Chronic Pain Patients Use of Self Care: Associations with Health Care Services and Patient / Provider Perspectives

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Background

- Chronic pain affects at least 116 million Americans at a cost of $50–635 billion
- 2011 Institute of Medicine and Dept of Defense/VAMC reports recommend self-management and primary care for treatment of chronic pain
- Participation in structured self-management programs improves functioning and pain outcomes; far less known about what patients are using on their own and the impact this may have
Key Study Questions Examined

- What self-care practices are patients using to manage chronic pain? How are active and provider-dependent self-care practices related to one another?
- How does the use of self-care for chronic pain affect utilization of health services?
- What are patient and health care provider attitudes about use of self-care practices for managing chronic pain?
Context and Setting

- Focus here on substudies of larger observational study of chronic musculoskeletal pain patients examining clinical and cost outcomes associated with use of CAM services in everyday practice environments.
Context and Setting

- Large Non-Profit HMO in Pacific Northwest
  - Availability of comprehensive electronic medical record (EMR) thus able to examine service use directly rather than rely on claims data
  - Extensive history of CAM integration (Washington State’s 1998 “All Providers” legislation)
  - Integrated care system allows understanding of sampling frame

- Combined use of modalities
  - Survey, EMR, and qualitative data used to examine correspondence of reported pain self-management practices, health service use patterns, and attitudes towards self-care of health care providers and patients
Relief Study

**RELIEF – Study Phases, Procedures and Chronic Musculoskeletal Pain (CMP) Participant Flow**

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  - HMO CMP patients (2000-2010)
  - electronic medical records (EMR) only
  - **Aim 1:**
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Substudy #1 - Methods

- **Survey**
  - All HMO members whose health care utilization patterns from 2006-2010 suggested diagnosis of chronic musculoskeletal pain invited to complete survey (online, mail, interview assisted)
  - Survey responses collected January thru May of 2011

- **Health Service Use thru Electronic Medical Medical Record**
  - Examined characteristics of respondents vs. non-respondents
  - Examined 2011 health service utilization patterns
Survey Administration

49,426 Brochures Mailed

10,398 Survey Responses

8,401 Reported CMP

7,223 Reported Self Care

Dear Kaiser Permanente Member:

Please tell us about your experiences with practices and treatments you have used to manage your chronic pain.

Many people who suffer from chronic pain believe that some treatments or therapies are effective for managing their pain. The Kaiser Permanente Center for Health Research recently conducted a survey of patients with chronic pain to learn more about what methods are used and effective. The survey was completed by a random sample of Kaiser Permanente members and included questions about the effectiveness of different treatments.

You may have received a survey booklet from the Kaiser Permanente Center for Health Research. If so, please complete and return the survey. The survey took about 10 minutes to complete. The results of the survey will help Kaiser Permanente understand how members manage their chronic pain and what treatments are most effective.

Thank you for taking the time to complete the survey. Your responses are important to us, and we hope you will be able to participate in this research.

Sincerely,

The Kaiser Permanente Center for Health Research

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### Comparisons of Survey Responders and Non-responders (EMR data)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Responders (N=9,935)</th>
<th>Non-Responders (N=39,491)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age – mean (st dev)</td>
<td>64.5 (14.0)</td>
<td>55.2 (17.9)</td>
</tr>
<tr>
<td>Female- %</td>
<td>6805 (68.5%)</td>
<td>24682 (62.5%)</td>
</tr>
<tr>
<td>White - %</td>
<td>9299 (93.6%)</td>
<td>32778 (83.0%)</td>
</tr>
<tr>
<td>Hispanic - %</td>
<td>229 (2.3%)</td>
<td>1896 (4.8%)</td>
</tr>
<tr>
<td>Pain type - %</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Osteoarthritis, Joint pain, Limb pain</td>
<td>9736 (98.0%)</td>
<td>37832 (95.8%)</td>
</tr>
<tr>
<td>Fibromyalgia, non-specific pain</td>
<td>4491 (45.2%)</td>
<td>16191 (41.0%)</td>
</tr>
<tr>
<td>Back pain, neck pain</td>
<td>8862 (89.2%)</td>
<td>34950 (88.5%)</td>
</tr>
<tr>
<td>Tension headache, TMD</td>
<td>4173 (42.0%)</td>
<td>18679 (47.3%)</td>
</tr>
<tr>
<td>Carpel tunnel, Other CMP</td>
<td>4481 (45.1%)</td>
<td>16547 (41.9%)</td>
</tr>
<tr>
<td>Mean # pain types</td>
<td>1.64 (1.07)</td>
<td>1.53 (1.10)</td>
</tr>
<tr>
<td>Comorbid MH diagnosis - %</td>
<td>4491 (45.2%)</td>
<td>21365 (54.1%)</td>
</tr>
<tr>
<td>Charlson Score – mean (st dev)</td>
<td>0.63 (1.12)</td>
<td>0.55 (1.13)</td>
</tr>
<tr>
<td>On Long-term Opiate Treatment - %</td>
<td>2365 (23.8%)</td>
<td>9754 (24.7%)</td>
</tr>
</tbody>
</table>
## Reported Self Care Practices (Survey responses)

<table>
<thead>
<tr>
<th>Type of Self Care</th>
<th>N (%) Using for chronic pain</th>
</tr>
</thead>
<tbody>
<tr>
<td>Any</td>
<td>7,223 (85.1%)</td>
</tr>
<tr>
<td>Active</td>
<td></td>
</tr>
<tr>
<td>Regular physical activity</td>
<td>5,446 (64.1%)</td>
</tr>
<tr>
<td>Movement practices (yoga/tai chi/qi gong)</td>
<td>2,244 (26.4%)</td>
</tr>
<tr>
<td>Nutritional supplements/herbs</td>
<td>3,753 (44.2%)</td>
</tr>
<tr>
<td>Meditation/mindfulness</td>
<td>2,171 (25.6%)</td>
</tr>
<tr>
<td>Special dietary practices</td>
<td>2,801 (33.0%)</td>
</tr>
<tr>
<td>Provider-dependent</td>
<td></td>
</tr>
<tr>
<td>Chiropractic</td>
<td>3,949 (46.5%)</td>
</tr>
<tr>
<td>Acupuncture</td>
<td>2,673 (31.5%)</td>
</tr>
<tr>
<td>Massage</td>
<td>4,156 (48.9%)</td>
</tr>
</tbody>
</table>
## Characteristics of Self Care Users
(Survey responses)

<table>
<thead>
<tr>
<th></th>
<th>No (N=3,256)</th>
<th>Yes (N=5,235)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Use of Active Self Care</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age- mean (st dev)</td>
<td>66.4 (14.0)</td>
<td>61.8 (13.4)</td>
</tr>
<tr>
<td>Female- %</td>
<td>1,918 (58.9%)</td>
<td>3,755 (71.7%)</td>
</tr>
<tr>
<td>White- %</td>
<td>2,795 (85.8%)</td>
<td>4,854 (92.7%)</td>
</tr>
<tr>
<td>Hispanic or Latino- %</td>
<td>58 (1.8%)</td>
<td>126 (2.4%)</td>
</tr>
<tr>
<td>&gt; Some College- %</td>
<td>1912 (58.7%)</td>
<td>4106 (78.4%)</td>
</tr>
<tr>
<td><strong>Pain Type- %</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Back &amp; Neck Pain</td>
<td>2,232 (68.6%)</td>
<td>3,749 (71.6%)</td>
</tr>
<tr>
<td>Headache &amp; TMD Pain</td>
<td>604 (18.6%)</td>
<td>1,238 (23.6%)</td>
</tr>
<tr>
<td><strong>Osteoarthritis/Joint/ Extremity Pain</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Muscle Pain</td>
<td>766 (23.5%)</td>
<td>1,723 (32.9%)</td>
</tr>
<tr>
<td>Fibromyalgia</td>
<td>279 (8.6%)</td>
<td>842 (16.1%)</td>
</tr>
<tr>
<td>Other Pain (RA, Neuropathy)</td>
<td>559 (17.2%)</td>
<td>1,091 (20.8%)</td>
</tr>
<tr>
<td>Mean # Pain Conditions</td>
<td>2.09 (1.20)</td>
<td>2.54 (1.30)</td>
</tr>
</tbody>
</table>

*all significant at p < .0001
# Utilization of pain and general health services

<table>
<thead>
<tr>
<th>(EMR data in column)</th>
<th>Use of Active Self Care (per survey)</th>
<th>P-Value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No (N=3,256)</td>
<td>Yes (N=5,235)</td>
</tr>
<tr>
<td>Emergency Room Visits</td>
<td>0.38 (0.8)</td>
<td>0.34 (1.0)</td>
</tr>
<tr>
<td>Primary Care Visits</td>
<td>3.44 (3.4)</td>
<td>3.33 (2.8)</td>
</tr>
<tr>
<td>Physical Therapy Visits</td>
<td>1.15 (3.0)</td>
<td>1.49 (3.4)</td>
</tr>
<tr>
<td>Telephone Visits</td>
<td>3.62 (4.2)</td>
<td>3.51 (4.7)</td>
</tr>
<tr>
<td>Email Visits</td>
<td>2.28 (4.8)</td>
<td>3.27 (5.8)</td>
</tr>
<tr>
<td>Days Opiate Supplied</td>
<td>95.87 (174.5)</td>
<td>111.9 (195.8)</td>
</tr>
<tr>
<td>Patient Morbidity Index (Charison Score)</td>
<td>0.56 (1.14)</td>
<td>0.57 (1.06)</td>
</tr>
</tbody>
</table>
### Active vs. Provider-dependent Self-Care

<table>
<thead>
<tr>
<th>Provider-dependent Self Care</th>
<th>Active Self Care</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>5,176 (61%)</td>
<td>917 (11%)</td>
</tr>
<tr>
<td>No</td>
<td>1,633 (19%)</td>
<td>765 (9%)</td>
</tr>
</tbody>
</table>

Active self care = physical activity, dietary practices, and stress reduction

Provider-dependent self care = acupuncture, chiropractic care, and massage

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Substudy #2 Methods

- Qualitative substudy exploring patients’ and health care providers’ attitudes and practices on pain treatment and self care, we interviewed:
  - 90 Patients with chronic musculoskeletal pain (11 focus groups and 10 individual interviews)
  - 25 Primary care providers
  - 13 physical medicine specialists (9 physiatrists & physical therapists; 4 nurses and social workers from pain clinic)
  - 20 CAM providers (6 health plan providers w/integrated practices; 8 acupuncturists; 6 chiropractors)
Key Themes and Representative Quotes: Primary Care Providers

- Limited tools to help their patients with chronic pain.
  - “Patient expectations are a problem. But the hardest patients are the patients who think that I can fix them, and patients who will not be a partner, or have a hard time accepting that they need to work on fixing this. Our modality of treatments are really limited.”

- “[patients say] don’t tell me to fix myself, you fix me, you’re my provider… It’s difficult to tell them I’ve done all I know how to do.”
...but appreciate of the role of self-care

- “You’re not going to get a 50-year old woman who’s 300 lbs and in poverty into a yoga class... so this whole just do some yoga and take care of yourself and eat healthy... all that is really important and I know why that’s important and the patient already knows why that’s important. But to get there is such a long journey in their minds, that I just try to work on the little pieces. So things like eat one vegetable today, or buy a vitamin at Costco where it’s really cheap... or help them sleep.”

- I really tend to advocate more for physical therapy to sort of undo the bad habits of ergonomics and/or stress. And patients don’t always like that...if it sounds easy it’s probably not going to be successful.”
Key Themes and Representative Quotes: Physical Medicine Specialists

- Strong focus on importance of active self-care
  - "I think there are benefits to massage stuff [but] it’s not empowering that person. It’s just another passive treatment that they can rely on, versus taking ownership of it”
  - "they need to show me that they’re going to… be compliant with what I’m asking them to do at home and when they are then you kind of earn your table time” (physical therapist)
…also emphasized active self-care

“A lot of times we have chronic pain because you’re weak and stiff. You haven’t used yourself in, I don’t know, twenty years. And so, you know, everything is weak and stiff. And so, yeah, I [patient] can’t get rid of the pain. But you go out and rake some leaves, because that’s what you used to do and then the pain comes back and you blame, oh wow, the drugs didn’t work. Or the acupuncture dind’t work. It isn’t. It’s the simple fact that you are really weak, really stiff, very deconditioned. And before you can get to do anything you have to go and retrain yourself. Just like an athlete, got to get strong and flexible and function, and then you’ll be fine.”
• …and collaborating with the practitioners that can best guide this

• “Doing good physical therapy is actually much harder than doing good acupuncture. You have to be intuitive almost, because you are now trying to help a person whose margins are very narrow. You sit around and do nothing all day, you’re never going to get well. You do too much, you’re going to hurt yourself and that’s counterproductive. So you have this little narrow band that you are in. And people with chronic pain, that band almost touches. But you still have to get in there and sort of pry this apart so they can begin that process of regaining function, right? And that’s where I have my physical therapy people do their magic. They seem to be able to pry those two bands apart.”
Key Themes and Representative Quotes: Acupuncturists

- …and sometimes appear more comfortable with their limitations than PCPs

  “The most important thing, is the initial connection you make with the patient. That connection is critical, because that patient needs to know they have, number one, hope. I sell hope here. I hate to admit this, but that is one thing that Western medicine does really badly.”
Key Themes and Representative Quotes: Patients

- ...know active self-care is important but also reported real world barriers
  - “[My chiropractor] was very instructive about what to do after he …put the body back in place. …You have to do certain exercises to keep those muscles from spasms again. Walking, exercising, different things like that, health-wise, looking at the whole body.”
  - “Because I’ve had so many different injuries, the number one remedy that would help me would be change jobs. And I’ve heard that from everybody. But I’m sorry. You know, at thirty-one bucks an hour, I ain’t changing crap!”
Conclusions / Implications of Findings...

- Pain patients most often use both provider-directed and active self care, helping them to use in most adaptive combination may be key

- Patients reporting use of active self care used primary care and emergency services less frequently yet these patients showed higher use of specific health services for pain (PT, opiates)

- Widespread agreement across various types of practitioners and pain patients on importance of active self care, yet
  - Patients need guidance in such activities and report barriers
  - CAM providers appear more comfortable than PCPs with the limitations of what they can provide directly for pain relief
Acknowledgements

- Project Principal Investigator
  - Lynn DeBar, PhD MPH

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  - Cheryl Ritenbaugh, PhD MPH
  - Charles Elder, MD
  - Rick Deyo, MD
  - Mikel Aickin, PhD

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  - Jennifer Webster, MS
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