Open Source Learning Health System Platform to Deliver Best Care

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Disclosure

Consultant for Jazz Pharmaceuticals
DSMB for Boston Scientific
Outline

1. Introduction to Pain Management
2. Pain Systems Biology and the Complexity of Chronic Pain
3. Reasons for measuring pain outcomes
4. Development and current applications of CHOIR
   - Patient Experience
   - Peri-operative Care
   - Primary Care
   - Clinical guides and potential research areas
5. Future collaborations
Stanford Pain Management Center

Tertiary Pain Management Center
Started in 1989 in a non-hospital section – trailer
14,000 patient visits
20 clinical pain faculty
  ✓ Anesthesiology
  ✓ Internal Medicine
  ✓ Neurology
  ✓ Physiatry
  ✓ Psychology
  ✓ Psychiatry
10 community ACF
The New Stanford Pain Center

February 2009
Increase from 2500ft\(^2\) to 7500ft\(^2\)
New targeted outpatient services
Integrating physicians from other departments:
- Rob Cowan / Sheena Aurora – Headache / Neuroscience
- Walter Park – GI Medicine
CHOIR Collaborators

- NIH Pain Consortium
- Stanford Center for Clinical Informatics
  - Susan Weber
  - Garrick Olson
  - Teresa Pacht
- Stanford Systems Neuroscience and Pain Lab (SNAPL)
- Northwestern/PROMIS
  - Karon Cook, PhD
  - David Cella, PhD
  - Richard Gerson, PhD
- University of Florida
- Massachusetts General Hospital
- UCSD – Mark Wallace
- University of Pittsburgh – Ajay Wasan
- Stanford-Packard Pediatric Pain Center
  - Eliot Krane, MD
- Richard Denisco, MD (NIDA)
- Dave Thomas, MD
PAIN - *definition*

“An unpleasant *sensory and emotional experience* associated with actual or potential tissue damage, or described in terms of such damage”

Self report remains the gold standard!

*IASP 1979*
Common Pain Conditions We Treat

• Back and neck pain
• Headache
• Neuropathic pain
  › Post traumatic, post surgical
• Abdominal and pelvic pain
• Cancer pain
• Myofascial / orthopedic pain
Chronic Pain Overview

• Challenge: Lack of complete cure
• Treatment subsequently focuses on condition management
• Similar to approach taken with other chronic conditions (e.g., diabetes)
• Overriding goal is to help patients learn how to live with pain & improve quality of life
Chronic Pain Overview

• Multidisciplinary treatment
  • Pharmacologic
  • Psychological
  • Physical Modalities
  • Procedural
What is Intrathecal Pain Therapy?
N-type Calcium Channels Control the Signaling of Pain to the Brain

Nociceptors initiate action potentials that lead to calcium influx through N-type calcium channels.¹

The result is neurotransmitter release into the synapses of the dorsal horn and propagation of the pain signal.¹,²

Pain Systems Biology: The Complexity of Pain Medicine

- Molecular Biology
  - 1,730 Proteins
  - 1,225 Genes

- Anatomy
  - 108 Muscles
  - 70 Nerves
  - 46 Entrapments

- Psychosocial
  - 26 Psychosocial

- Evaluation
  - 456 Physical Exams
  - 431 Regional Diagnoses

- Treatment
  - 201 Interventions
  - 157 Medications

Stanford University
Why Measure Pain Outcomes?
Medical Practice Pressures: Patient-Centered Care

Patient (consumer) empowerment
  ▪ Rising patient expectations, knowledge
Importance of patient satisfaction (e.g. Press Ganey, Picker, Yelp), loyalty
New FDA reliance on quality of life data
Shift of perspective
  ▪ Aging population
  ▪ Shift from cure to chronic disease management
    › Emphasis on function, quality of life, palliation
Medical Practice Pressures: Information-driven

- Excess of Mixed-Quality Information
- Difficult to know what works and at what cost

Medical Practice Pressures: Regulatory

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Data capture and sharing</td>
<td>Advance clinical processes</td>
<td>Improved outcomes</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Stage 1: Meaningful use criteria focus on:</th>
<th>Stage 2: Meaningful use criteria focus on:</th>
<th>Stage 3: Meaningful use criteria focus on:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Electronically capturing health information in a standardized format</td>
<td>More rigorous health information exchange (HIE)</td>
<td>Improving quality, safety, and efficiency, leading to improved health outcomes</td>
</tr>
<tr>
<td>Using that information to track key clinical conditions</td>
<td>Increased requirements for e-prescribing and incorporating lab results</td>
<td>Decision support for national high-priority conditions</td>
</tr>
<tr>
<td>Communicating that information for care coordination processes</td>
<td>Electronic transmission of patient care summaries across multiple settings</td>
<td>Patient access to self-management tools</td>
</tr>
<tr>
<td>Initiating the reporting of clinical quality measures and public health information</td>
<td>More patient-controlled data</td>
<td>Access to comprehensive patient data through patient-centered HIE</td>
</tr>
<tr>
<td>Using information to engage patients and their families in their care</td>
<td></td>
<td>Improving population health</td>
</tr>
</tbody>
</table>

http://www.healthit.gov/providers-professionals/how-attain-meaningful-use
Medical Practice Pressures: Economic

- Shifting reimbursement models
- Rising costs: labor, biotech, high tech
- Evolving settings of care: day surgery or fast-track to home
- Insurance coverage decisions made in absence of clear data
- Pay for performance
Goal: To develop, implement and expand an open source, open standard, highly flexible, and free health and treatment registry.

Registry will be used to collect outcomes data on large numbers of patients suffering from chronic pain (and other health conditions).

- Point of care decision making
- Software based decision making ("Learning Health Systems")
- Comparative effectiveness research
- Longitudinal outcomes research
- Large simple trial designs, Practice Based Evidence trials
# CHOIR: Staff View of Appointments

## Stanford Pain Management Center

### Schedule

<table>
<thead>
<tr>
<th>MRN</th>
<th>First Name</th>
<th>Last Name</th>
<th>Appl Type</th>
<th>Appt Time</th>
<th>Survey Type</th>
<th>Appt Status</th>
<th>Recommended Action</th>
</tr>
</thead>
<tbody>
<tr>
<td>10001-6</td>
<td>George</td>
<td>Washington</td>
<td>NPV60</td>
<td>03/05/2014 06:00 AM</td>
<td>Initial.0114</td>
<td>Select one...</td>
<td>![In progress (3 of 29)]</td>
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<tr>
<td>10003-2</td>
<td>John</td>
<td>Adams</td>
<td>RPV60</td>
<td>03/05/2014 10:30 AM</td>
<td>FollowUp.0114</td>
<td>Select one...</td>
<td>![Nothing (already printed)]</td>
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<tr>
<td>10009-1</td>
<td>George</td>
<td>Burns</td>
<td>RPV60</td>
<td>03/05/2014 03:15 PM</td>
<td>FollowUp.0114</td>
<td>Select one...</td>
<td>![Start assessment]</td>
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<tr>
<td>10015-6</td>
<td>Mona</td>
<td>Lisa</td>
<td>RPV60</td>
<td>03/05/2014 05:00 AM</td>
<td>FollowUp.0114</td>
<td>Select one...</td>
<td>![Start assessment]</td>
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<tr>
<td>10005-7</td>
<td>Martha</td>
<td>Washington</td>
<td>NPV60</td>
<td>03/05/2014 04:45 AM</td>
<td>Initial</td>
<td>Select one...</td>
<td>![Print results]</td>
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<tr>
<td>10002-4</td>
<td>Uly</td>
<td>Grant</td>
<td>RPV60</td>
<td>03/08/2014 10:15 AM</td>
<td>FollowUp</td>
<td>Select one...</td>
<td>![Start assessment]</td>
</tr>
</tbody>
</table>

**Total Patients:** 6  **To Enroll:** 0  **To Start:** 3  **To Finish:** 1  **To Print:** 1  **Done:** 1
CHOIR Runs on All Web Enabled Devices

- PCs (Windows, Mac, Linux)
- Tablets (iPad, Android)
- Smart Phone (iPhone, Android, others)
- 53% are completing at home vs 47% in clinic

At home:
- 66% use PC
- 13% use iPhone
- 9% use iPad
- 10% use Android tablet or phone
Initial and Follow-Up Surveys

- **Initial Survey – 22 min**
  - Demographics
  - Prior Treatments, Pain Beliefs
  - Interactive Body Map
  - PROMIS 9 domain measures:
    - Pain Intensity, Pain Behavior, Pain Interference, Fatigue, Physical Function, Depression, Anxiety, Sleep Disturbance, Sleep Related Impairment
  - Pain Catastrophizing Scale (PCS)

- **Follow up Survey – 9 min**
  - Interactive Body Map
  - PROMIS 9 domain measures as above
  - PCS

- **CHOIR PEN – Patient experience survey with 14 days of visit**
Stanford Pain Management Center Outcomes

Body Map

Pain Intensity

5 areas selected on the most recent body map

PROMIS Outcomes Measures

<table>
<thead>
<tr>
<th>Measures</th>
<th>Score %ile</th>
<th>Category</th>
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</thead>
<tbody>
<tr>
<td>Depression</td>
<td>44</td>
<td>Minimal</td>
</tr>
<tr>
<td>Anxiety</td>
<td>46</td>
<td>Normal</td>
</tr>
<tr>
<td>Anger</td>
<td>41</td>
<td></td>
</tr>
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</table>

<table>
<thead>
<tr>
<th>Measures</th>
<th>Score %ile</th>
<th>Category</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical Function</td>
<td>60</td>
<td>84</td>
</tr>
<tr>
<td>Pain Interference</td>
<td>57</td>
<td>76</td>
</tr>
<tr>
<td>Pain Behavior</td>
<td>59</td>
<td>82</td>
</tr>
</tbody>
</table>

*Scores and percentages have been inverted

<table>
<thead>
<tr>
<th>Measures</th>
<th>Score %ile</th>
<th>Category</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fatigue</td>
<td>49</td>
<td>46</td>
</tr>
<tr>
<td>Sleep-Related Impairment</td>
<td>45</td>
<td>31</td>
</tr>
<tr>
<td>Sleep Disturbance</td>
<td>50</td>
<td>None to Slight</td>
</tr>
</tbody>
</table>

Stanford University
Sandra with Complex Regional Pain Syndrome

2004 - 20 y/o college student involved in MVA

“It’s that feeling, if you’re digging through the bottom of a cooler, and you just get that burning sensation because your arm is so cold,”

Full story at: https://alumni.stanford.edu/get/page/magazine/article/?article_id=66226
CHOIR: Using Dynamic Outcomes to Inform Clinical Care

![Graphs showing measures of depression, anxiety, fatigue, physical function, pain interference, and pain behavior.](image-url)
CHOIR: Using Dynamic Outcomes to Inform Clinical Care

- Depression
- Anxiety
- Fatigue

- Physical Function *
- Pain Interference
- Pain Behavior

Health Education

Desipramine
Low-dose Naltrexone
## CHOIR CAT: Reduction in Patient Survey Burden

<table>
<thead>
<tr>
<th>Domain</th>
<th>NIH PROMIS # Items</th>
<th>Legacy Instrument</th>
<th># Items</th>
<th>Burden Reduction</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anger</td>
<td>6.24 ± 1.21</td>
<td>Buss-Perry Aggression Questionnaire (BPAQ)</td>
<td>29</td>
<td>88%</td>
</tr>
<tr>
<td>Anxiety</td>
<td>4.93 ± 0.97</td>
<td>Generalized Anxiety Disorder 7-item (GAD-7)</td>
<td>7</td>
<td>30%</td>
</tr>
<tr>
<td>Depression</td>
<td>4.97 ± 1.07</td>
<td>Patient Health Questionnaire (PHQ-9)</td>
<td>9</td>
<td>45%</td>
</tr>
<tr>
<td>Fatigue</td>
<td>4.78 ± 0.76</td>
<td>Functional Assessment of Chronic Illness Therapy-Fatigue (FACIT-F)</td>
<td>40</td>
<td>88%</td>
</tr>
<tr>
<td>Physical Function</td>
<td>4.11 ± 0.48</td>
<td>Health Assessment Questionnaire-Disability Index (HAQ-DI)</td>
<td>20</td>
<td>79%</td>
</tr>
<tr>
<td>Pain Interference</td>
<td>4.19 ± 0.71</td>
<td>Brief Pain Inventory</td>
<td>7</td>
<td>40%</td>
</tr>
<tr>
<td>Pain Behavior</td>
<td>4.06 ± 0.45</td>
<td>N.A.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sleep Disturbance</td>
<td>4.95 ± 1.41</td>
<td>Sleep Disorders Questionnaire (SDQ)</td>
<td>12</td>
<td>59%</td>
</tr>
<tr>
<td>Sleep-Related Impairment</td>
<td>4.54 ± 1.24</td>
<td>Epworth Sleepiness Scale (ESS)</td>
<td>8</td>
<td>43%</td>
</tr>
<tr>
<td><strong>Overall</strong></td>
<td>38.7 ± 7.9</td>
<td></td>
<td>132</td>
<td>71%</td>
</tr>
</tbody>
</table>
CHOIR Computer-Assisted Documentation

Patient-reported history components are displayed according to the provider’s needs for documentation.
Current Status

• Rolled out at Stanford Pain Management Center August 14, 2012
• Integrated into clinic using web and Apple iPhone or iPad / Android devices
• Staff helped with implementation
• Approximately 5,000 unique patients and 50,000 longitudinal data assessments
• Implemented local CAT engine – CHOIR CAT
  • Faster response time
• Changing the culture and how we practice pain management
Psychometric properties of Pain Clinic population

- Pain Behavior: 61 +/- 3.35
- Anxiety: 59 +/- 9.88
- Fatigue: 63 +/- 9.57
- Pain Interference: 68 +/- 6.18
- Depression: 58 +/- 9.82
- Physical Function: 34 +/- 7.59
• My tribe believed there were gods living among them.
• The beliefs of the tribe were important.
• For example, if a shaman or their doctor was bad at their job and could not heal patients, the tribe would rise up and kill the doctor.
Patient Satisfaction and the Challenges of Chronic Pain (2012)
Stanford Patient Experience Questionnaire (SPEQ): Motivation

Existing patient satisfaction surveys, including

- Consumer Assessment of Healthcare Providers and Systems (CAHPS)
- Treatment Outcomes of Pain Survey (TOPS)
- Press Ganey

An unmet need

- Comprehensive capture of patient experience touchpoints
- Concise item stems
- Actionable results
- Free
<table>
<thead>
<tr>
<th>Domain</th>
<th>Contribution</th>
</tr>
</thead>
<tbody>
<tr>
<td>Scheduling &amp; Coordination</td>
<td>29%</td>
</tr>
<tr>
<td>Respect</td>
<td>24%</td>
</tr>
<tr>
<td>Phone</td>
<td>16%</td>
</tr>
<tr>
<td>Provider</td>
<td>50%</td>
</tr>
<tr>
<td>Wait</td>
<td>16%</td>
</tr>
<tr>
<td>Referring Provider</td>
<td>47%</td>
</tr>
<tr>
<td>Outcomes</td>
<td>22%</td>
</tr>
<tr>
<td>Outcomes &amp; Provider</td>
<td>15%</td>
</tr>
<tr>
<td>Care Coordination</td>
<td>32%</td>
</tr>
<tr>
<td>Access &amp; Scheduling</td>
<td>22%</td>
</tr>
<tr>
<td>Nursing &amp; Assistant</td>
<td>15%</td>
</tr>
<tr>
<td>Referring Provider</td>
<td>50%</td>
</tr>
</tbody>
</table>

In this data, the **domain-factor Provider** contribute only about **20%** to patient satisfaction.

The largest and most influential factors surround **Care Coordination**, including the domains:

- Care Coordination
- Access & Scheduling
- Nursing & Assistant

**Care coordination** domain is the most “central” domain (highest average correlation $r = 0.74$)

- Higher than Outcomes domain and Overall domain

**Outcomes** domain

- Strongly associated with Care Coordination ($r = 0.89$)
- Shows weaker correlations with other domains (average $r = 0.59$)
Care Coordination at Stanford Pain Management Center

- Centralized Stanford Health Care call center
- Customer Relations Management (CRM) integration into EMR
- Team of RNs and MAs
- Direct consultation telephone line to physician during business hours

- CHOIR Primary Care
  - Common issues faced by PCPs
  - Guidance for common opioids medication management questions
  - Guidance for common pain complaint management first-steps
  - Guidance for Pain Clinic referral and timely evaluation

- CHOIR Peri-operative
  - Guidance for peri-operative pain management
  - Guidance for Pain Clinic referral and timely evaluation
Preoperative emotional distress highly predictive of:
- Poorer surgical outcomes
- Increased pain intensity and duration
- Increased use and duration of postop opioids
- Increased length of stay
**Opioid Risk Mitigation**

**Stanford Pain Clinic Opioid REMS Algorithm**
**Opioid REMS Tips Sheet**
**AAPM & APS Opioid Treatment Guidelines**
**CURES**

### Rapid Doc
- **Impression**:  
- **Instructions**:  

### Major Conditions
- **CRPS**
- **Total Body Pain**
- **Oral Facial Pain & Headache**
- **Nerve Entrapments**

<table>
<thead>
<tr>
<th>Opioid</th>
<th>Morphine</th>
<th>Methadone</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dose (mg/day)</td>
<td>24</td>
<td>10</td>
</tr>
</tbody>
</table>

### Daily Dose
- 0 mcg/hr Buprenorphine transdermal
- 60 mg Codeine (Tylenol #3, #4)
- 0 mcg/hr Duragesic
- 15 mg Hydrocodone
- 0 mg Hydromorphone (Opioid)
The principal clinical problem of “fibromyalgia” is not the rigorous research definition of fibromyalgia, but the medical problem of ruling out other conditions. **With CHOIR CG we can have both.**

1. **Differential diagnosis and work-up guidance**

   - **Approach**
     - "Vital body parts are not the subject of this study."
     - "The differential diagnoses include..."

   - **Work-up**
     - We recommend basic work-up for rheumatologic and endocrine problems. We also recommend obtaining basic mood environments.
     - Additional domains of differential diagnosis will also include neurologic and infectious disease conditions.

   - **Rheumatologic**
     - Manifestations of rheumatic disease: CRP, ESR, VDRL
     - Arthritis, tendinitis, myalgia
     - Imaging: Diagnostic of musculoskeletal sarcoma

   - **Endocrinologic**
     - Thyroid: Free T4
     - Calcium, metabolism, fasting glucose
     - Vitamin D: vitamin D

   - **Mood**
     - PANS: Depression
     - PANS: Anxiety

   - **Referrals**
     - Pain Management Center
     - Neurology and Rheumatology Center
     - Endocrinology Clinic
     - Infectious Disease Clinic
     - Psychiatry Clinic

2. **Documentation is generated based on results**

   - After other work-up is completed, ACR 2010 Fibromyalgia criteria or newer guidelines

   - OHSU – Kim Jones, RN Arth Care Res 2014
The Future for CHOIR: Collaborations

- Expanding to multiple clinics/sites and expanding outside of just pain
  - Spine CHOIR, Ortho CHOIR, GI CHOIR
  - Other Academic Pain Centers
    - University of Florida: bridge to EPIC
    - University of Pittsburgh, MGH, UCSD

- Currently providing source code with minimal licensing restrictions
Open Source Public-Private Partnership Learning Health System Platform: Collaborative Health Outcomes Information Registry (CHOIR)

Networked Learning Health Systems

CHOIR | LHS
Best Care at Lower Cost

Population Health

CHOIR | Cohort
Population Health Management

Targeted Therapy

CHOIR | CER
Comparative Effectiveness

Care Coordination

CHOIR | PEN
Patient Experience Network

Clinic

CHOIR | Clinic
Outcomes Tracking & Decision Support

Surgery

CHOIR | Peri-Op
Optimal Prehabilitation for Surgery

Inpatient

CHOIR | Hospital
Optimizing Hospital Experience

NIH
Academia
Private

Payer

OREGON HEALTH & SCIENCE UNIVERSITY
Stanford University
Thank you

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