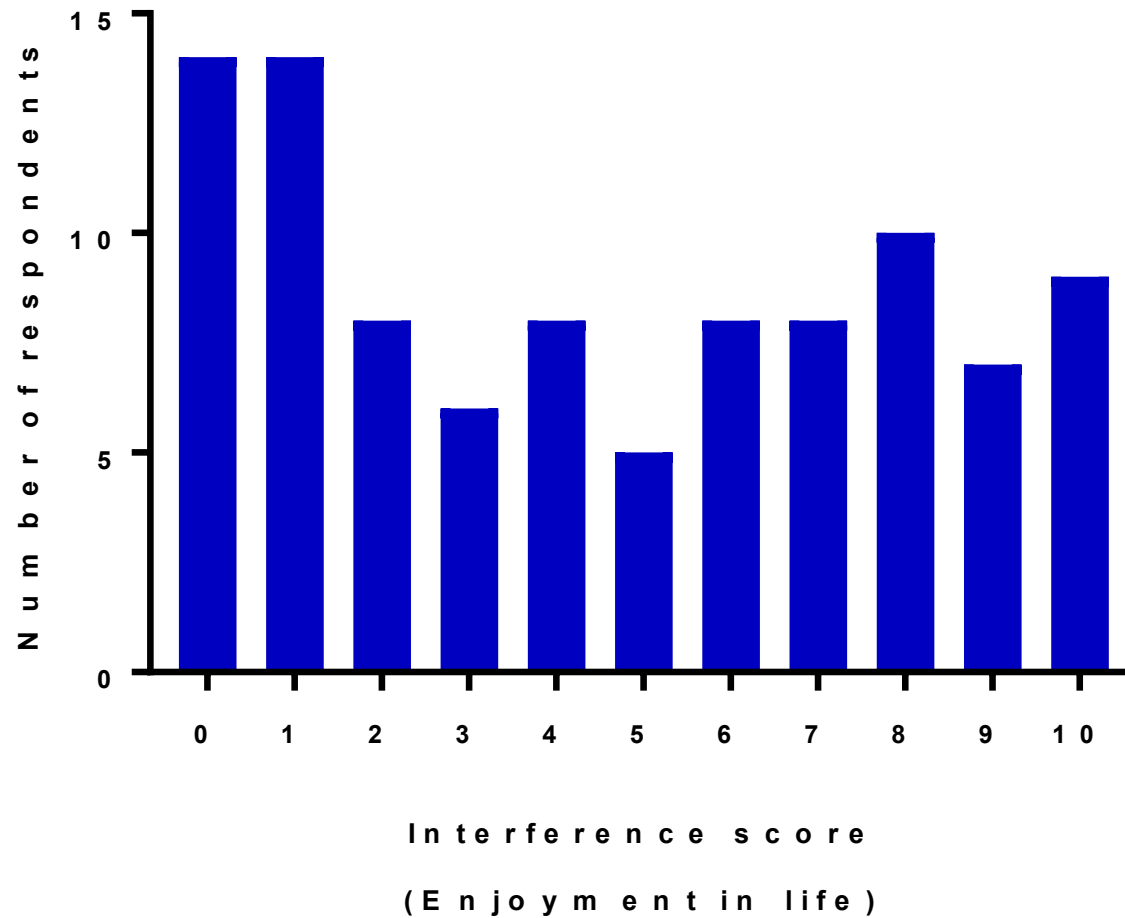


Brief Pain Inventory: Pain Interference



- 83% (86 of 104) report interference ≥ 3 in one or more area of function or feeling
 - General activity: 5 (range 0-10)
 - Enjoyment in life: 4 (range 0-10)
 - Mood: 5 (range 0-10)
 - Work: 5 (range 0-10)
 - Relationships with other people: 3 (range 0-10)
 - Sleep: 5 (0-10)

Distribution of Pain Interference



Pain Treatments

- Most common methods that patients reported using
- Patient satisfaction with treatment

Non-prescription medications (such as Tylenol, Advil, Aleve, Aspirin)

- 95 responders taking currently or in the past
 - 34 satisfied, 25 unsatisfied

Bisphosphonates

- 50 responders taking currently or in the past
 - Alendronate: 14
 - 3 satisfied, 4 unsatisfied
 - Pamidronate: 18
 - 9 satisfied, 3 unsatisfied
 - Zoledronate: 18
 - 8 satisfied, 7 unsatisfied

Gabapentin

- 30 responders taking currently or in the past
 - 7 satisfied, 14 unsatisfied

Opioids/Narcotics

- 78 responders taking currently or in the past
 - 48 satisfied, 19 unsatisfied

Mindfulness/Meditation

- 38 responders taking currently or in the past
 - 14 satisfied, 4 unsatisfied

Exercise

- <Once a month: 28
- Few times a month: 15
- Weekly: 19
- Few days a week: 33
- Daily: 10

Additional Analyses Needed

- Frequency of treatment
- Length of treatment
- Reported benefits
- Adverse effects
- Physician satisfaction with treatment
- Reason for stopping medications