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

**Pain score**
(Average for today)

**Number of respondents**

- Pain score distribution chart showing the number of respondents for each pain score from 0 to 10.
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

![Distribution of Pain Interference](image)
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