The Experiences of People Living with Chronic Pain While Receiving Opioids To Manage Their Pain in the Primary Care Setting

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Disclosures

○ Nurse Practitioner Healthcare Foundation/Purdue Pharma – Pain Management Award 2013-2014
○ Board of Directors, ASPMN 2013-2015
○ Consultant for CO*RE (REMS project): FDA Blueprint

Background

○ Chronic pain is an epidemic, negatively impacting over 100 million Americans

○ Costing more than heart disease and cancer combined. More than accidents, diabetes, GI tract problems, respiratory diseases combined

Background

- Since 2010, studies show increase in risk of misuse or overdose associated with use of opioids
  (Jena et al., 2014; Dunn et al., 2010; Gomes et al., 2011; Bohnert et al., 2011; Paalzow et al., 2020)
- Overdose death rates in the US more than tripled since 1990 with most deaths caused by prescription medicines

Background

- Positive outcomes from prescription opioid use for pain
  - Restore function
  - Interact with friends and family
  - Give them life back
- Negative outcomes from prescription opioid use for pain
  - Concerns of addiction
  - Losing control
  - Inadequate management of pain
  - Stigma

Opioid Prescribing in the US

- 4.3% of the world’s population
- 83% of the world’s oxycodone
- 99% of the world’s hydrocodone

Rept of International Narcotics Control Board, 2008
Opioid Prescribing in the US

- Between 1997 and 2002
  - Prescriptions for oxycodone increased by 227%
  - Prescriptions for fentanyl increased by 463%

- Between 1997 and 2006
  - Oxycodone sales increased by 8-fold
  - Methadone sales increased by 9-fold

(Saper, 2010)

- In 2009, there were >250 million opioid prescriptions written

**Amount of prescription painkillers sold by state per 10,000 people (2010)**

**Drug overdose death rates by state per 100,000 people (2008)**
Background

- **Chronic Pain**
  - 116 million people
  - $635 billion (Institute of Medicine, 2011)

- **Drug Abuse**
  - 4.5 million – nonmedical use of Rx pain relievers (Substance Abuse and Mental Health Services Administration [SAMHSA], 2012)
  - Costing: $467.7 billion per year (SAMHSA, 2009)

Source Where Pain Relievers Were Obtained for Most Recent Nonmedical Use among Past Year Users Aged 12 or Older: 2011-2012

High Opioid Dose and Overdose Risk

*Overdose defined as death, hospitalization, unconsciousness, or respiratory failure.*
In 2009, 39,147 Americans died from drug poisonings. Nearly 14,800 deaths involved prescription opioids.

For every 1 death there are:
- 10 treatment admissions for abuse
- 32 ED visits for misuse or abuse
- 36 people who abuse or are addicted
- 215 nonmedical users

National Institute of Health
September 29-30, 2014

- What is the long-term effectiveness of opioids?
- What are the safety and harms of opioids in patients with chronic pain?
- What are the effects of different opioid management strategies?
- What is the effectiveness of risk mitigation strategies for opioid treatment?

National Institute of Health
September 29-30, 2014

- What is the long-term effectiveness of opioids? Insufficient evidence
- What are the safety and harms of opioids in patients with chronic pain? Insufficient evidence
- What are the effects of different opioid management strategies? Insufficient evidence
- What is the effectiveness of risk mitigation strategies for opioid treatment? Insufficient evidence
Problem: Challenges to Health Care Providers

- Ambiguity of how to manage patients with coexisting addiction and pain conditions
  - Time consuming
  - Low success rate
  - Undertreating vs. over-prescribing opioids
- Managing pain without furthering addiction

(Berg, et al., 2009; Upshur, et al., 2006; Wilsey, et al., 2008; Baldacchino, et al., 2010)

Challenges in Primary Care

- Barriers of providers in chronic pain management
  - Absence of objective or physiological measures of pain
  - Lack of expertise in pain and addiction
  - Colleague issues
  - Limited insurance coverage for everything except opioids

(Berry, et al., 2010)

Problem: Challenges for Patients

- Addiction
- Stigma
- Pain not well treated

(Campbell & Cramb, 2007; Trafton, et al., 2004)
The “Double Whammy”

- When addiction was out of control, pain was worse.
- When pain was out of control, addiction was worse.
- Each caused mutually reinforcing cascade


Background and Significance

- Primary care providers identified barriers
  - Fear of causing harm
  - Subjectivity of pain
  - Lack of education
  - Problems with opioid conversions
  - Stigma
  - Patient and family concerned about abuse by family and caregivers
  - Chronic nonmalignant pain – frustration

Spitz et al., 2011. BMC Geriatrics, 11:35
Participants’ recommendations to prevent prescription opioid abuse

- “It’s the same pills you help me with that hurt me.” (Dennis)
- Higher level opioids
- Reduce opioids in steps
- Watch pain reduce
- Non-addictive analgesics
- Acupuncture
- Six days
- Relationship
- Support sobriety


Experiences of People Living with Chronic Pain While Receiving Opioids to Manage their Pain in the Primary Care Setting

**Aim of Study**

Examine the narratives of people who experience chronic pain and receive opioids for the treatment of chronic pain through a primary care clinic

**Inclusion Criteria**

- Purposefully selected sample composed (n=12)
  - experienced pain for more than 6 months
  - received opioids for the treatment of pain in a primary care clinic in Midwest metropolitan area
  - willing to tell the story of their experiences
Method

- Narrative Inquiry
  - In-depth interviews
  - 90-minute interviews
  - Described experiences
    - Living with chronic pain and receiving opioids for pain
    - Healthcare experiences
    - Interview guide
- Thematic analysis

Demographics

- Gender = 50-50
- Ethnicity
  - Caucasian = 8
  - African American = 3
  - Hispanic = 1

Demographics

- Education
  - 4 completed college
  - 4 completed some college
  - 4 completed GED
- Addiction history
  - 8 history of Substance Use Disorder
  - 1 no history
  - 3 active use (buy opiates off street)
Demographics

- Pain diagnosis
  - 1 with Deg Joint Disease shoulders from sports
  - 3 with Fibromyalgia (combined with other diagnosis)
  - 4 with headache (combined with other diagnosis)
  - 1 gunshot wound
  - 4 low back pain (combined with other diagnosis)
  - 1 pancreatitis
  - 1 rheumatoid arthritis

Theme:
Difficult to obtain legitimate prescription opioids for pain

- Feeling like primary care doctor not listening to them

- “What makes me mad is just because a person was a addict – it was so hard just to find a doctor to help me with pain”

Theme:
Fears of losing access to opioids for pain

- Participants stated that individuals who misuse their prescription opioids were “wrecking it for those who need it for pain.”

- They reflected that media coverage of people overdosing was why healthcare providers were “cracking down” on prescribing opioids for those with pain.
Theme: Difficult to obtain legitimate prescription opioids for pain

- All participants felt they were mistreated by physician in primary care or emergency room at one time or another.
- “If I’m not getting it from my doctor then I gotta find other ways to get it.”
- “...they understand why I’m doing it, because nobody else is willing to help me. I’m tired of suffering.”

Theme: Protecting their sobriety

- “Won’t use heroin because I’m more scared of that than anything, you know what I’m saying?”
- “I don’t wanna screw up my sobriety. I don’t wanna get addicted. I was very frightened about getting addicted and frightened about craving [from prescription opioids for pain].”

Theme: Low risk or high risk behaviors for misuse of opioids were present

- The investigator interpreted low risk or high risk behaviors based on participants’ descriptions.
- One low risk participant stated, “Ever since I had the pain, I’ve always had my sobriety in the back of my mind.” She set up her own regimented protocol to protect her sobriety.
Theme: Low risk or high risk behaviors for misuse of opioids were present

- The investigator interpreted low risk or high risk behaviors based on participants' descriptions.
- 3 participants described high risk behaviors:
  - Distract his provider’s attention away from his SUD with prescription opioids.
  - Obtaining illicit prescription opioids.

Theme: Non-medicine ways of managing pain

- Massage
- Physical therapy
- Walking dogs
- Changing their diet to healthy food
- Exercise and stretching on their own
- Distraction by working at their jobs
- Background noise
- Sitting and walking with good posture
- Swimming, fishing, meditation

Advice from Participants for Others

- “You can’t just treat yourself with drugs.”
- Keeping company with healthy people, “If you hang with people that use, you’re a user.”
- Healthy mind - counseling, meditation
- Developed protocol for medication taking
Theme: Healthcare experiences while seeking relief for their pain

Positive healthcare experience: One participant stated “... because they care, I care.” When they felt confident in healthcare, they experienced less stress, more ability to cope with pain even when pain intensity was high.

Negative healthcare experience: Receiving inconsistent communication about their care, and feeling stigmatized. “… it’s hell being somebody ... [with] drug and alcohol problems, then walk into a doctor and say, ‘I need narcotics’ [for pain], because they do not wanna give them to you.”

One participant went to the emergency room for abdominal pain flare, was told to go to his primary care provider, went to his primary care provider who told him to go the emergency department. In his frustration he went home, drank alcohol, and was admitted to the hospital with acute pancreatitis.

Exemplar narrative:

Trajectory:
- Low back pain, 14 surgeries
- Prescription opioids, tapered
- Reinjured back (Repeated last two steps)
- 200 mg po hydromorphone (Dilaudid)/day, and fentanyl patch
- “prisoner of my own body”
- Intentional overdose ... woke up
- Told family and wanted to live
Exemplar narrative (Cont.)

- Family brought him to family practice physician
- He had patient admitted through ED
- Started opioid drip for the next 4 days, "have as much as you want".
- Discharged to a metropolitan free-standing pain clinic
- Put on 8 oxycodone/day

Exemplar narrative (Cont.)

- Withdrawal symptoms
- Transferred to another pain clinic
- Started on buprenorphine/naloxone (Suboxone) and stabilized
- Had bilateral mastectomies, another back surgery, and hip surgery
- Did fine, until relapse with morphine tablets sent home with him
  - wife found that he did this.
- A couple weeks later, relapsed with ETOH.

Exemplar Narrative Summary

- He gave hints to his physicians
- 3 places had him under contract
  - insurance company, pharmacy, and Primary Care Physician
- No intervention
- Hospitalization for 4 days only
  - had consulting
  - treated his depression
  - no referral to treatment
Exemplar Narrative Summary (cont.)

- What does he tell us are the risks?
  - High volumes and dosages
  - People should not be home with it
  - "I think it will happen to some, I don’t think I’m unique to this…"

- What made him decide to take his own life?
  - "I was afraid of losing the drug... I felt the walls were coming in on me with the doctors... I was running out of ways to approach the smaller refills”

Exemplar Narrative Summary (cont.)

- Design his pain management!
  - Mandatory group therapy, every 3 weeks, as a condition for getting prescription opioids.
  - AA, everyone has one thing in common
  - This mandatory group therapy, everyone would have prescription opioid in common

Monitoring for Emergence of Relapse -Other Primary Care Participants (cues)-

- Usual protocol for analgesic regimen is skipped out of desperation due to pain, by the patient (Ann)
- Self medicating emotional pain
- “Now I feel [pain] throughout the whole back, and that’s like OMG, I just have so much more pain. I just need to take another pill. One’s not doing it. On top of that I’m taking tylenol and over the counter meds. Yeah, I feel that I’m in a way, losing a little bit of control. To be honest, I don’t like that” (Carl)
Chronic Pain and Addiction

- Majority of chronic pain patients on chronic opioid therapy do not develop the disease of addiction

- Opioid misuse behaviors exist on a continuum
  - Misuse is not = the disease of addiction

- Predisposing factors can exist for developing addiction (not reliable indicator)

Pain and Addiction Specialists Working Together

- Use matter-of-fact and unapologetic tone when referring
- Explain importance of assessing factors of each problem of addiction and of pain
- Assure that referral does not mean transfer of care
- Help make the evaluation appointment

Provider Communication 2014

“Since I switched clinics, having a family practice and a pain clinic and they both talk to each other. That has been so helpful... They do case management together. This has been wonderful”
**Patient-Clinician Relationship**

- Critical for patients with coexisting addiction and pain
- They have already felt demeaned and devalue and they anticipate further criticism of substance use and discount of their pain
- They blame themselves
- Respect and concern need to be present
  - Explain that pain and addiction are uninvited chronic illnesses and both need to be treated conscientiously.

**Conclusions**

- This study provided knowledge of the phenomenon of chronic pain when opioids are prescribed to manage the pain from one primary care setting.
- Prescribing opioids long term is complex
  - Some have been helped
  - Some have been hurt

**Chronic Pain and Active Addiction**

- Start addiction treatment
- Defer opioids until begin
- Nonopioid analgesics determined by pain pathology
- Implement non-medicine ways of managing pain
Chronic Pain and in Recovery

- Reconditioning as determined by functional evaluation
- Complementary therapies
- Treatment of comorbidities
- Monitor

Talking with Patients with Chronic Pain

Treatment Improvement Protocol (CSAT-TIP)

- “Opioids are not the centerpiece of your pain treatment”
- “They are not going to give you 100% relief.”
  - On average people with chronic pain only get 40% relief.
- “You will still need to do the other techniques for pain relief”
- “We’ll need to monitor your urine, do pill counts, and make sure only one prescriber.”


Recommendations

- New approaches are needed
  - Patient-centered
  - Evidence-based
- Prevention of prescription opioid abuse
  - Assessment and early intervention
- Management of pain when they have active or past SUD
QUESTIONS??