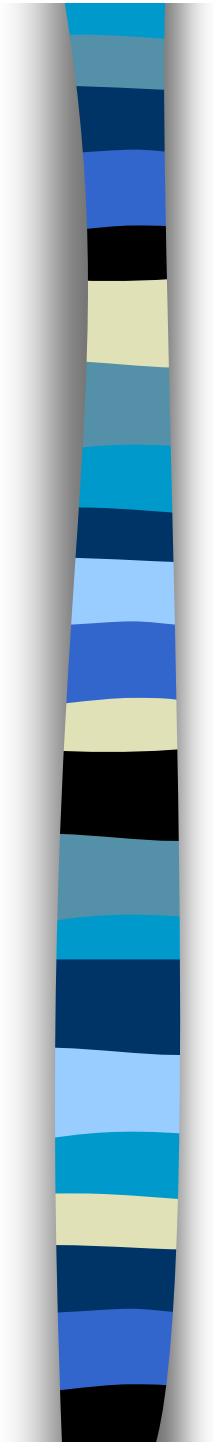


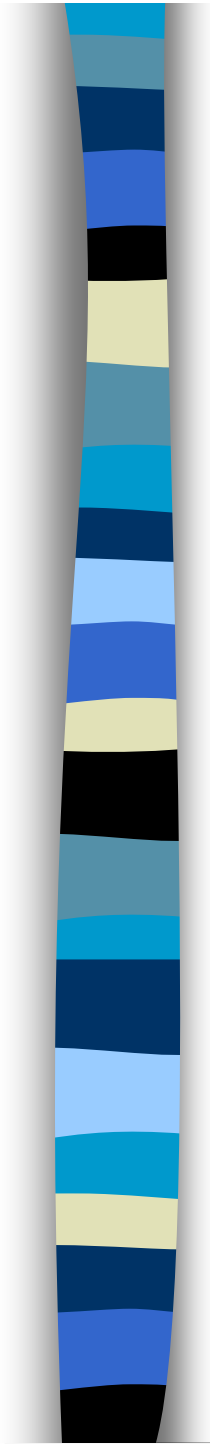
# The Phenomenon of Pain in Thalassemia

**PI-Dru Haines, RN,MS, PNP**; Felicia Trachtenberg; PhD, Marie Martin, RN;  
Susan Carson, RN, MSN,PNP; Sage Green, BA; Olivia Oliveros Vega, BS;  
Eric Gerstenberger, MS; Thomas Coates, MD.





- “I always have some kind of pain in some part of my body. There isn’t a day that goes by that I am not in some kind of pain.”

- 
- “My whole body has pain and the pain medicine helps me tolerate it”



# History of Pain in Thalassemia

- Increase in patients reporting pain over last decade.
- Pain not a symptom associated with thalassemia.
- No research studies with specific goal of assessing pain.



# Assessment of Pain Study-Goals:

- Assess the percentage of thalassemia patients who report pain.
- For those with pain, assess:
  - Pain severity, duration and sites.
  - Assess whether age, diagnosis, transfusion status or gender affect pain.
  - Assess the impact of pain on life activities.
  - Assess whether pain is influenced by transfusions.



# Assessment of Pain Study: Participants

- 251 patients with thalassemia in US and Canada.
- Age range: 12- 71 years old (ave.28.8)
- Diagnosis:
  - Beta Thalassemia (80%)
  - E Beta Thalassemia (11%)
  - Hemoglobin H (6%)



# Assessment of Pain Study: Participants

- Transfusion Status:
  - Chronically transfused (80%, n=201)
  - Intermittently transfused (6%, n=14)
  - Non-transfused (14%, n=37)



# Assessment of Pain Study: Method

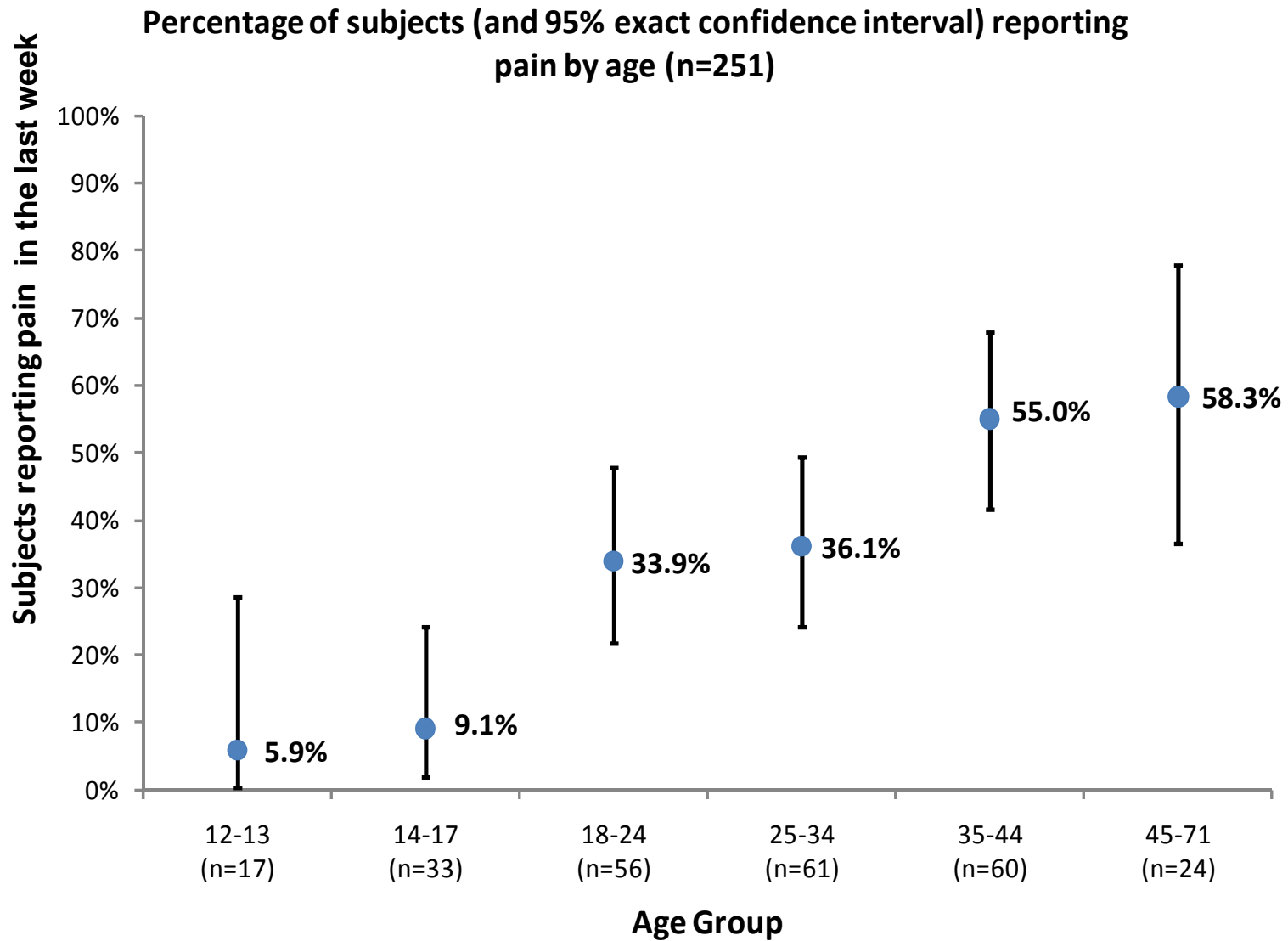
- Participants completed the Brief Pain Inventory quarterly.



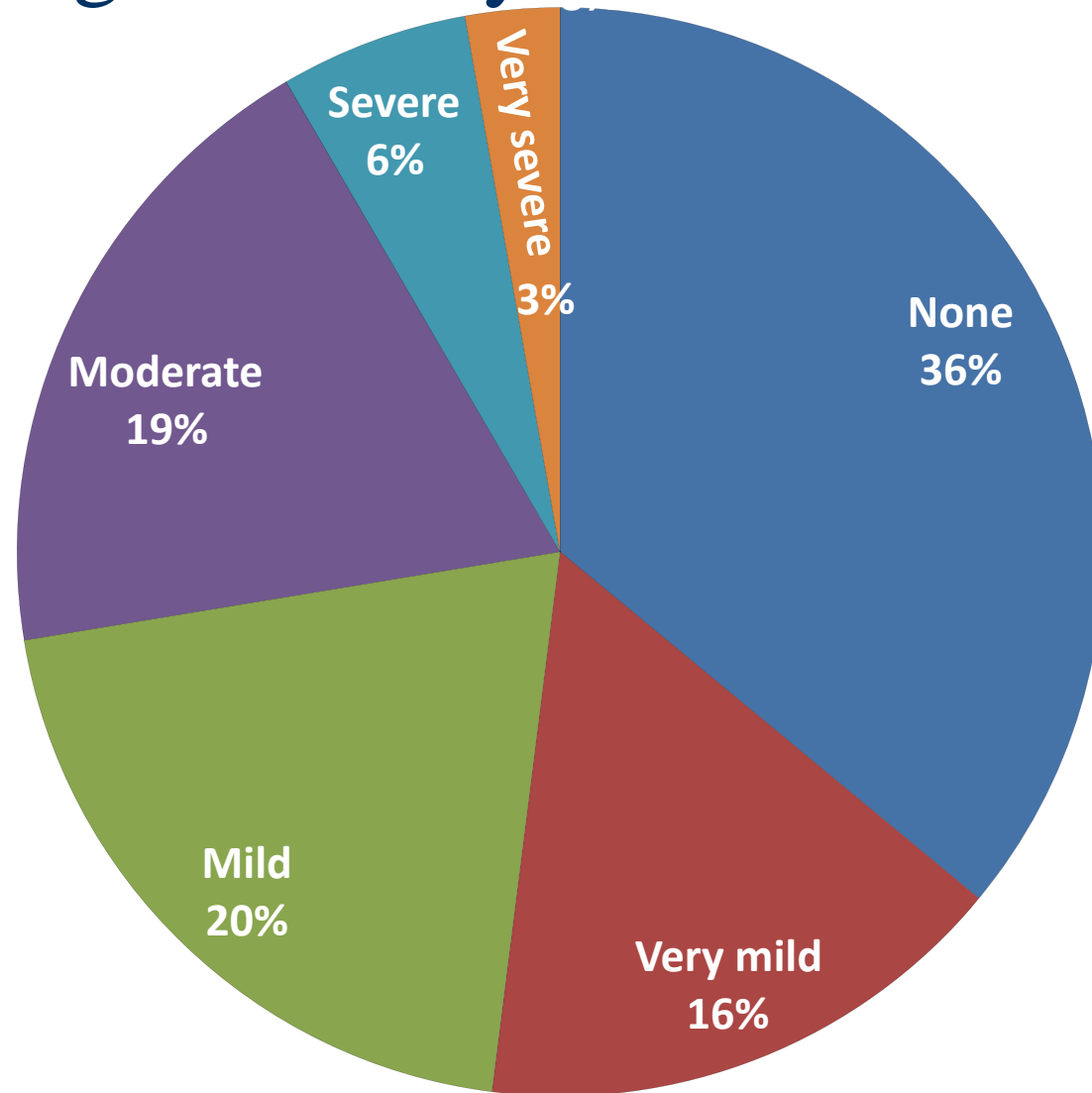
# Assessment of Pain Study: Findings

- 64% reported experiencing pain in the last 4 weeks, 73% 20 years and older.
- 14% reported daily pain.
- Comparison: 26% of US adults 20 years and older report pain in the last 4 weeks.

# Assessment of Pain Study: Findings- Age

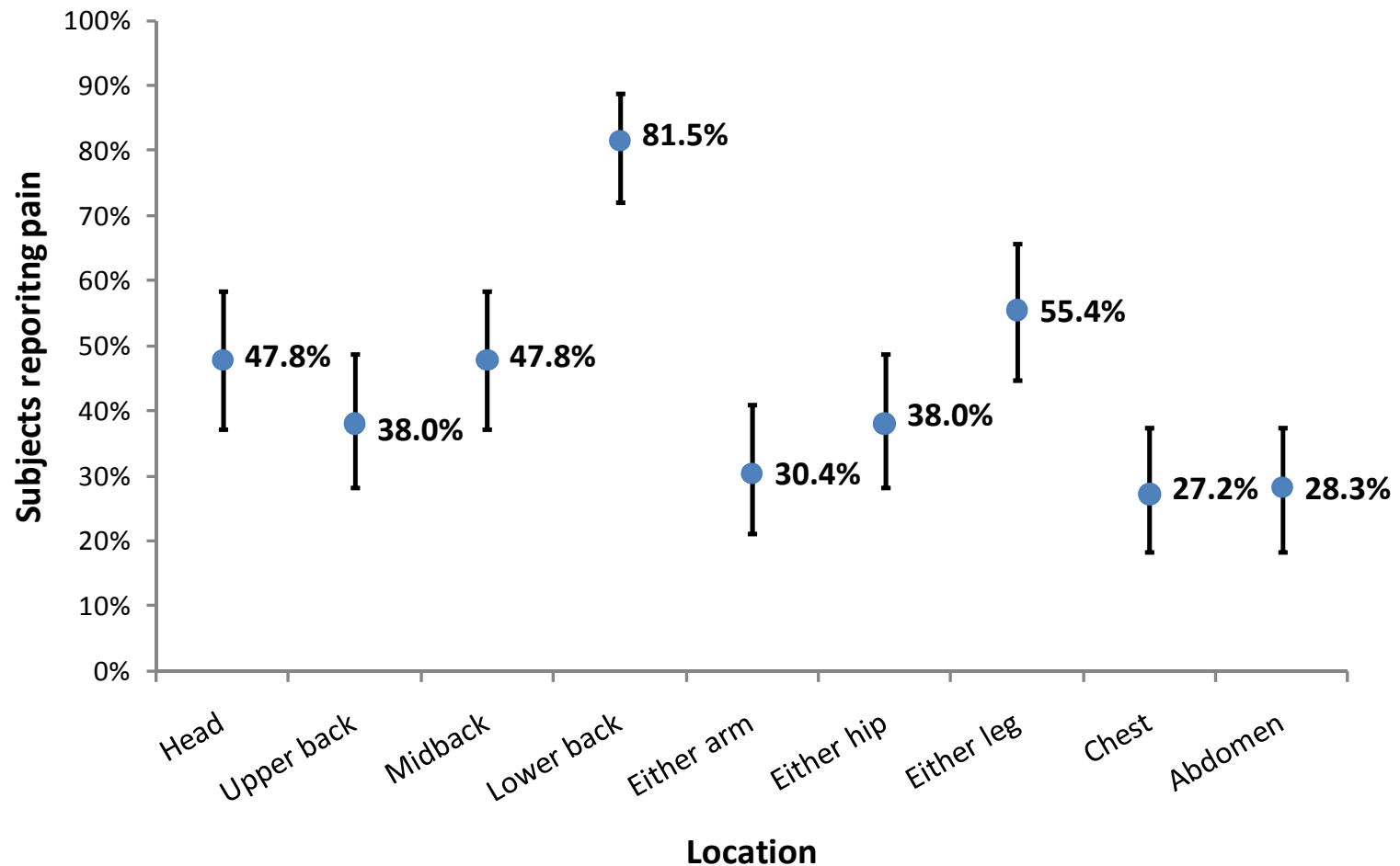


# Assessment of Pain Study: Findings- Severity

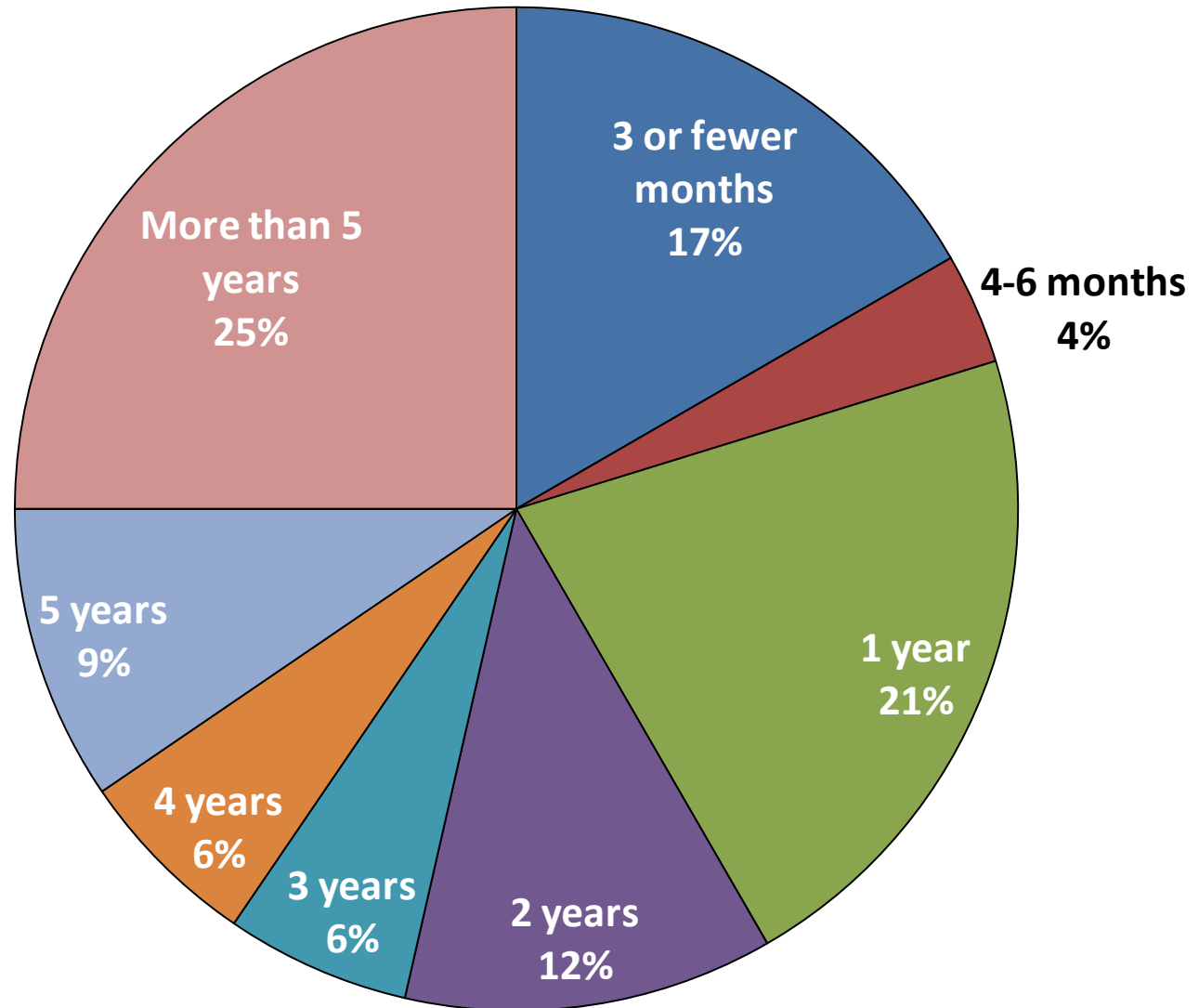


# Assessment of Pain Study: Findings- Pain Sites

Percentage of subjects (and 95% exact confidence interval) reporting pain by site of pain (n=92)

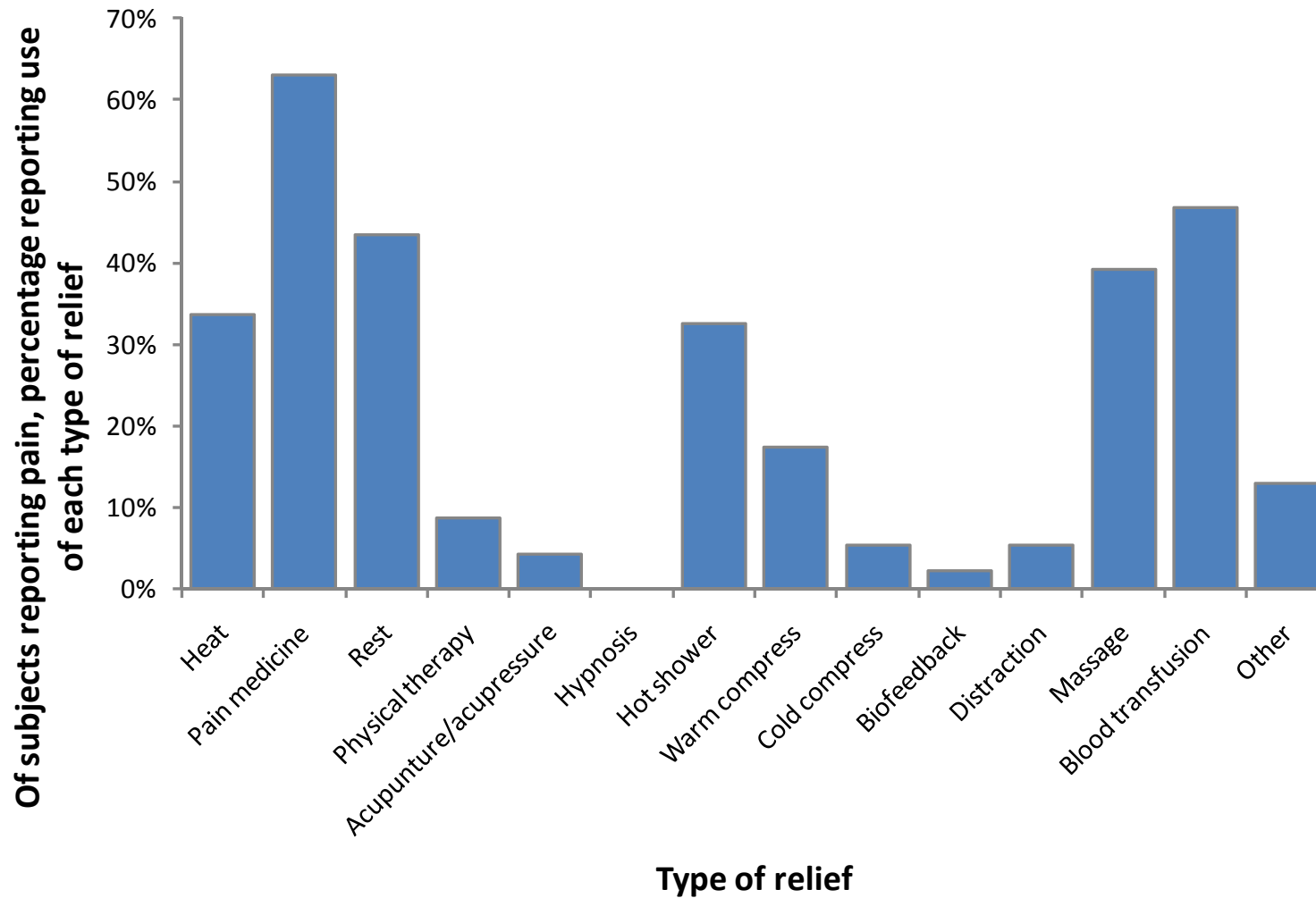


# Assessment of Pain Study: Findings-Pain Duration (n=84)



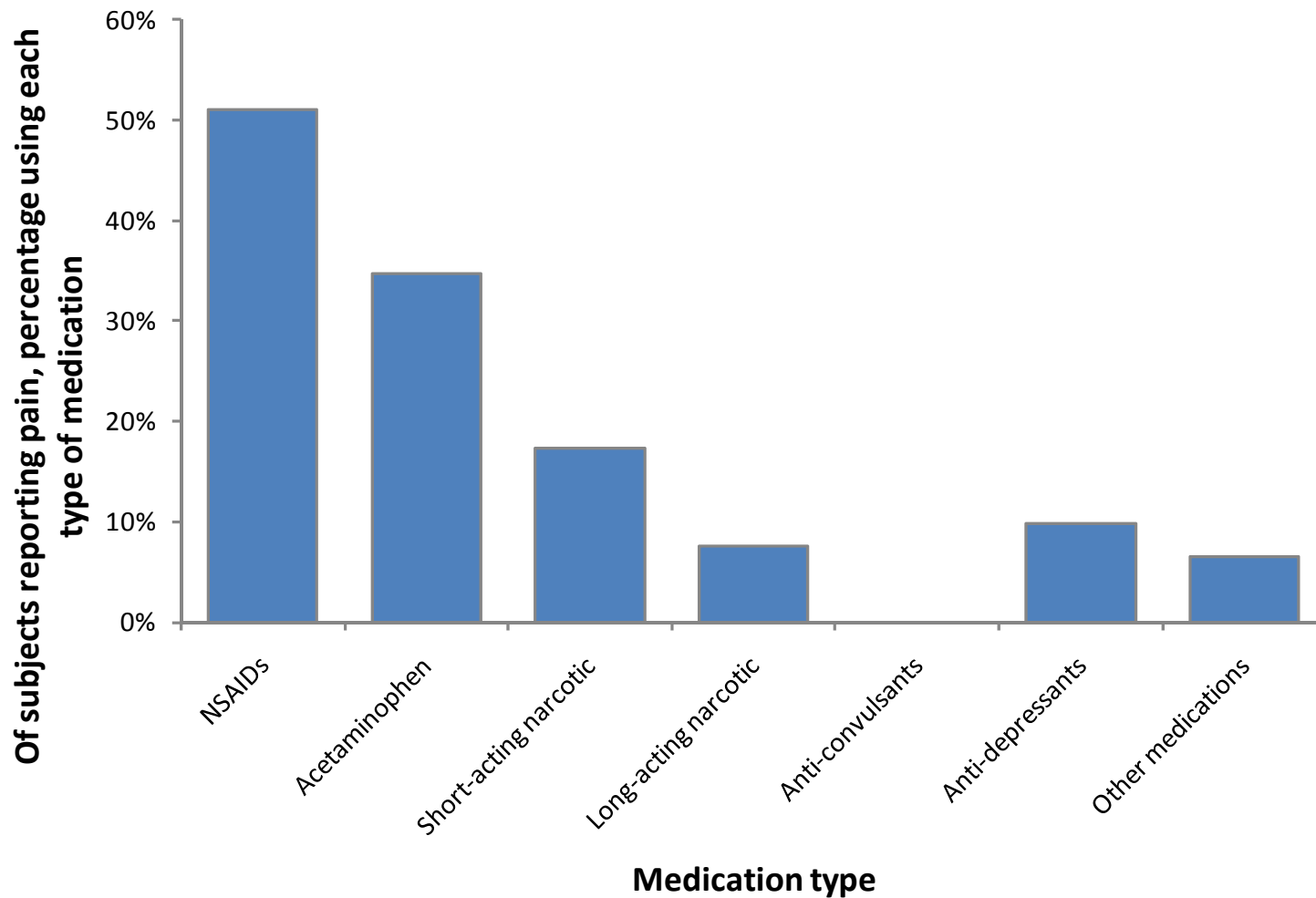
# Assessment of Pain Study: Findings-Pain Relief

Of subjects reporting pain (n=92), sources of relief

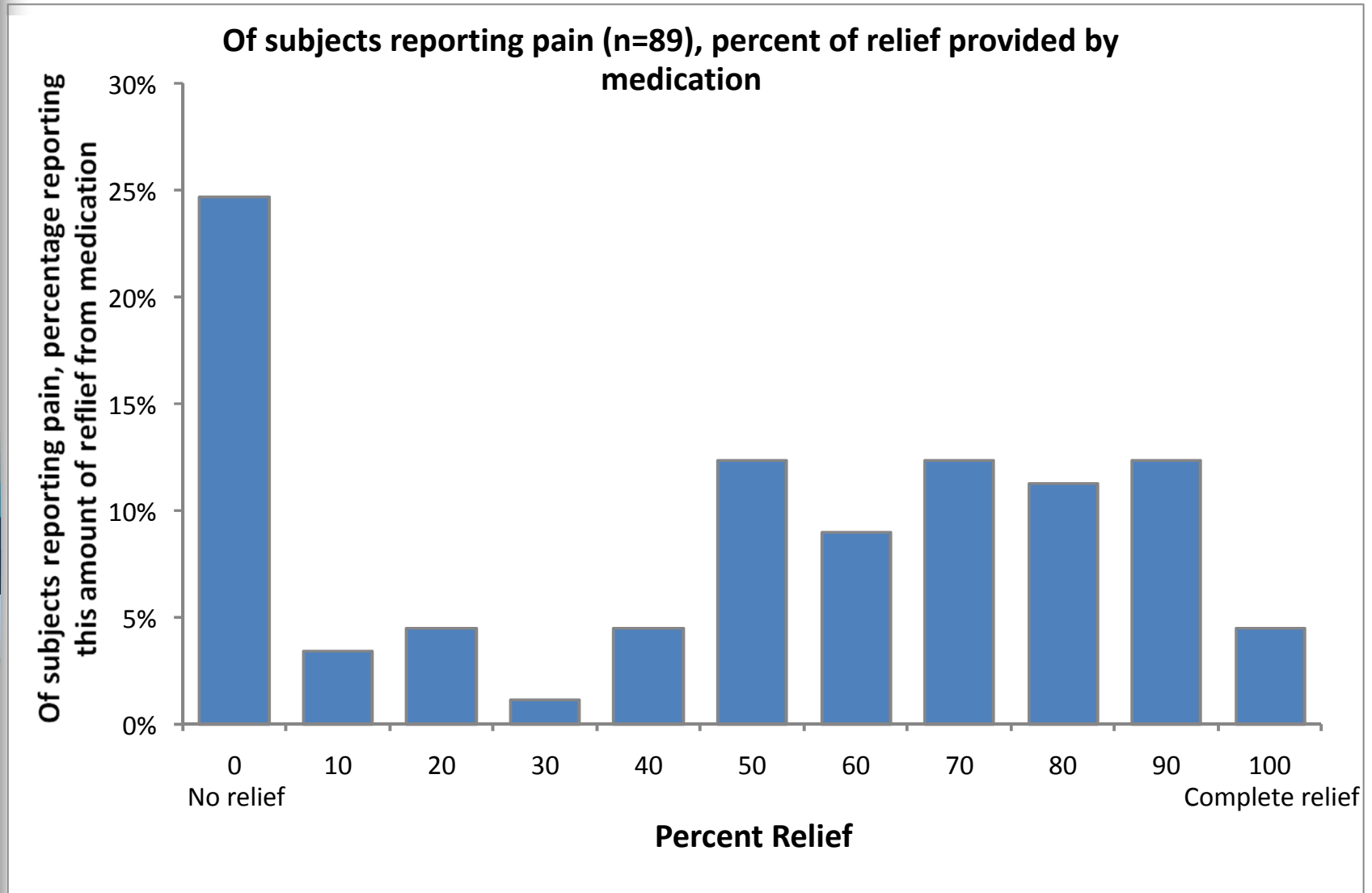


# Assessment of Pain Study: Findings-Pain Medications

Of subjects reporting pain (n=92), type of medications used

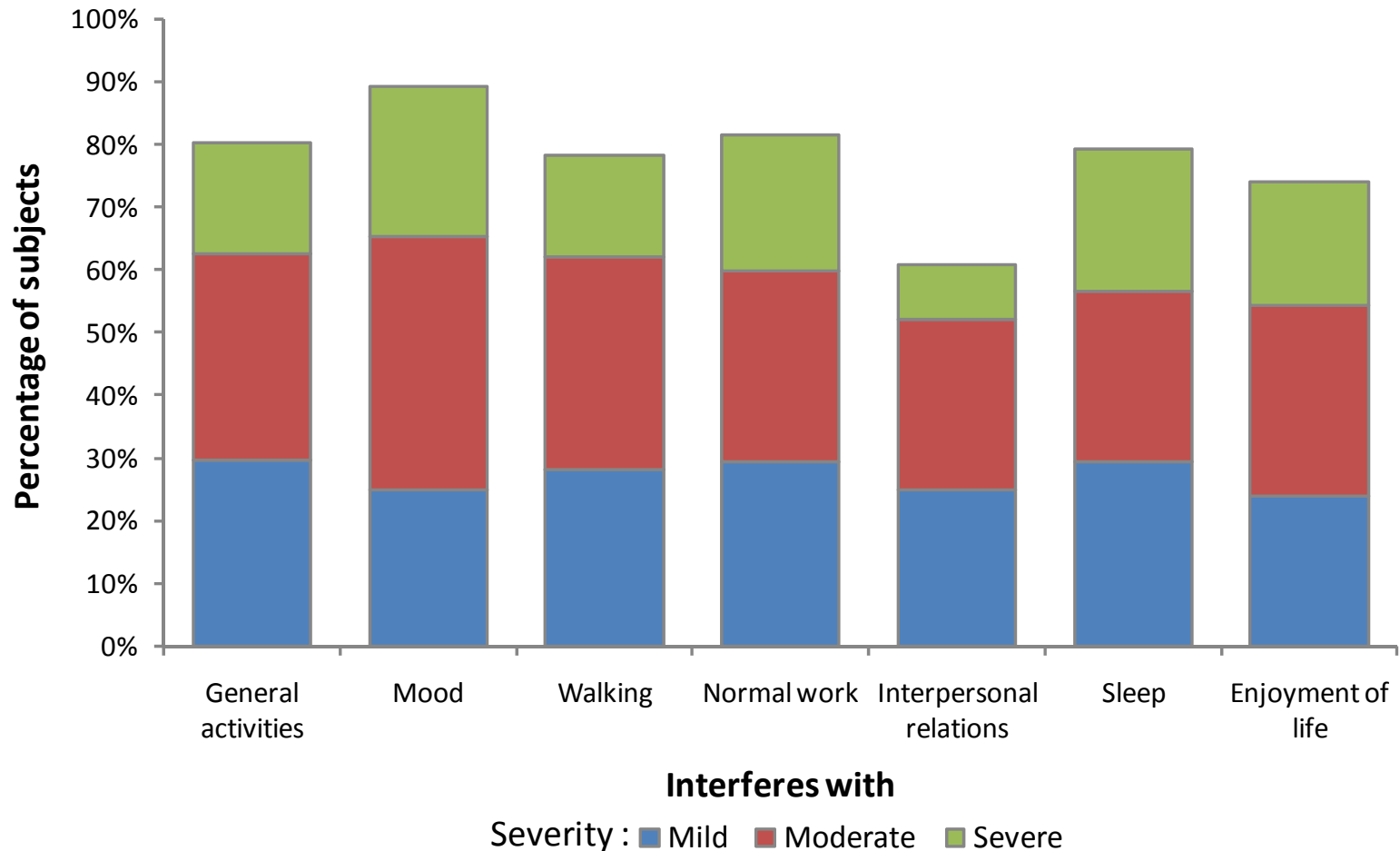


# Assessment of Pain Study: Percent of Pain Relief



# Assessment of Pain Study: Findings-Pain impact on Life

Percentage of subjects reporting interference by  
severity (n=92)





# Assessment of Pain Study: Conclusions

- Pain is a significant issue for thalassemia patient
  - Pain significantly increases with age ( $p < 0.001$ )
  - 64% experience pain monthly
  - 14% experience pain daily
  - 28% describe severity as moderate or greater
  - 79% report pain duration greater than 1 year
  - 17% requiring short acting and 11% long acting narcotics for pain management



# Transfusion and Pain

- Patient reports and clinical wisdom suggests that increased pain is associated with decreased hemoglobin.



# Transfusion and Pain: Participants

- 32 transfusion dependent thalassemia patients who reported pain in the last 7 days.
- 15 patients 18-29
- 17 patients 30 +



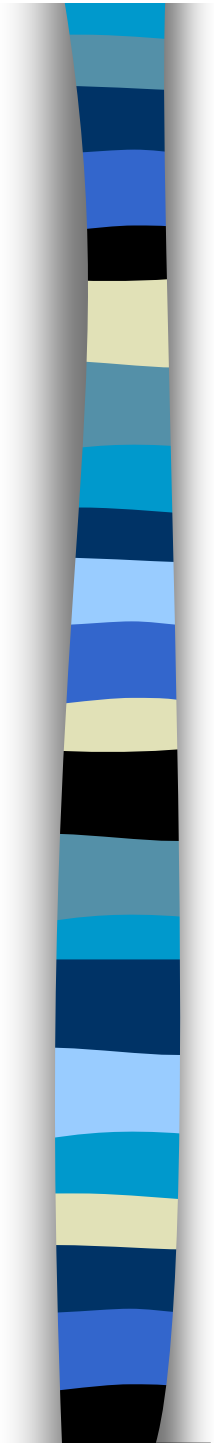
# Transfusion and Pain: Method

- Participants rated pain daily during a transfusion cycle using the Brief Pain Inventory-short form.
- Participant rated pain during 3 different transfusion cycles at least 3 months apart.



# Transfusion and Pain: Findings

- Lower hemoglobin levels were not associated with increased pain.
- Transfusion cycles of 14 days or less were associated with greater pain severity.



- “I would love to do the things I used to do and still accomplish the things I still want”



# Contributing Institutions:

- **Children's Hospital & Research Center Oakland- PI-Dru Haines PNP**, Olivia Oliveros Vega, Elliott Vichinsky,MD
- **Children's Hospital Los Angeles-Susan Carson NP**, Thomas Coates, MD
- **Children's Hospital Philadelphia-** Marie Martin RN, Sage Green, Janet Kwiatkowski, MD
- **Children's Hospital Boston-** Jennifer Braunstein PNP, Ellis Neufeld, MD.
- **Children's Memorial Hospital Chicago-** Diane Calamaras, NP
- **Toronto General Hospital-** Cecilia Kim BS, Nancy Oliveri, MD
- **Weill Medical College of Cornell-Dorothy Klienert NP**, Patricia Giardina,MD
- **The Hospital for Sick Kids, Toronto-** Manuela Merelles-Pulcini MSN
- **Children's Healthcare of Atlanta-** LeAnn Schilling MPH
- **Baylor College of Medicine-** Bogdan Dinu,
- **Stanford University-** Michael Jeng, MD
- **Children's and Women's Health Center, British Columbia-** Jennifer Keis, RN
- **New England Research Institute-** Felicia Trachtenberg PhD, Eric Gerstenberger MS
- **MD Anderson Cancer Center, Dept. of Symptom Research-** Tito Mendoza PhD.