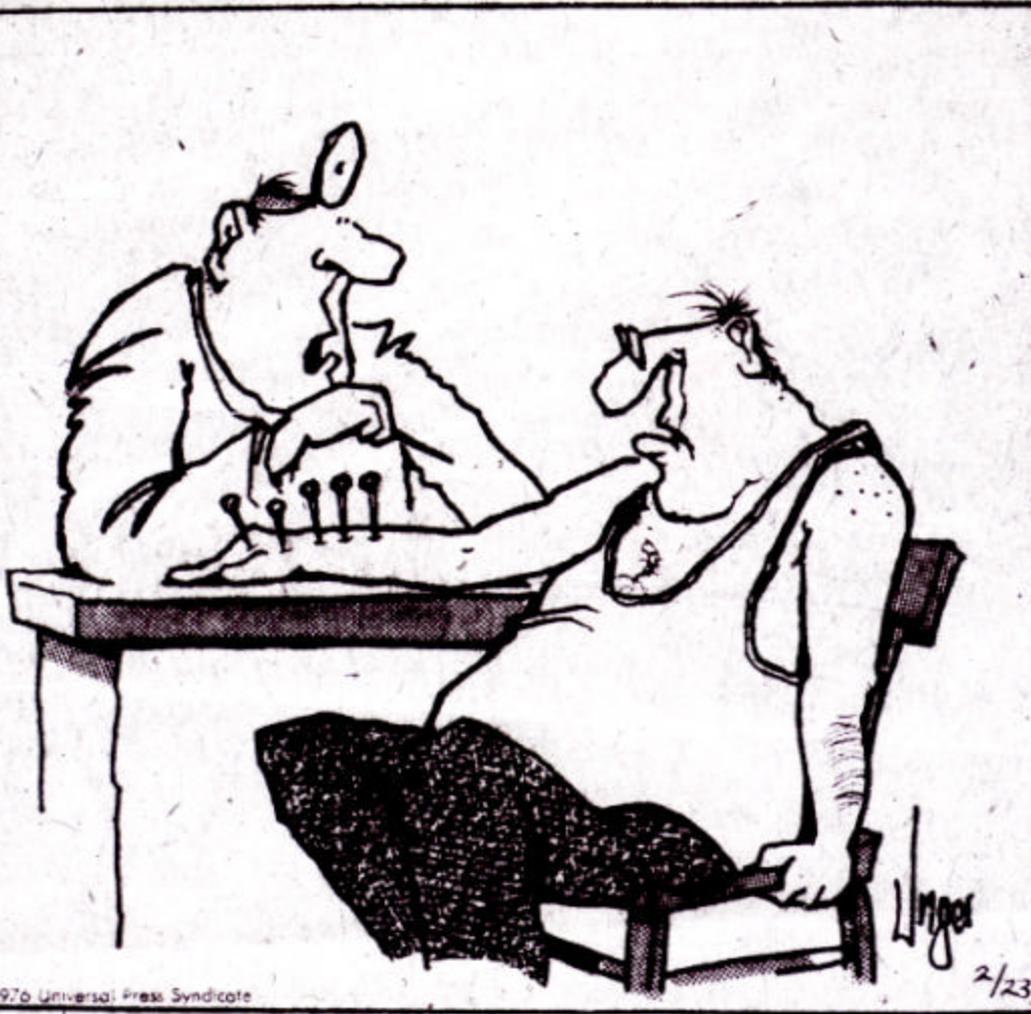

Assessing the Impact of Chronic Pain in Real-Time

Dennis C. Turk, Ph.D.

University of Washington

HERMAN



"I'll work my way up your arm and you tell me when you feel anything."

Pain is a subjective perception and as such, the only ways we can know another's pain is by what we are **told** or what we **observe**.

Why is accurate assessment of pain important?

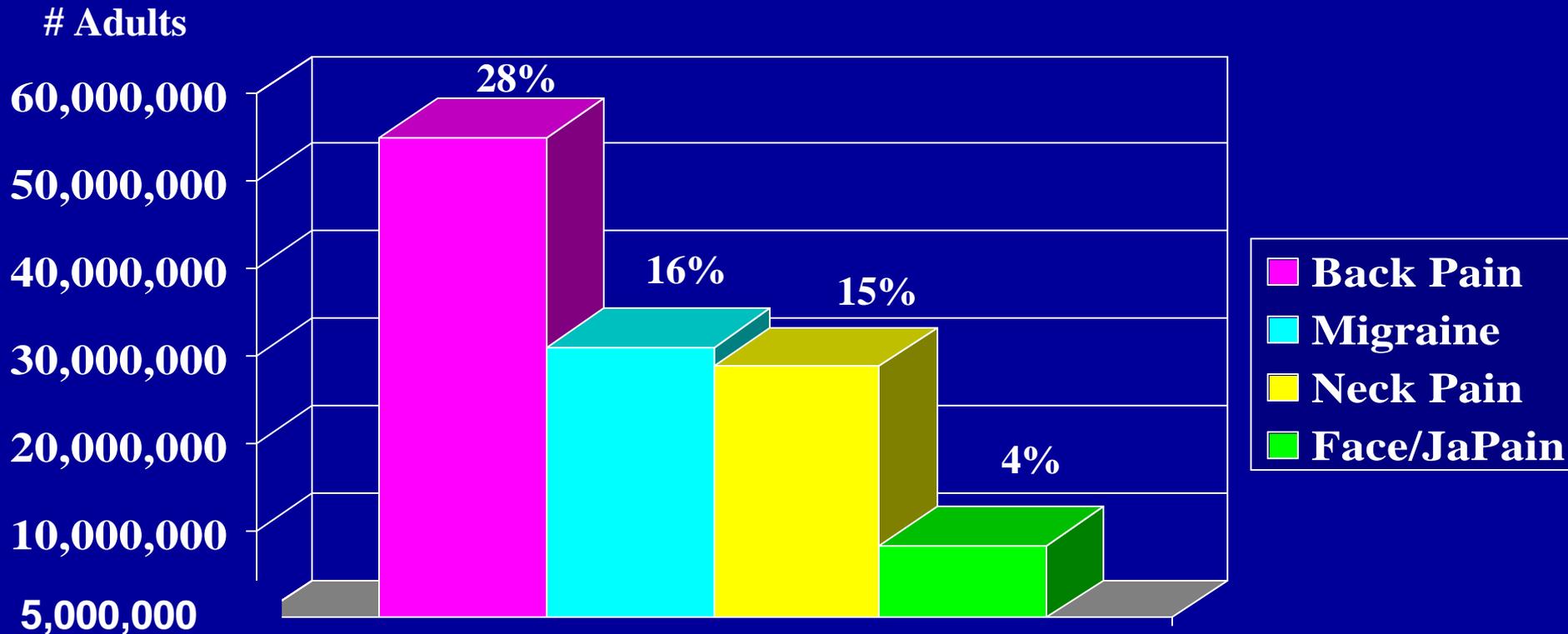
- **Policy decisions regarding pain are based on data provided by people**
- **Treatment decisions often based on self-reports that are presumed to be reliable and valid**
- **Assessment of efficacy of treatment depends on reliability of self-report**
- **Determination of disability associated with pain must consider self-reports**

Why I never ask statisticians a question....

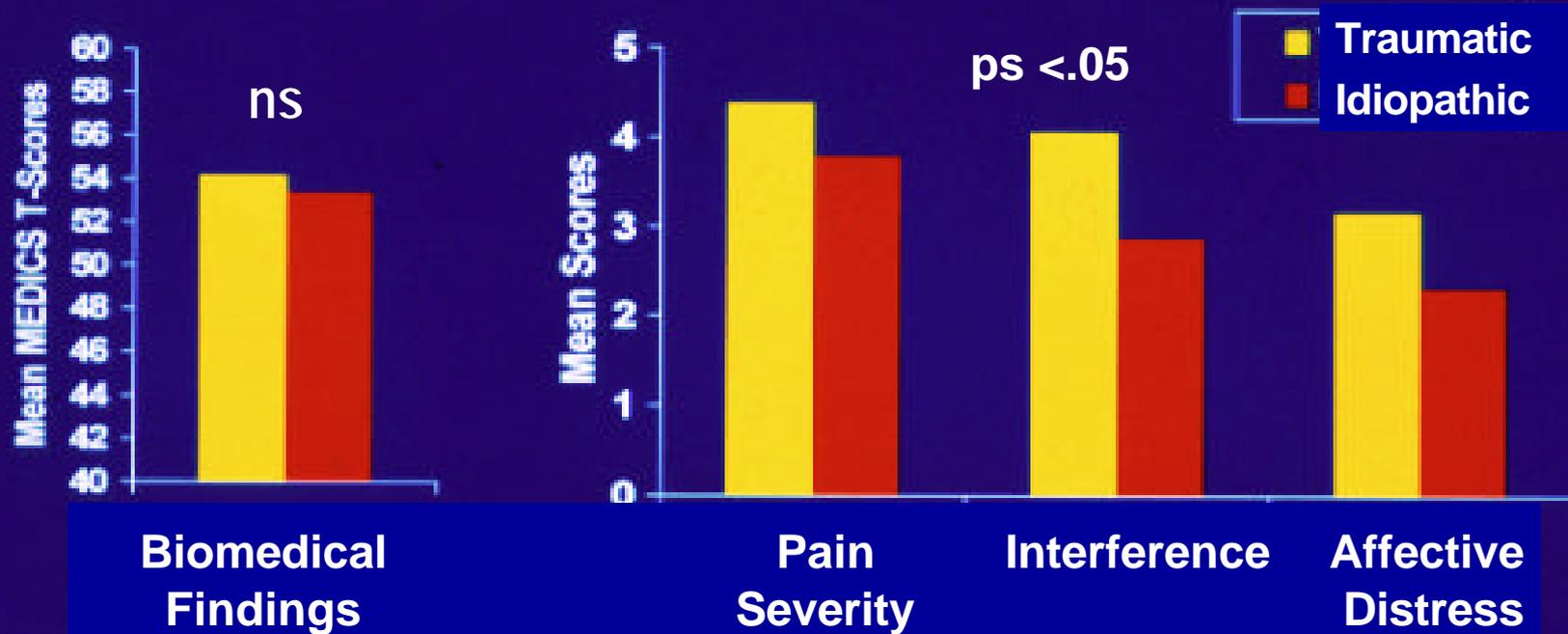
“When the right thing can only be measured poorly, it tends to cause the wrong thing to be measured well. And it is often much worse to have good measurement of the wrong thing -- especially when, as is so often the case, the wrong thing will IN FACT be used as an indicator of the right thing -- than to have poor measurement of the right thing.”

John Tukey, 1979

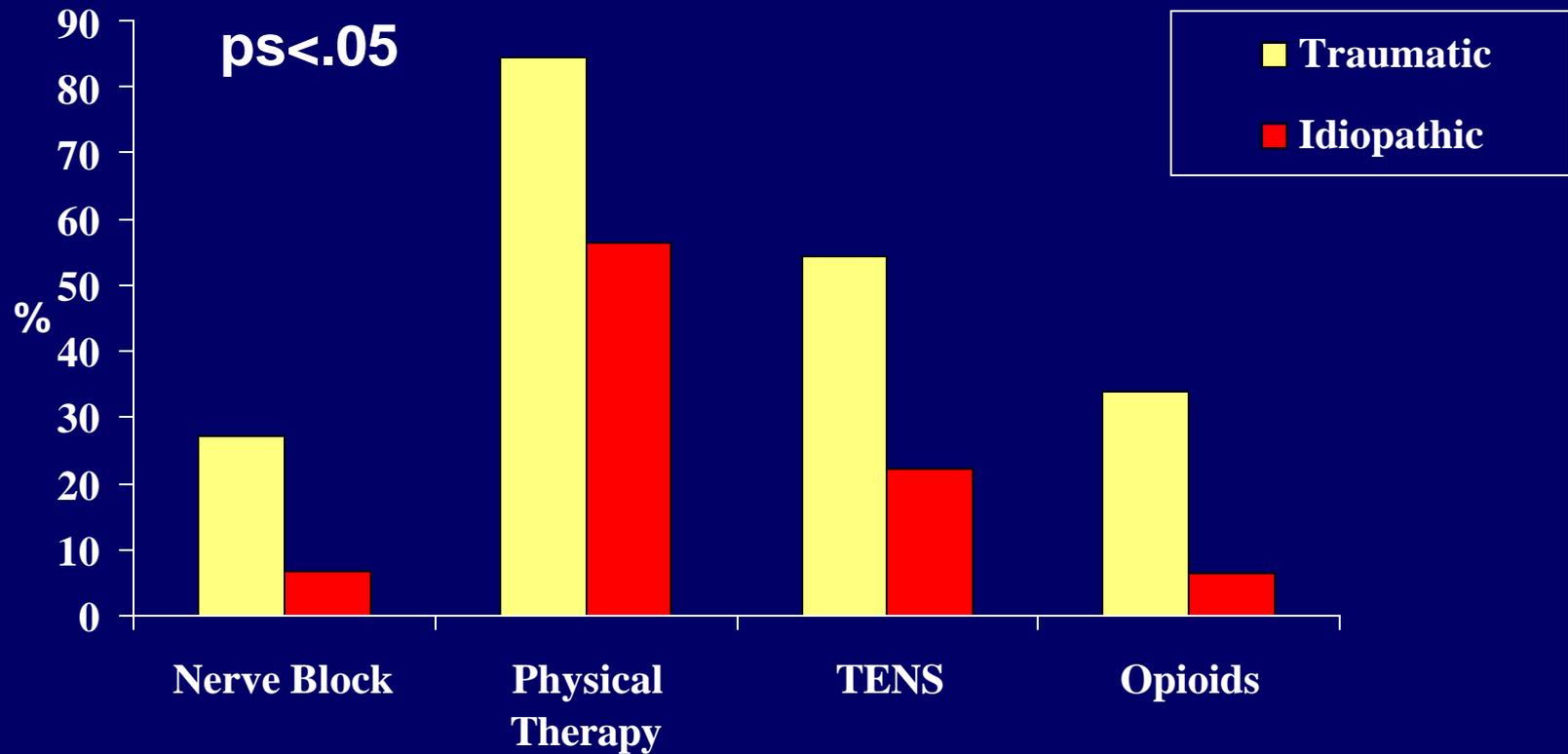
Frequency of Common Pain Problems in US in Past 3 Mos (n = 197,304,000)



Biomedical and Psychosocial Findings by Onset in Chronic Pain Patients (Turk & Okifuji, 1996)



Previous Treatments



Turk et al., 1996

Key Issue

Since pain can fluctuate depending on activity, mood, cognitive factors, contextual factors, and current motivation how should patient self-reports be interpreted?

ACR Classification of Fibromyalgia Syndrome

- **History of widespread pain**
- **Pain response to at least 11 of 18 tender points**
- **Fatigue, emotional distress, low levels of activity, and co-morbid physical sx's. common characteristics**

Why Real-time Assessment for FMS?

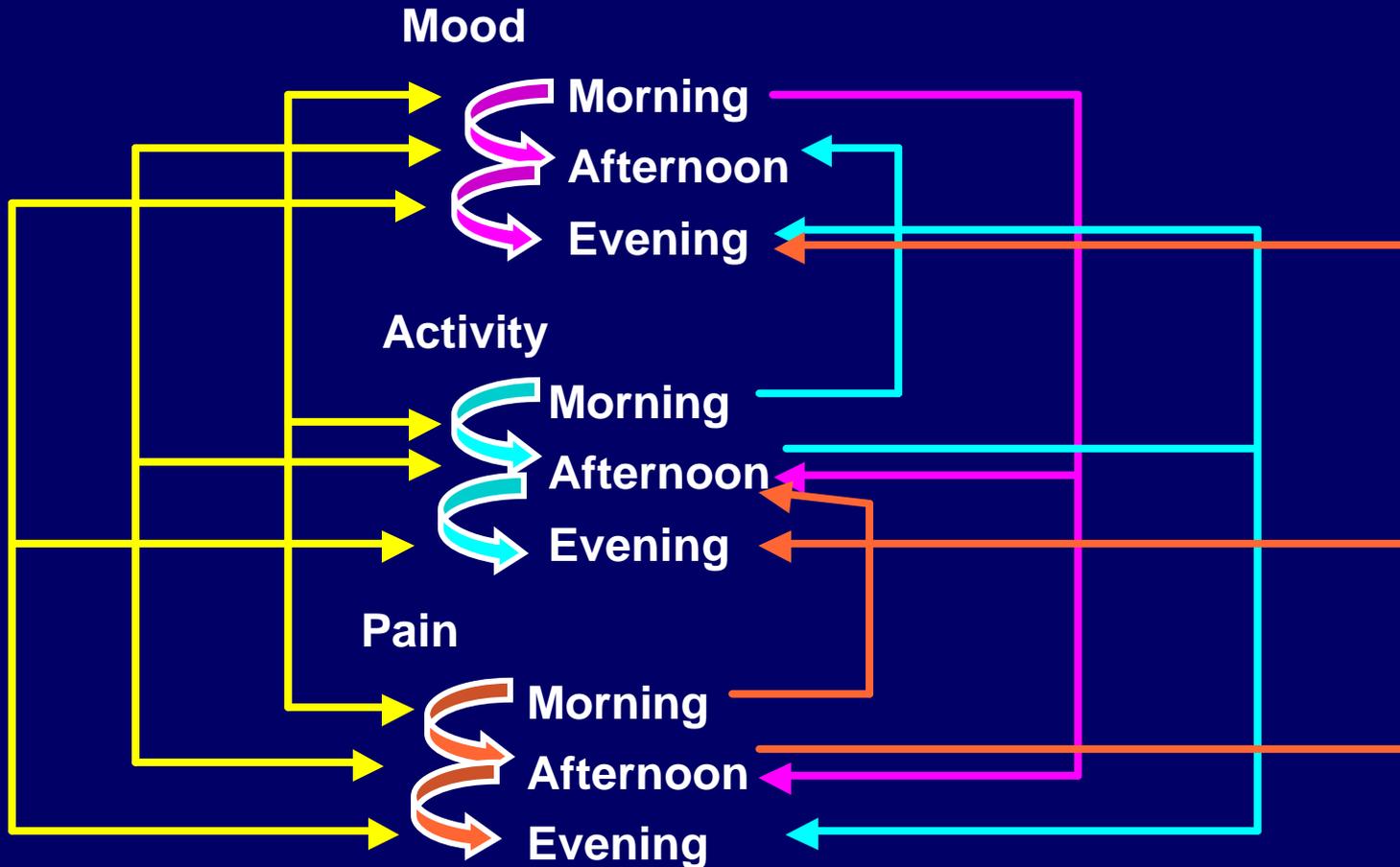
- **Pts with FMS report that activity at some times of the day will exacerbate pain and excessive fatigue at a later time.**
- **Is this an accurate observation?**
- **Does it depend on other factors such as mood, presence of others, type of activity?**
- **Do these associations change following tx?**

Issues of Particular Interest for Fibromyalgia Syndrome

- Establish fluctuations of pain, fatigue, mood, and contextual factors during single day and over multiple days
- Determine covariations among pain, mood, activity, fatigue, and contextual factors
- Evaluate lagged effects of pain, mood, activity, and fatigue on subsequent pain, mood, activity and fatigue
- Determine role of people present on reports of pain, mood, fatigue, and activity

Pretreatment and Post treatment

Each day, 1-14

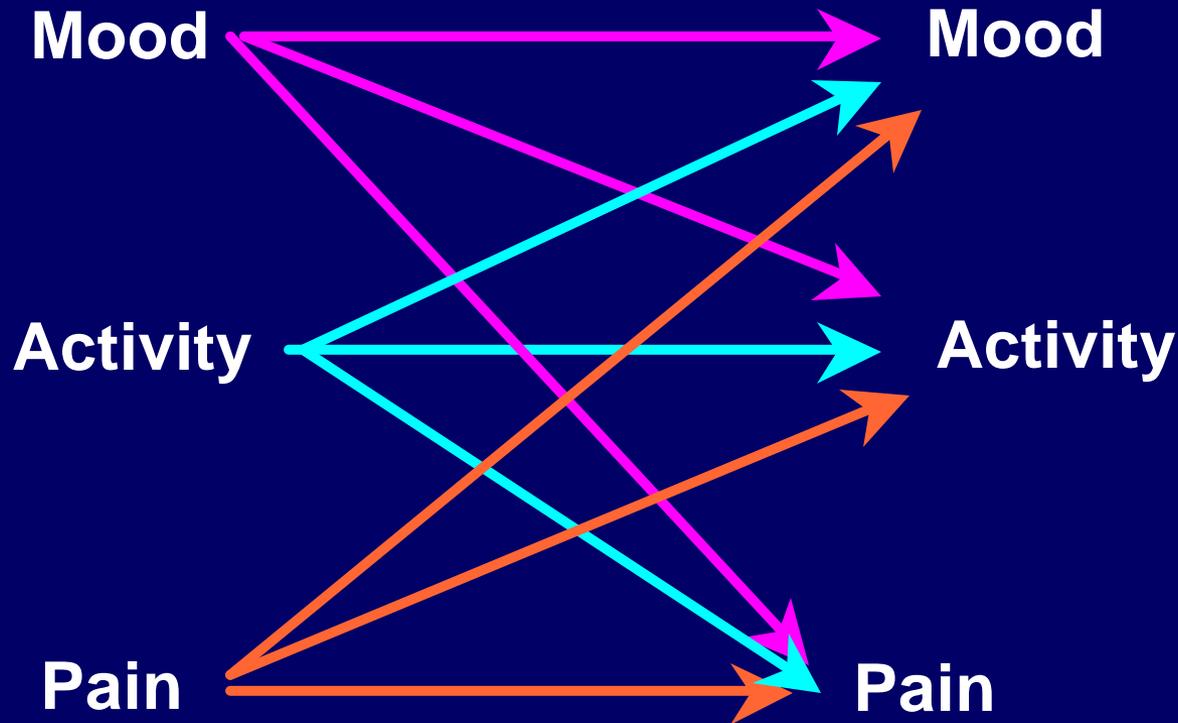


Pretreatment and Post treatment

Day 1

Day 2

.....Day 14

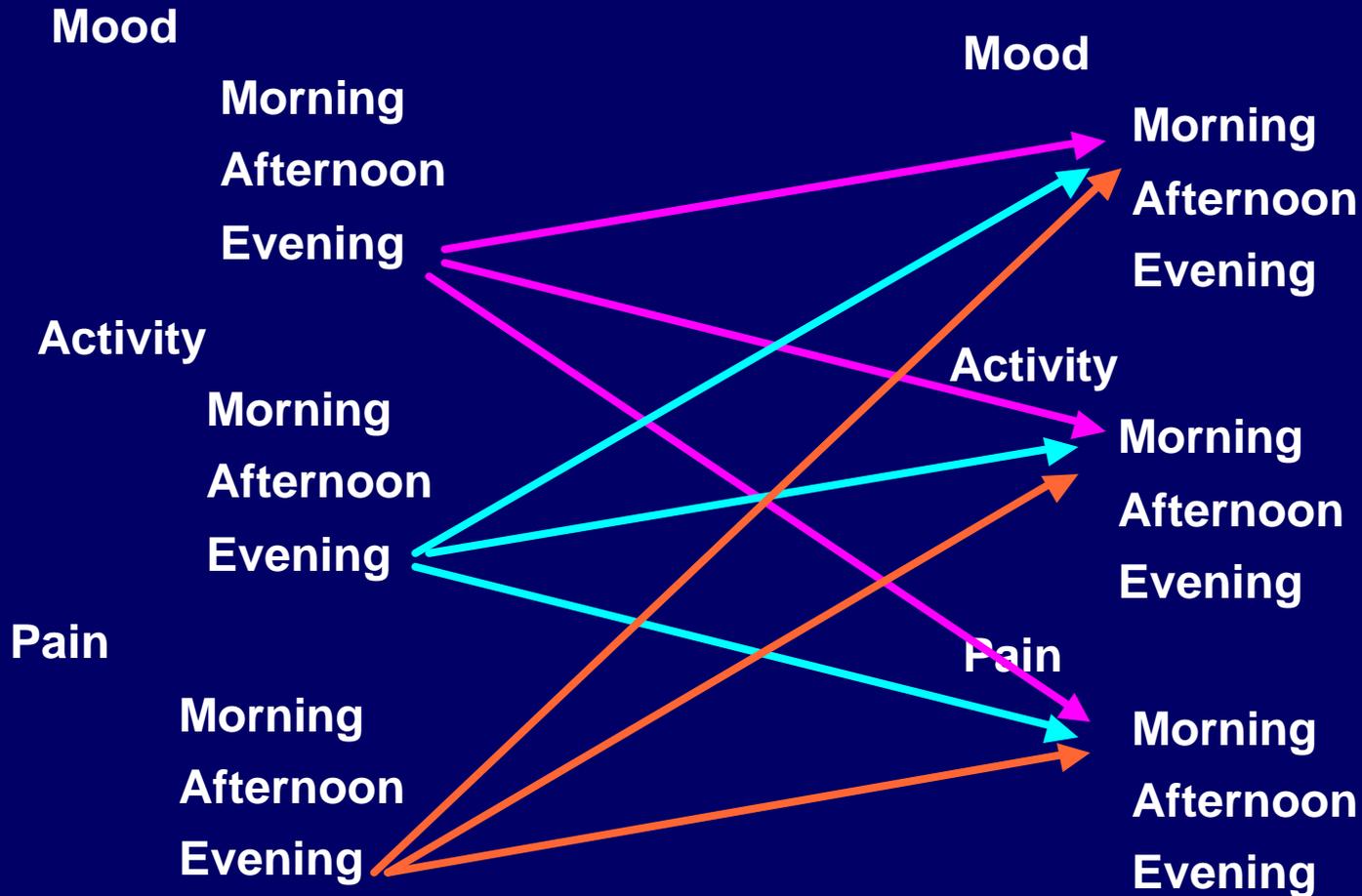


Pretreatment and Post treatment

Day 1

Day 2

....Day 14



Questions Included EMA-FMS Study

- 1. Current activity (e.g., sitting, standing)?**
- 2. Presence of others (spouse, coworker)?**
- 3. Who present at time of responding?**
- 4. Current pain severity?**
- 5. Current level of fatigue?**
- 6. Current level of emotional distress?**
- 7. Current state of relaxation?**
- 8. Level of body tensions and stiffness?**

Sample screen

Page Break

University of Washington

#4. How bad is your pain right now?

0 1 2 3 4 5 6

No Pain< >Worst Pain

#5. How tired/fatigued do you feel
right now?

0 1 2 3 4 5 6

Not Tired< >Very Tired

Go To Question #6

FMS Treatment Study – EMA component*

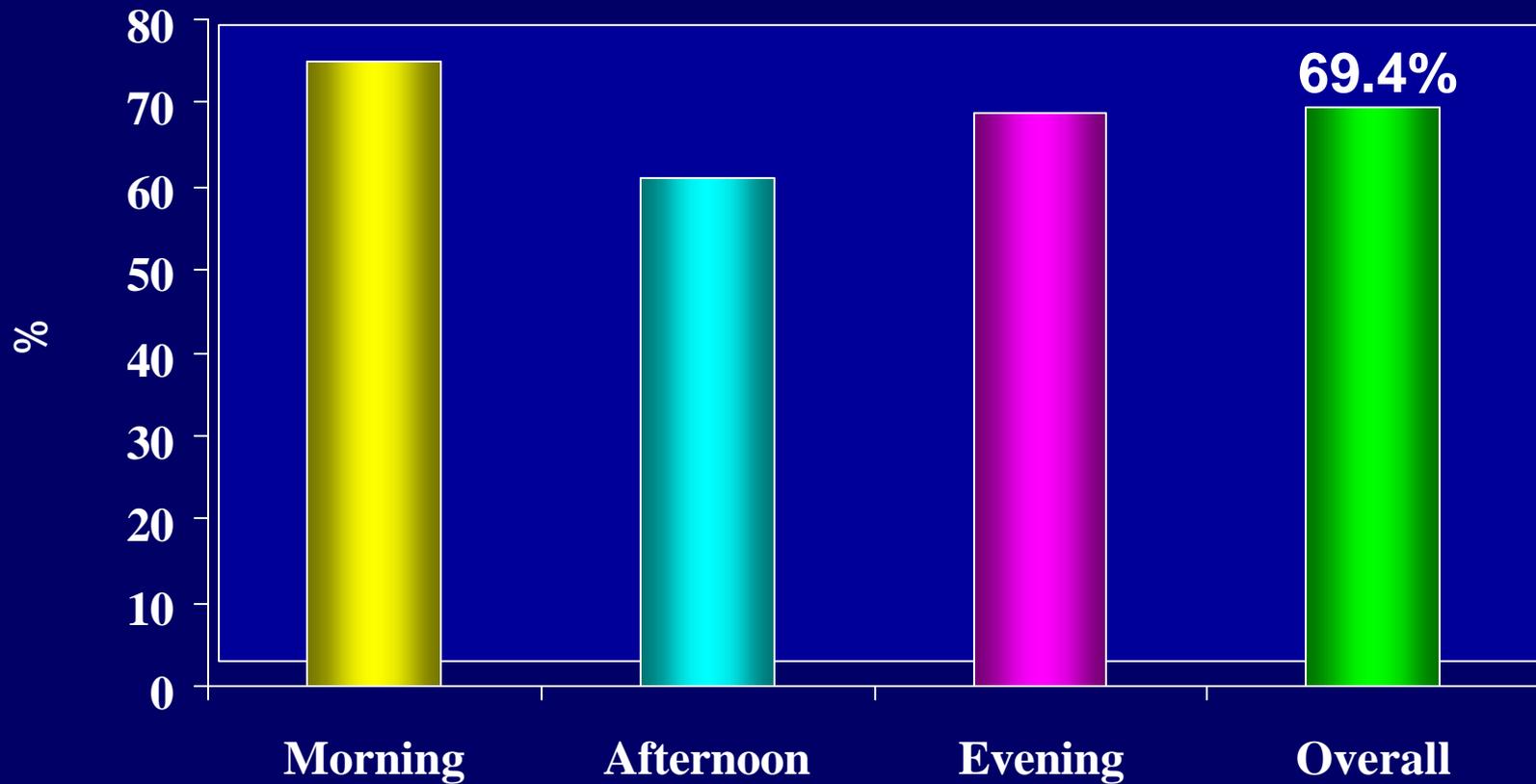
- Initiated November, 1997; N = 241 recruited for tx study
- 14 day trial pre-treatment, post treatment, follow-up
- 8 question included
- Recording 3 times/day (randomly once in morning, afternoon, & evening). Total number of prompts, 42 pretreatment, 42 post-treatment, 42 follow-up
- 166 (69.4%) agreed to participate in EMA phase (64 refused, 11 out of paging area). Those who declined had significantly lower household income. Accepted, 50%>\$50k; Declined, 24%>50k

*Support by DHHS NIAMS

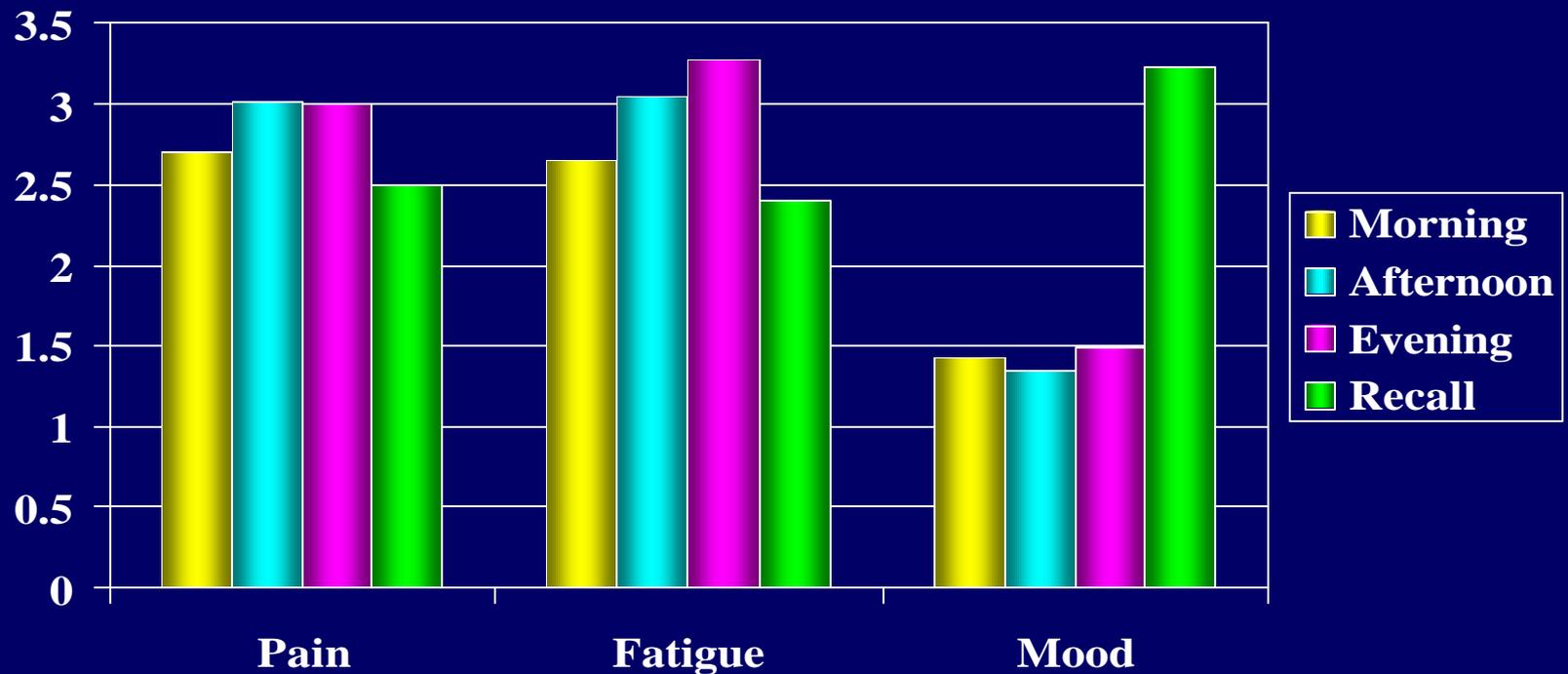
Reasons for Decline to Participate in EMA Phase

- **Did not wish to take/complete multiple times – intrusive, general**
- **Did not wish to take/complete at work – intrusive, at work**
- **Inconvenient – additional visits to research site**
- **Not comfortable with technology**
- **Did not want to take responsibility for the computer**

Response Rate (n = 159)

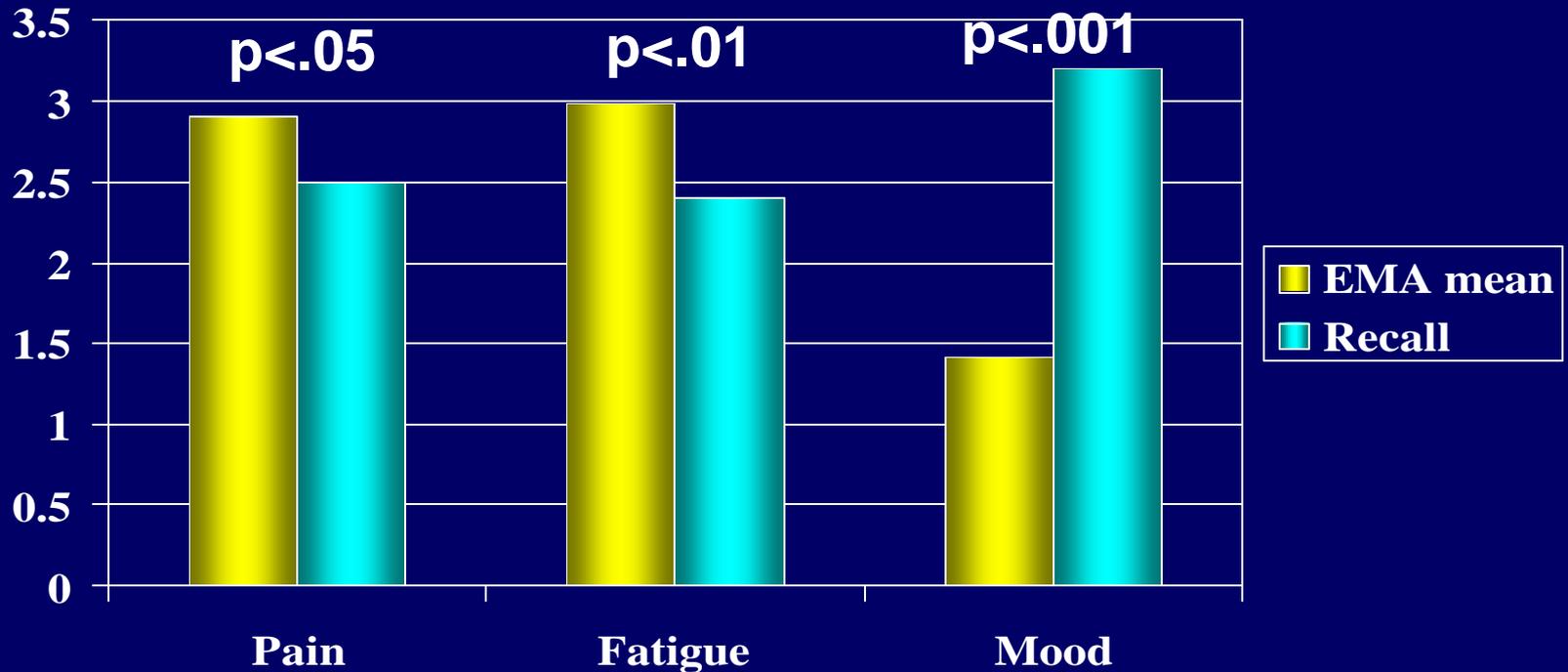


14 days of Ratings, 3 times/day vs. 1 Week Recall (n = 159)



0 = none/not tired/distressed; 7 = worst/very tired/distress

14 days of Ratings, 3 times/day vs. 1 Week Recall (n = 159)



0 = none/not tired/distressed; 7 = worst/very tired/distress

Sources of Problems Encountered

- **Software**
- **Hardware/Technical**
- **Participant/Operator**

Problems Encountered - Software

- **Depended on external paging service – proved not to be reliable**
- **At times program skipped question and participant could not return to answer**
- **Problems with batteries resulted in loss of data and loss of program**

Problems Encountered – Hardware/Technical

- **Touch screen malfunctions/Broken screen**
- **Inability to turn on computer**
- **Computer not receiving/accepting pages**
- **Computer turned on randomly – depleting batteries**
- **Battery life too short**
- **Battery corrosion**
- **Pager not loud enough**
- **Malfunction in master computer that sent paging requests**

Problems Encountered – Participant/Operator

- **Problems changing batteries resulting in lost data and loss of program**
- **Failure to keep computer accessible**
- **Perceived as inconvenient**
- **Reactivity of multiple responding intervals**
- **Loss/breakage of computer**
- **Placement of computer near electronic equipment, loss of pager capacity**

Additional Problem Encountered

- **Began with 16 palm-top computers**
- **End of the 5th year none were functional**

Conclusions

- **Potential fluctuation in symptoms and mood associated with chronic pain makes real-time data essential.**
- **Results from daily ratings differ significantly from recall.**
- **EMA does include some problems that need to be understood and addressed.**
- **Response rates overall were < 70%**
- **Sources of participant resistance need to be addressed.**
- **Software and hardware advances should reduce many of the problems encountered.**