Living with Pain: A Patient’s Perspective

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It’s not always the tears that measure the pain. Sometimes it’s the smile we fake.
Where are we?

AN HONEST ASSESSMENT
Chronic pain is the most prevalent, costly & disabling U.S. health condition

**PREVALENCE**
- 100 million American adults (NAM, 2011)
- 126 million American adults had some pain in last three months (NHIS, Nahin, 2012)

**COST**
- $560-635 billion annually (NAM, 2011)

**DISABILITY**
- In US: Painful arthritic, back/spine disorders #1 cause of disability (CDC, 2005, 2012)
- Globally: Low back pain, migraine, neck pain & musculoskeletal disorders in the top 10 leading causes of ‘years lived with disability’ in 2016 (Global Burden of Diseases, Injuries, and Risk Factors Study 2016)

**FEDERAL PAIN RESEARCH INVESTMENT**
- <1% of annual cost
Missing from the Conversation

Voices of People with Pain
Where does the public stand?

Most Americans Know Someone Who Sought Pain Medicine

Do you know anyone who experienced pain so severe that they sought prescription medicines to treat it?

- Yes: 63%
- No: 27%
- Not sure: 10%

Source: A ResearchAmerica poll of U.S. adults conducted in partnership with Zogby Analytics in March 2013.
Where does the public stand?

Majority: Chronic Pain Tends to be Dismissed by Doctors, Public

Which statement is closer to your view?

- 60%: Chronic pain tends to be dismissed by doctors and the public
- 16%: Chronic pain is overstated as a health condition
- 24%: Not sure

Source: A Research!America poll of U.S. adults conducted in partnership with Zogby Analytics in March 2013.
Where does the public stand?

MAJOR Disconnect

### Chronic Pain Ranks Below Many Other Conditions as Major Health Problem

Which of the following would you describe as a major health problem in the U.S.? (multiple responses allowed)

<table>
<thead>
<tr>
<th>Condition</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cancer</td>
<td>59%</td>
</tr>
<tr>
<td>Heart disease</td>
<td>52%</td>
</tr>
<tr>
<td>Diabetes</td>
<td>52%</td>
</tr>
<tr>
<td>Drug addiction</td>
<td>47%</td>
</tr>
<tr>
<td>Depression</td>
<td>42%</td>
</tr>
<tr>
<td>Alcoholism</td>
<td>37%</td>
</tr>
<tr>
<td>Alzheimer’s disease</td>
<td>34%</td>
</tr>
<tr>
<td>Chronic pain</td>
<td>18%</td>
</tr>
<tr>
<td>Parkinson’s disease</td>
<td>15%</td>
</tr>
<tr>
<td>Not sure</td>
<td>15%</td>
</tr>
</tbody>
</table>

Source: A Research!America poll of U.S. adults conducted in partnership with Zogby Analytics in March 2013.
#1: Using same word to describe different pain states

“Pain” is used to describe both a symptom and a chronic disorder

“Pain” brief acute warning mechanism

“Pain” transient secondary to cancer, etc.

“Pain” Chronic neurologic disorder in itself

REALLY CONFUSING
Reasons for Public Disconnect – Many & Complex

#2: Specific pain condition vs. “chronic pain” or “chronic pain disorder”

--Umbrella term that encompasses huge number of conditions

- What factors influence self-identification?

arthritis  IBS  migraine
Reasons for Public Disconnect – Many & Complex

#2: Specific pain condition v. “chronic pain”
--Does this distinction exist as a function of time and # of pain diagnoses?

TIME

“I have migraine”  “I have IC”  “I have RA”

.. and so on … 10 years later… 5 diagnoses … multisite pain …

“ I just have chronic pain”

Meaningful to patients?
Reasons for Public Disconnect – Many & Complex

#3: Complexity of the biopsychosocial pain experience

- Age 50, fibromyalgia, fatigue, impaired physical function
- Age 50, fibromyalgia, good psychosocial & physical function
- Age 50, fibromyalgia, sleep disorder, depression & dyscognition
Reasons for Public Disconnect – Many & Complex

#4: Stigma / Personal Biases

Now acceptable to *have* chronic pain ... "WEAK"

but *not to be impacted* by it ...

>PAIN IS WEAKNESS LEAVING THE BODY.

>NO PAIN NO GAIN

>MIND OVER MATTER
Reasons for Public Disconnect – Many & Complex

#5: Criminalization of pain

--Unintended consequence of policies, debate & media stemming from opioid epidemic

--Patients don’t disclose pain condition because of common misconceptions:

1. You take opioids
2. You’re an addict
3. Your main concern is access to opioids
4. You are a drug seeker
5. You are stockpiling medications
6. Or – all of the above (and/or others)

CHRONIC PAIN ≠
OPIOID USER ≠
OPIOID ABUSER
OPIOID MISUSER ≠
NOT DESERVING OF THE BEST, MOST HUMANE & EMPATHIC MEDICAL CARE
Reasons for Public Disconnect – Many & Complex

#5: Criminalization of pain

“Pain medication is inadequate. But with it I am more consistently functional and can minimize being housebound, bedridden, or hospitalized. I can be a responsible homeowner, spouse, parent; I can work as a teacher, a writer, an editor.”

“I’ve never been arrested, found to be out-of-compliance, had a substance-related accident or hospitalization, but increasingly I am a suspect, treated less as a patient and more as a criminal.”

“The feelings of humiliation and degradation don’t fade; they simmer.”

“… abuse of prescription pain medication is a serious problem; people are dying. But a vastly larger group of us are living — in unremitting pain, in the face of which we do the best we can to remain productive and independent, to benefit, rather than burden, our families and society at large. Most of us have accepted ever-more-onerous restrictions, no matter how humiliating — urination on command, guilty-until-proven-innocent — regardless of how they clash with American values and medical ethics.”
One of many tweets circulated after an ad aired for pain-related opioid-induced constipation:

*Bill Maher*  
@billy Maher

Was that really an ad for junkies who can't shit? America, I luv ya but I just can't keep up

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**Computer that determines how much pain a patient is in just by looking at their face could help doctors spot fakers**

- Researchers believe the system will be useful in separating ‘real pain from fake’
- People express pain differently, which makes it hard for doctors to gauge
- The system is personalized by taking into account age, sex and complexion
- Researchers hope the system will one day be available as an app on phones
- Past research suggests computer systems are 30% more effective than humans

By ALEXANDRA THOMPSON HEALTH REPORTER FOR MAILONLINE
PUBLISHED: 10:39 EDT, 4 September 2017 | UPDATED: 10:43 EDT, 4 September 2017

A computer is being developed that rates how much pain someone is in by detecting small changes to their facial expressions.
Public Disconnect – End Result

Is it really that hard to understand why people with pain remain silent?

Pain is when you're slowly dying on the inside and you're way too weak to speak about it so you keep silent and suffer, alone.
Pendulum Swing in the Medical Scientific World

<table>
<thead>
<tr>
<th>No one gets opioids</th>
<th>Everyone gets opioids</th>
</tr>
</thead>
<tbody>
<tr>
<td>Basic science focus - drives all else</td>
<td>Prioritization of translational/clinical</td>
</tr>
<tr>
<td>Biologic measures w/ little-to-no self-report</td>
<td>Prioritization of Patient Reported Outcomes</td>
</tr>
<tr>
<td>Placebo-controlled RCTs</td>
<td>Pragmatic/real world trials</td>
</tr>
<tr>
<td>No patient/stakeholder involvement in research</td>
<td>Patient-driven research &amp; multi-stakeholder networks</td>
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What’s best for patients
Translation?

Are scientific discoveries surviving the valley(s) of death and translating to improved treatment options?
In the interim ....

what’s happening with patients?
Cha·os (noun): complete disorder & confusion

- Shortage of pain specialists
- Primary Care treating chronic pain without education, expertise & time
- No medical home with multimodal coordinated treatment
- The field of chronic pain treatment being “strikingly deficient” in quality evidence to assess benefits and risks (FDA, 2016)
- Well-meaning clinicians left without evidence to guide clinical decision-making
- Experimenting with myriads of treatments, many with unknown benefits & risks
- Profound impact on health and all aspects of quality of life and functioning
IT'S OUR RESPONSIBILITY
Patient Hopes for Research

1. Objective measures of pain

2. Dynamic measures that account for complexity of the chronic pain experience
   - How do you define “improvement?”
   - Does VAS really measure what you think it’s measuring? Does a number matter?
   - How can you incorporate sleep, mood, fatigue, function, etc., into a better, more well-rounded measure?

3. Animal and human models that account for the complexity of the chronic pain experience
   - Multi-system illness involving neurological, endocrine & immune systems
   - Bidirectional impact of non-pain domains on pain (i.e., fatigue, mood, sleep, etc.)

4. Trials that account for complexity & individuality of pain experience
   - What is going to work for me – PMI?
   - Combinations of treatments | Impact of other pain/non-pain conditions
   - Function, QOL & individualized goal setting

5. Reverse Translation & Broad Inclusion
   - Listen to and learn from patients
   - Include patients (and other stakeholders) early and often in the research process
Patients Essential Partners in Research

“…patients bring unique and important perspectives to health care, as well as the ability to spark improvement; both of which are essential to closing important gaps in health system performance and ensuring that care is effective.”

“Unfortunately, patients, families, and caregivers too often are not engaged as meaningful decision makers in their own care or as partners in health research.”

“This shortcoming has been associated with improvements in the effectiveness, safety, and patient experience of care.”

Broad Stakeholder Inclusion

- Patients
- Researchers
- Clinicians
- Industry
- Funders
- Health Systems
- Insurers
- Gov Agencies
- Policy makers

Success
What do patients need?

Hope is being able to see that there is light despite all of the darkness.

Desmond Tutu
“My chronic pain continues to worsen, despite my best efforts and those of my health care providers. Research is one of a few things that still gives me hope. I’m so grateful to pain researchers who devote their todays to making my tomorrow better.”
IT'S OUR RESPONSIBILITY