The Perspective of People with Pain

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www.ChronicPainResearch.org
EPIDEMIC OF CHRONIC ILLNESS
in·vis·i·ble

Source: PainExhibit.org
mis·un·der·stand·ing (noun): 
failure to understand something correctly
STATE OF CONFUSION
“PAIN” : Symptom? Disorder? Both?

... same term used to describe a symptom, secondary condition and a disease state?
“I have chronic pain”

vs.

“I have RA”

“I have IBS”

“I have migraine”

Central component of pain - but also other system-specific symptoms
Comorbidities & Biopsychosocial Experience: Not all “Chronic Pain” Looks the Same

Diabetic Neuropathy
+ Diabetes
+ Obesity
+ Sleep Disorder

FM, IC, Migraine, TMD
+ Cognitive Impairment
+ Sleep Disorder
+ Chronic Fatigue
+ Mood Disorder
+ Sexual Dysfunction
stigmatisation
action of regarding someone as worthy of disgrace or great disapproval

bias
cause to feel or show inclination or prejudice for or against someone
NO PAIN NO GAIN

PAIN IS WEAKNESS LEAVING THE BODY.

THE PAIN you feel today will be THE STRENGTH you feel tomorrow.

MIND OVER MATTER
It’s now become somewhat acceptable to have pain ...

but not to be **WEAK** enough ...

to allow yourself to be impacted by it ...
what you label me
cha•os
a state of utter confusion
a total lack of organization or order

cr•sis
an unstable or crucial time in which
a decisive change is impending

cr•sis
a dramatic emotional or circumstantial
upheaval in a person's life

Insufficient workforce
No team-based medical home
Myriad of heterogenous pain disorders/subtypes
Symptom-based classification
Lack of scientific understanding
Lack of objective measures, markers, diagnostics

Susan: “To live in pain is to live in isolation.”

100 million
$600 billion
#1 Cause Disability Deaths

www.PainExhibit.org
Explosion of Therapies

But ... what works for whom? At what risk? At what cost?

“Unfortunately, the field of chronic pain treatment is strikingly deficient in high-quality scientific evidence.”

Former FDA Commissioner Dr. Robert Califf
NEJM 2016;374:1480-5
Current Treatment of Chronic Pain: “Blindfolded Darts”
May be Good for Team-Building ... but not so much for Personalized Medicine

“Without data, we are just docs with opinions.”
What does pain research mean to patients?
“Some people cannot be cured, but everyone can HEAL.”
~Unknown
Patient Hopes for Pain Research

1. Objective measures, markers, predictors

2. Dynamic outcome measures that account for chronic pain complexity
   - How to define “improvement?”
   - Does VAS measure what we think? Does it really matter?
   - Develop well-rounded measures that incorporate function, QOL, sleep, mood, etc.

3. Animal/human models that account for chronic pain complexity
   - Multi-system illness - neurological, endocrine & immune systems
   - Bidirectional impact of fatigue, mood, sleep, etc. on pain
   - Bidirectional impact of other chronic diseases on pain

4. Trials that account for complexity & individuality of pain experience
   - What is going to work for me – PMI?
   - Impact of pain & non-pain comorbid conditions
   - Effect of treatment combinations (Rx & NonRx)
   - Function, QOL & individualized goal setting

5. Reverse Translation & Broad Inclusion
   - Listen to and learn from patients
   - Include patients (and other stakeholders) early and often
Mutual Value & Respect

Doctor: Don’t confuse your Google search with my 6y at medical school.

Patient: Don’t confuse the 1-hour lecture you had on my condition with my 20y of living with it.

Slide Courtesy of: Dr. Christine Chambers @drcchambers
Knowledge Translation

“\textit{It takes 17 years to turn 14 percent of original research to the benefit of patient care}” *


Include All Stakeholders & Implementation Science Plans Early and Often

Bridge the Translational Divide

Ensure Successful Implementation

Reduce the Knowledge Translation Gap