SELF-MANAGEMENT OF CHRONIC PAIN: TREATMENT STRATEGY OR OUTCOME?

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OUTLINE

• **Thesis:** self-management is a goal (outcome) as well as a means (treatment strategy) in chronic pain care.

Pain intensity reduction is neither sufficient nor necessary for success in chronic pain care.

• **Example:** self-management as alternative to long-term opioid therapy for chronic pain - NIDA-funded Pilot Randomized Trial of Opioid Taper Support

  • **Why would patients abandon opioid therapy for “no treatment at all?”**
OUTLINE (CON’T)

• IOM Pain Report: self-management is important, inescapable, essential foundation

• Self-management of chronic pain:
  • dissemination is an unsolved clinical problem
  • as a means and end of chronic pain treatment

• Turning to self-management: importance, confidence, grieving

• Self-management: management of illness, pain, or self?
PILOT RANDOMIZED TRIAL OF OPIOID TAPER SUPPORT

• **Need:**

1. risks of long-term opioid therapy
2. doubts about efficacy of long-term opioid therapy
3. patient ambivalence about long-term opioid therapy
4. >90% failure rate for patients with opioid use disorder
5. **Self-care is the foundation for effective chronic non-cancer pain care**
PILOT RANDOMIZED TRIAL OF OPIOID TAPER SUPPORT

• Rationale for focus on psychiatric & psychological support:

1. Fear of pain more important than pain itself in maintaining opioid use; pain levels do not increase when opioids tapered as part of multidisciplinary pain rehabilitation programs.

2. Preventing all opioid withdrawal symptoms not as important as addressing psychiatric disorders underlying opioid use and lack of pain self-management skills.

3. Taper using the opioids patient is taking, first long-acting then short-acting (to allow patients a sense of control).
PILOT RANDOMIZED TRIAL OF OPIOID TAPER SUPPORT-- DESIGN

• Co-investigators: Judith Turner PhD, Kari Stephens PhD, Ya-Fen Chan PhD, Angela Roof PA, Rachel Kramer BA

• Sample (N=50):
  • Pain Center patients on at least 50mg MED daily for chronic pain
  • without current substance abuse (nicotine, cannabis excepted)
  • who are interested in tapering opioids at least 50%

• Recruitment:
  • Screen for prescription opioid difficulties, provider referrals
  • Engagement: video testimonials, motivational interviewing

• Control: Unrestricted usual care (no buprenorphine)
PILOT RANDOMIZED TRIAL OF OPIOID TAPER SUPPORT-- DESIGN

• **Intervention:**
  - Motivational interviewing, video patient testimonials
  - Psychiatric consult (psychopharmacology, anticipated taper challenges)
  - 22 weekly taper visits with physician’s assistant
    - Taper 10% of original dose per week until reach 30% of original dose, then taper by 10% of this dose
    - CBT-derived self-management training by manual
  - **Primary Outcome:** opioid daily dose achieved at 22 and 34 weeks, adjusted for starting dose
PILOT RANDOMIZED TRIAL OF OPIOID TAPER SUPPORT – PREDICTORS

• Potential predictors of outcome
  • History of substance abuse, current nicotine or cannabis
  • Depression, anxiety, PTSD, insomnia
  • Opioid dose/duration, concurrent sedatives
  • Pain type, sites, severity, interference
  • Pain self-efficacy, taper importance/confidence/readiness, taper goals
  • Treatment adherence, perceived helpfulness of treatment

• Pilot trial is not powered to examine these predictors
• Recommendation 3-1. Promote and enable self-management of pain. Health care provider organizations should take the lead in developing educational approaches and materials for people with pain and their families that promote and enable self-management. These materials should include information about the nature of pain; ways to use self-help strategies to prevent, cope with, and reduce pain; and the benefits, risks, and costs of various pain management options. p. 24
For many such individuals, pain management on a daily basis takes place outside any health care setting. They must respond to and attempt to control their own pain while they are at home, at work or school, or in their communities as they go about their lives as actively as they can, or think they can. From that vantage point, the assistance provided by health professionals is largely a matter of guiding, coaching, and facilitating self-management. p. 114
IOM REPORT ON RELIEVING PAIN IN AMERICA

PAIN CARE BEGINS WITH PAIN SELF-MANAGEMENT

- self-management, perhaps in consultation with family and friends — whose prior experience and knowledge, whether accurate or not, will play a key role — but with little systematic guidance or intervention from a clinician; p. 116

- CHRONIC PAIN CARE ALSO ENDS WITH SELF-MANAGEMENT
SELF-MANAGEMENT IS ITSELF AN END — IN 3 SENSES

1. It is the **final phase of care** for an illness that has no cure.

2. It is not simply a **means** to pain relief.
   - It may be judged adequate by the patient without achieving any particular level of pain relief (e.g., 30%)

3. It is **itself a valuable and essential goal**
   - as a form of patient empowerment
DISSEMINATING SELF-CARE OF CHRONIC PAIN IS AN UNSOLVED PROBLEM

- Cognitive-Behavioral Therapy for chronic pain
  - 42 RCTs showing CBT superior to active controls on disability and pain catastrophizing at post-treatment, but not pain or mood, and many benefits do not persist (Williams, 2012)
  - Access to CBT is limited due to costs/insurance coverage, access to trained therapists, patient resistance. Some success at utilizing clinician-guided internet-delivered CBT (Dear, 2013)
DISSEMINATING SELF-CARE OF CHRONIC PAIN IS AN UNSOLVED PROBLEM

- **Chronic Illness Self-management Groups**
  - Many successful randomized trials of lay led group programs, including internet delivered programs (Lorig, 2001), but took volunteers
  - Implemented in UK as Expert Patient Programme where 4 RCTs show increased self-efficacy, but not improved health or decreased costs--which have been achieved by professional led disease-specific rehabilitation programs (Griffiths, 2007; Vadiiee, 2012)
INTEGRATING SELF-CARE OF CHRONIC PAIN INTO PRIMARY CARE IS AN UNSOLVED PROBLEM

• Chronic Care Model Critique of Expert Patient Programme: teaching patients self care skills is unlikely sufficient for effective self care:
  • “self-management support can’t begin and end with a class.”

• Chronic Care Model engages patient, practitioner, and healthcare organization in self-care effort. (e.g, diabetes, Schiotz, 2012)
  • improved collaboration and integration between providers
  • integrated health information technology system
  • ongoing training of healthcare professionals.
  • broader evidence base re: patient-professional interactions.
INTEGRATING SELF-CARE OF CHRONIC PAIN INTO PRIMARY CARE IS AN UNSOLVED PROBLEM

• Health care professionals need more than CBT training to provide effective support for self-care.

• They need to rethink their role, including tensions between patient autonomy, professional responsibility, and delivering evidence-based care. Supporting self-care often takes them beyond their professional comfort zone.
SELF-CARE PREREQUISITES: IMPORTANCE AND CONFIDENCE

Perceived Importance
Beliefs regarding
cost/benefit ratio
Learning history
Current contingencies

Self-Efficacy
Personal experience
Modeling
Verbal Persuasion
Perceived barriers

Readiness to change
(or maintain) self-management behaviors

Self-Management Behaviors (Coping)
- Exercise
- Pacing
- Relaxation
- Assertiveness
- Task persistence
- Body mechanics
- Positive self-statements
- Ignoring pain
- Avoid asking for assistance
- Avoid guarding
- Avoid catastrophizing
- Avoid pain contingent rest
- Avoid pain contingent analgesics

BARRIERS TO CHRONIC PAIN SELF-CARE FROM WITHIN PROFESSIONAL MEDICINE

- Pain care can undermine self-care by reducing its importance
  - If a surgical cure or effective long-term opioid therapy is available, why bother with self-care?
BARRIERS TO CHRONIC PAIN SELF-CARE FROM WITHIN PATIENTS’ EXPERIENCE

- Pain care can undermine self-care by ignoring barriers to patient confidence

- Chronic pain is a barrier to self-management of other chronic illnesses:
  - Diabetes (Krein, 2005), Depression (Thielke, 2007), Anxiety (Roy-Byrne, 2013)

- But opioid treatment of chronic pain appears to undermine self-care (Braden, 2012)
BARRIERS TO CHRONIC PAIN SELF-CARE FROM WITHIN PATIENTS’ EXPERIENCE

- Lack of self-efficacy
  - depression, catastrophizing, fear of movement
- Lack of skills for self-care
  - exercise, relaxation, pain flare-up plan, goal setting, pacing
- Skills training must be accomplished skillfully:
  - Legitimize the person's own self-management strategies.
  - Must be timely, according to illness career and condition
  - Make compatible with the pre-existing use of services
- Motivations for self-care must be internalized by patient
PATIENTS WHO REJECT PAIN SELF-MANAGEMENT

“I need to get my pain under control before I can do what you are asking me to do.”

THANKS TO BECCA TAYLOR, RN, PHD
PATIENTS WHO ACCEPT PAIN SELF-MANAGEMENT

“I realize that its not going to get better, and I have to figure out what I am going to do.”
BETWEEN REJECTION AND ACCEPTANCE OF PAIN SELF-MANAGEMENT LIES GRIEVING

Denial
• “I am not going back to work until this back pain is gone.”

Anger
• “I do not deserve this awful pain in my neck.”

Bargaining
• “If you give me some more oxycodone, then I can go to PT.”

Depression
• “This pain is never going to get better, I can’t do anything fun.”

Acceptance
• “Even if I hurt, I still like taking care of my grandchildren.”
DIABETES SELF-MANAGEMENT AS A MODEL: AADE7: AM. ASSOC. OF DIABETES EDUCATORS
7 SELF-CARE BEHAVIORS

- Healthy eating
- Being active
- Monitoring ➔ not pain level, but progress toward life goals
- Taking medication ➔ less focus on taking medication
- Problem solving ➔ self-care coping plan for pain flare-ups
- Reducing risks ➔ no risky tx with only short-term benefit
- Healthy coping ➔ keep fun alive, stay connected, self-compassion
IS SELF-MANAGEMENT OF CHRONIC PAIN CARE OF ILLNESS, PAIN, OR SELF?

- Self-care involves management of the self as well as management of the illness
  - Management not only of illness, or its symptoms, but of one’s relationship with symptoms
  - More obvious in Acceptance and Commitment Therapy (ACT) than in CBT, acceptance is more obviously self-directed than correction of cognitive distortions concerning pain or illness
  - Mindfulness (MBSR) specifically rejects attempts to control or avoid pain and suffering
IS SELF-MANAGEMENT OF CHRONIC PAIN CARE OF PAIN OR CARE OF SELF?

• Recent meta-analysis of 22 controlled studies of ACT and MBSR totaling 1235 patients with chronic pain revealed an effect size on pain of 0.37 and an effect on depression of 0.32. (Veehof, 2011)
  • This reduction in pain is achieved through therapies that specifically reject efforts to reduce pain intensity.
• A study of 508 persons with MD, MS, PPS, SCI showed that pain acceptance more strongly predicted outcomes than pain intensity. (Kratz, 2013)
  • Activity engagement predicted lower pain interference and depression, and greater quality of life and social role satisfaction.
  • Pain willingness predicted less pain interference and depression.
IS SELF-CARE
CARE OF ILLNESS OR CARE OF SELF?

• Patients want to return to their former lives and resist the suggestion that they cannot

• Healing in chronic pain is not so much recovery as re-invention of oneself (Reynolds Price, A Whole New Life).

• This re-invention is possible through a grief process:

  “The kindest thing anyone could have done for me, once I’d finished 5 weeks’ radiation, would have been to look me square in the eye and say this clearly, ‘Reynolds Price is dead. Who will you be now? Who can you be and how can you get there, double time?’ “
PRESENTATIONS TO FOLLOW

Emeran Mayer, UCLA
Neurobiological Mechanisms Underlying Effectiveness of CBT in IBS Patients

Magdalena Naylor, MD, PhD
Can Integrated Pain Management Strategies of CBT and Relapse Prevention Alter CNS Function and Structure?

Stephen Wegener, PhD
Patient Utilization of Pain Self-Management Strategies
CONCLUSIONS:
SELF-CARE AS GOAL FOR CHRONIC PAIN CARE

- Chronic illness changes the nature & role of self-care more than initially apparent
  - Inescapable, no finish, not just a means, valuable in itself
- There is now conflict between specialty medical pain care & self-care
  - Specialty medical pain care tries to rescue patients from chronic pain, but often provides little long-term benefit (surgery, pumps, stimulators, blocks, opioids)
  - Multidisciplinary pain care strived to foster pain self care, but has largely disappeared
    - Tied to academic, tertiary care medical settings
    - Multiple doctoral-level practitioners: expensive, not portable
CONCLUSIONS: OPPORTUNITIES FOR SELF-CARE

• ‘Opioid epidemic’ has rekindled interest in therapies with less adverse effects and more long-term benefits, such as self-management.

• With the re-invention of primary care as Patient-Centered Medical Home and Accountable Care Organizations, new opportunities exist to implement chronic pain self-care in the primary care setting using the Chronic Care Model.
IT IS NOT DEATH OR PAIN THAT IS TO BE DREADED, BUT THE FEAR OF PAIN OR DEATH.

EPICETUS