Patient Chronic Pain Education: Taking self-management from the classroom to the clinic

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VISN 20

• Significant investment in provider and patient education since 2006
• Cynthia Joe, MD
  – Chair, VISN 20 Pain Committee
• Provider education module 2008; 2012
• Patient Education module 2012
Overview

- Assumptions and definitions
- Why is patient education important?
- Where do patients learn about chronic pain? What are they learning?
- What do patients NEED to learn about pain? How can we teach them?
- National strategies in patient education
- VISN 20 educational “intervention”
Educational Problem

• Our most “difficult pain patients” respond poorly to educational efforts
  – The overwhelmed and the overwhelming refuse to engage in self-management
  – Unmotivated: don’t want to help themselves
  – Secondary gain: compensation, drugs, etc.
Educational Solution

• “Education” is an ongoing clinical process
• Every prescription, referral, or treatment we attempt… or refuse… teaches the methods, goals, outcomes, and responsibilities
• Recognizing the conflict between what we teach the patient in the classroom and what they learn from us in the clinic
Key Assumptions

• Chronic pain is a lifelong condition which is not "curable"

• Treatment goals are functional; self-management is essential

• Patient beliefs and expectations regarding pain and its treatment are major determinants of treatment outcomes

• Clinical decision-making is the result of the interaction of patient and provider beliefs
Chronic Pain Experience

• Chronic pain is best understood as a process that evolves over time

• The chronic pain experience results from the entire progression of the patient’s illness, the sociocultural context in which it occurs, and the interactions between health care professionals and patients

Key Distinction

• “Simple” chronic pain responds to standard treatments
  – Pt. is generally functional
  – Interactions are mutually satisfying

• “Complex” chronic pain does not respond to standard treatments...including education
  – Syndrome across all painful conditions
  – Declining function over time in spite of progressively more aggressive, expensive, and risky medical treatments
  – Hx “enigmatic” presentations to multiple providers
  – Mutually unpleasant interactions
Why is education important?

  - Proposed radical changes to the pt-provider relationship in primary care management of chronic illness
  
  “informed, activated patients interact with prepared, proactive practice teams”
Why is education important?

• Bodenheimer and colleagues (2002) JAMA series: “chronic care model”
  – Traditional care: providers as experts, patients as passive recipients of care
  – Chronic care model: provider as consultant offering guidance and support to patient who functions as his/her own principal caregiver with regard to chronic condition
Why is education important?

• Self-management is the core of the chronic care model
• Inevitable in all chronic illness
• Day-to-day decisions about medications, lifestyle, exercise, managing stress, compliance, etc., that have significant influence on health and functioning
Why is education important?

• Responsible for creating and maintaining new life roles and coping with their emotional reactions to their conditions

• Patients share responsibilities for outcomes
Why is education important?

- Structural initiatives: Medical home, PACT
- “Patient-centered care”, “collaborative care”, “shared decision-making”
- Assume well-educated patients will make more rational decisions about their treatment, self-management, etc.
Why is education important?

• Particularly important with chronic pain where misinformed patients
  – May expose themselves to undue risks
    • Surgeries, invasive procedures, high-dose opioids
  – Drive up health care costs with unreasonable demands
    • Unnecessary tests and referrals
Why is education important?

- Chronic pain and patient education
  - Coping, self-management, and pain management skills training has been recognized as a key component of multidisciplinary care for decades
Why is education important?

• Increased attention within VA system
  – VHA National Pain Directive 2009-053
    • One specific objective is to include patients and families as active participants in pain management
    • Consistent with recommendations of JCAHO, professional organizations, and advocacy groups

• Increased national attention
  2010 Army Pain Management Task Force
  – 2011 IOM report
Useful Distinction

• Education
  – information and knowledge base
  – necessary but not sufficient

• Training
  – skills building

• Learning: life experiences
  Often conflict with what we are trying to teach
• Where do patients learn about pain?

• What are they learning?
Sources of pain learning

- Where do patients learn about pain?
  - Own experience
  - Friends and family
  - Society and media
  - Internet
  - Interactions with provider
Sources: own experience

• Everyone has experience with acute pain
• Acute pain and chronic pain “feel” the same
• Pain is an “emergency signal”
  – Symptom of an underlying problem
  – Injury or disease
• Go to the doctor
  – Find the cause...get a treatment...fix the pain
• Patient is passive and helpless
• Doctor is active and responsible for outcomes
Sources: Family and friends

• Initial response is with sympathy, support, advice
• Chronic pain: relationships become complicated
  – Family of origin: illness and help-seeking models
  – Current family dynamics
• Advice may conflict with rational treatment
  – My uncle’s neighbor’s mailman had the same back problem and they fixed it with a surgery
  – Go get another...and another...and another opinion
Sources: Society and the Media

• Medical “miracles” are in the news every day
• If they can put a man on the moon...they certainly can fix my pain
• “ER”; “House” not “The Arthritis Clinic”
Sources: Society and the Media

- Pharmaceuticals are big business
- “A pill for every ill”
Sources: Internet

- Expert ratings of 240 websites
- Overall quality poor; agrees with other studies of health care information on the web
- Most commonly searched keywords: pain, chronic pain, back pain, arthritis, fibromyalgia
Sources: Internet

- Pain: 989,000,000 hits
- Chronic pain: 49,600,000
- Back pain: 435,000,000
- Arthritis: 97,800,000
- Fibromyalgia: 26,400,000
Sources: Internet

- 9 highly rated websites
- WebMD Health
- Two patient advocacy organizations
  - American Pain Foundation
  - American Chronic Pain Association
Source: Health Care Provider

- Vast majority of pain treated in primary care
- Problems are defined
- Solutions are offered
- Goals and Outcome expectations are communicated
- Roles are informed
Source: Health Care Provider

• Most health care providers are very poorly trained in chronic pain
• Trained in biomedical model
• Urgent pain relief is primary goal
• Acute pain strategies make chronic pain worse
Cycle of complex chronic pain

• Hopeful phase
• Share a biomedical model
• Urgent pain relief is the goal
• Standard treatments tried
• Diagnostic tests ordered
• Consultations are made
• Clinical decisions are rational
Hopeful Phase: Cooperation

Patient

Other Problems

Pain

Provider

Other Problems

Pain

Other Problems
Cycle of complex chronic pain

- Doubtful phase
- Tests are negative
- Standard treatments are not working
- Specialist treatments fail
- Patients are returned unchanged and more frustrated
Doubtful Phase: Conflict

Patient

Other Problems

Pain

Provider

Pain

Other Problems

Pain is not the primary problem. 
We conclude we have little to offer.
Cycle of complex chronic pain

- Non-rational phase
- Little to offer: more of same
  - Repeat tests
  - Escalate meds
- Improbable diagnoses
- Refer to more specialists
  - Further escalate meds
  - Consider unproven tx
- Returned to primary care
What has the patient learned?

- Incompetent
- Uncaring
- Withholding treatment because of costs, fear of regulators, etc.
- Keep looking until you find the right doctor
Fundamental problem

• Both pt. and provider share a biomedical model that is inadequate to address the complexities of complex chronic pain
Biomedical model: problematic beliefs

• Pain is the primary problem
• Pain is a symptom of an underlying condition that can be objectively identified
• Medical solutions are possible if pain is “real”
• Provider is the expert responsible for fixing the problem
• Pt. is a helpless victim of a disease or injury
• Patients who are overwhelmed by chronic pain will always choose (false) hope for effortless and complete pain relief over the hard work of self-management and coping
Biomedical Model

- Medical solutions are possible
- Fix the pain...fix life problems
- Promise of cure
- No effort
- No responsibility
Self-management

- No cure; Pain is inevitable misery is optional
- Rehab and coping can be difficult
- Share responsibility
- Must deal with problems other than pain
• What do patients need to learn?
• How can we better teach them?
Biomedical Model

- Doesn’t work for chronic pain
- Insanity: doing the same things over and over again and expecting a different result
- Many short-term solutions create long-term problems
Self-management

- Appropriate goals are long-term, functional
- With effort, practice, and patience life can be better
Facilitate a Truce

- Pain is not the “enemy”
- Goal is not to “kill” the pain
- Goal is to assist pt. in returning to a full, satisfying, productive life... even if they hurt.
Biomedical Model: Pain as Symptom

Nociception → Pain → Suffering Disability
Biopsychosocial Model: Pain as Experience

Nociception → Pain → Suffering → Disability
Pain is the primary problem
Self-management perspective

Pain

Drugs/alcohol

Emotional Problems

Family Problems

Recreational

Financial/Vocational
Self-management perspective

- Pain
- Drugs/alcohol
- Emotional Problems
- Recreational
- Financial/Vocational
- Family Problems
Breaking the cycle

• Reconceptualize the problem

• Redefine helping

• Redefine methods, goals

• Transfer hope from medical solutions to self-management efforts
### Comparing Models of Pain Management

A biopsychosocial approach rewrites rules and expectations about treatment.

<table>
<thead>
<tr>
<th></th>
<th>Biomedical</th>
<th>Biopsychosocial</th>
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</thead>
<tbody>
<tr>
<td>Mind and body relationship</td>
<td>Body and mind separate</td>
<td>Holistic - &quot;Total Person&quot;</td>
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<tr>
<td>Pain defined as...</td>
<td>Symptom</td>
<td>Complex problem</td>
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<tr>
<td>Assessment goal...</td>
<td>Identify cause</td>
<td>Identify effects</td>
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<td>Diagnostic strategy...</td>
<td>High technology</td>
<td>Comprehensive psychosocial</td>
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<td>Treatment goal...</td>
<td>Cure</td>
<td>Restoring function</td>
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<td>Time span...</td>
<td>Short term - pain relief</td>
<td>Long term - reactivation</td>
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<tr>
<td>Provider role...</td>
<td>Expert</td>
<td>Teacher/coach</td>
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<tr>
<td>Patient role...</td>
<td>Passive/helpless</td>
<td>Active/responsible</td>
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<tr>
<td>More appropriate for...</td>
<td>Short-term - pain relief</td>
<td>Long term - reactivation</td>
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Comparing Models of Pain Management

- The biopsychosocial model subsumes the biomedical model.

Although it's useful to compare models, it's important to understand the biopsychosocial model subsumes the biomedical model. All rational and appropriate medical treatments are offered but in a context that recognizes the complexity of the chronic pain experience.
Collaborative self-management

• Full range of medical interventions are employed but in a context that emphasizes the far greater importance of the efforts the patient makes in his or her own long term rehabilitation

• Not effort to convince pt that their pain is “caused” by psychosocial factors

• Not a grim alternative to failed medical treatments
Collaborative self-management

• Supporting the patient as a person while challenging the belief that pain is the primary problem and that medical interventions are the only solution

• Urgent pain relief is not the primary focus of treatment
Collaborative self-management

VEMA Model  Click on each for more information

Validation  more >

Much of our struggle with patients relates to our communication of doubt.

Education  more >

The basis of effective, long-term care is a shared understanding of chronic pain. [ref xx]

Motivation  more >

Patients vary in their willingness to engage in self-management.

Activation  more >

The primary clinical focus is on changing the way patients react to pain.
Collaborative self-management

• Goal is to shift the locus of hopefulness from medical treatments to your patient's own rehabilitation efforts.

• Deemphasizing urgent pain relief and focusing on self-management does not absolve you from all responsibilities. It creates new ones.
Collaborative self-management

• The essential clinical tasks are to:
  – establish a collaborative relationship.
  – shift the patient from a biomedical model to a biopsychosocial model.
  – identify long-term functional goals
  – facilitate self-management.
  – support efforts to address other life problems
Collaborative self-management

• Treatment is a process of educating your patient:
  – Acknowledge and identify problems other than pain.
  – Separate urgent pain relief from suffering and disability.
  – Understand how normal reactions make problems worse.
  – Engage in self-management efforts to address these issues
Collaborative self-management

• Our job is not to “fix” the pain
• Our primary responsibility is to create an environment that facilitates adaptive choices
• Arguing for self-management always results in arguments why it is impossible to change because of pain.
• Patients have a right to remain the same. Educate them about the likely consequences of their decisions.
Current National Projects
National Pain Education Workgroup

• Increasing national and legislative interest in pt. education
• Workgroup formed 1/09 to facilitate access to high quality information
• Strategies
  – Review existing VA and non-VA resources
  – Evaluate web resources
  – Develop partner relationships
• Coordinate with other national committees
• V20 web-based pt. education project
How is education delivered in VA?

• Health Analysis and Information Group Survey
  – 81% of facilities have pain education activities
  – Only 32% have formal pain educational programs
How is education delivered in VA?

• PEWG findings
  – Wide variability in quality
• Small number of high-quality “pain schools” or educational group programs
• Many relied on local handouts or info from government agencies, self-help books, etc.
How is education delivered in VA?

• VA/DoD patient websites have little pain information
  – MyHealtheVet
    Postdeployment.org
How is education delivered in VA?

• Little integration between pain provider and patient education

• Pts and providers are taught different content that may conflict
  – Providers: biomedical approach to evaluation and treatment
  – Patients: biopsychosocial approach to self-management and coping
National VA Patient Education Goals

• Identify or develop standardized, high-quality information

• Provide universal access across VA
  – Accessible at point of contact
  – Convenient for both patients and providers
  – Multiple platforms and media

• Coordinate with content of provider educ.
National VA Patient Education Strategies

• Build national partnerships
  – Private, VA, DoD groups involved in pt. education

• Create internet accessible “toolkits”
  – Educational materials: facilitate useful discussions and promote rational clinical decisions
  – Curricula for “pain schools”, group education, etc

• Develop web-based interactive education
Develop a “toolkit”

• Most typically: list of resources
• PEWG: educational materials to facilitate rational clinical decisions and useful discussions
  – “demedicalize” ; teach biopsychosocial model
  Realistic treatment outcomes
  – Understanding risks and benefits: opioids, interventions
  – Minimize inappropriate utilization
  – Facilitate self-management
Current Status: Projects and Initiatives

• Active partnerships
  – Private: American Chronic Pain Association
  – VA: MyHealtheVet
  – DoD: National Center for Telehealth and Technology (T2)
    • afterdeployment.org
National Partnership: Private

• American Chronic Pain Association
• High quality website: theacpa.org
  – Excellent written materials
• Peer support group training and assistance
  – “move from being a patient to being a person”
• VA pilot programs
  – Seattle, Anchorage
• Facilitated expansion to 10 other sites
## ACPA VIP 2011

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<th>Date</th>
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<td>Muskogee, OK</td>
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National Partnerships: VA

- Partner with National Patient Education office
  - My HealtheVet
  - Web portal for VA
- Several starts/stops as MHV develops strategy and technologies
- Veterans Health Library
  - Soft launch scheduled for April 2012
- Initial pain content: opioids
- Will be available in clinic areas, printable handouts
- Pts can access from home
National Partnerships: VA

• National Post Deployment Integrated Care Initiative
  – Post-Deployment Integrated Care wiki
    evolving, collaborative platform that consolidates the vast knowledge about post-combat care
  – Knowledge repository for pain information

• National VA Pain website
National Partnerships: DoD

• National Center for Telehealth and Technology (T2)
  – Afterdeployment.org
  – T2/VAPSHCS/UW collaboration to develop pain content
  – Pain Library, Pain Self-Assessment, Pain Workshops, Pain Workbook, Personal Pain Stories, and Pain mobile applications

• Information developed will be shared between VA and DoD
VISN 20 Web-based training

• Patients and providers who share a biopsychosocial model of pain will be more likely to form collaborative treatment relationships that result in lasting improvements in patient functioning
VISN 20 Educational Strategy

- Teach similar content from different perspectives
  - Realistic expectations of medical “solutions”
  - Emphasize self-management and long-term functional improvement

- Target of change is the patient-provider interaction
  - Deemphasize urgent pain relief
  - Promote “collaborative self-management”

- Goal: Improve clinical decision-making
  - Promote rational treatment decisions
  - Avoid iatrogenesis
The Educational Process

Provider Education
- Patient’s experience
- Biopsychosocial model
- Formulation
- Communication skills
- Clinical scenarios
- Opiates

Clinical Interaction
- Collaboration
- Realistic Expectations
- Self-management
- Functional goals

Patient Education
- What is pain?
- What your doctor can do for you.
- What you must do for yourself.
- REHAB approach
Living Well with Chronic Pain

Chronic pain is like any chronic health problem.
To live well, change the way you think
about your health care and your life.

The American Chronic Pain Association describes this change as
"Moving from being a patient to being a person."

"Waiting for a medical solution before your life gets better is not
a plan. It's a plea. You must become your own pain expert."
Living Well with Chronic Pain

*Patient* with pain
- Puts life on hold until pain is fixed
- Waiting for a medical solution while life problems get bigger
- Stuck on a medical merry-go-round

*Person* with pain
- Doesn’t wait to be pain-free
- They become more active in their own care
- They understand what doctors can and can’t do for chronic pain

“Waiting for a medical solution before your life gets better is not a plan. It’s a plea. You must become your own pain expert.”
The REHAB Approach

Strategies for living well: The REHAB approach.
Free yourself from chronic pain.

- Redefine the problem and the solutions.
- Expect some pain — but reject disability and suffering.
- Have a plan for bad days.
- Activate, activate, activate.
- Build a healthy and hopeful lifestyle.

"REHAB goals: become independent and live as well as you possibly can."
V20 Patient Education

• Medical solutions are limited. Self-management is essential
• Chronic pain is an unpleasant and stressful but unavoidable part of life
  – False alarm not emergency signal
• Change how you react to change pain experience
  • Cognitive: disabling pain beliefs
  • Emotional: negative emotions “turn up the volume”
  • Physical: relaxation skills
  • Behavioral: “use it or lose it” is true in all areas of life
V20 Patient Education

• Customized content
  – OEF/OIF
  – Current functioning/disability level
  – Specific disabling beliefs
  – Opioid tx preferences and SUD hx

• Customized feedback
  – Pre-post testing report
Educational Hypothesis

• Better educated and supported providers working with better educated and motivated patients will be able to form collaborative treatment relationships that result in lasting improvements in patient functioning
Change the patient’s experience of pain by changing their experience of healthcare
Self-Management Training

Coping with Chronic Pain:
A Guide to Patient Self-Management

Richard W. Hanson
Kenneth E. Gerber

The Guilford Press, 1990