

A Patient's Perspective
NIH Pain Consortium Symposium
June 1, 2017

Cindy Steinberg
National Director of Policy & Advocacy
U.S. Pain Foundation
Policy Council Chair
Massachusetts Pain Initiative
Leader, Boston-area Pain Support Group
csteinberg@rcn.com



Guide Through My Talk

- My Story
- A Change Agent in an Entrenched System
- A Patient's View of "Multidisciplinary Strategies for Pain Management"
- My Research Wishes
- Thank You's

My Story

- More than 15 years ago, I was crushed in an accident at work where I was a corporate manager
- Opened a file drawer of a very large cabinet
- Unbeknownst to me, moving men stacked cubicle walls against the back of the cabinet
- Cabinet and walls fell on me & pinned me to the ground
- Accident tore & damaged nerves and ligaments in thoracic spine
- Left me with daily band of burning, gnawing pain across mid-back & muscle spasms when upright that never went away
- Pain & spasms can become severe after an hour upright



My Search for Help

- Sought help for excruciating daily pain while holding on to my career
- Surgery not an option
- Tried nerve blocks, injections, PT, OT, Prolotherapy, braces, acupuncture, massage & more
- At best, told by h/c providers can't help you
- At worst, treated in a demeaning, dismissive manner, accused of being a malingerer simply by seeking help for debilitating pain
- Five year journey through h/c system until finally found a doctor who helped me



Roller Coaster of Chronic Pain Treatment: Hope & Disappointment



- Torturous route “roller coaster” of trial & error investing time, money & energy to find a way to lessen the pain
- Research & try treatments, try to stay hopeful—only to have hopes dashed

State of the Art of Pain Treatment Then....and Now



- Doctors blindfolded, trying different treatments in the hopes of hitting the target
- A lot of misses & occasionally something helps

My Search for Connection

- Felt isolated but thought could not be the only one living w/ this much pain
- Hung sign at local library; starting a pain support group
- People started showing up; a few & then more & more
- With a myriad of conditions that result in pain: carpal tunnel, migraines, disc disease, rheumatoid arthritis, cancer, neuropathy, back pain
- Conditions I never heard of: CRPS, EDS, Marfan's, pudendal neuralgia, fibromyalgia, TMJ, vulvadynia, IBS, interstitial cystitis, etc
- Has been 17 years, still going, more than 350 people have been to group



My Boston-area Pain Group



Pain Does Not
Discriminate

Importance of Long-term Support

- Group provides long-term support, education & social connection
- Teach skills for self-management: coping, communication with healthcare professionals, tracking your pain
- Expose members to every possible treatment and therapy through guest speakers and program group research
- Teach practical tips for living with pain
- Discuss psychosocial issues: stages of grief & pain, pain and the family, relationships, self-esteem

Common Experience of Life with Chronic Pain

- Regardless of original etiology, chronic pain becomes *the disease* itself
- Causes changes in the central nervous system, spinal cord and brain that amplify nerve signals, self stimulate & can worsen over time
- Most pain sufferers see at least 4 -5 practitioners before they find help; often dismissed & demeaned
- Pain devastates lives; destroys ability to work, earn a living, sleep, socialize, care for family, pursue interests, find enjoyment in life
- Fundamentally different experience of pain than normal acute pain; can be stabbing, gnawing, burning, knifing, crushing pressure, etc
- Sense of being imprisoned in your body w/no means of escape
- But worse cause imprisoned & tortured 24/7



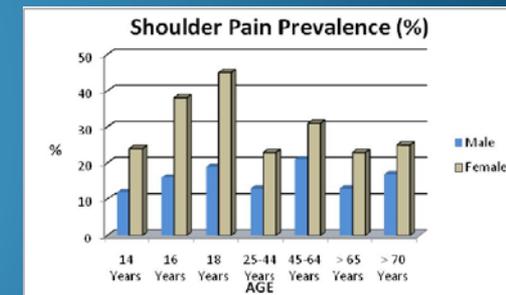
What Are Root Causes of Inadequate Pain Care in the US?

- *Underinvestment in Research* – Pain is the number one reason Americans visit their doctor, only 2% of NIH annual budget spent on pain research
- *Do Not Understand the Basic Mechanism of Pain in the Human Body* Pain is a neurobiological disease we do not fully understand
- *Lack of Trained Physicians* – Less than 1% of doctors are specialized in pain management
- *Very Little Time Spent Educating Doctors & Other H/C Professionals About What We Do Know About Pain* – On average med students get 9 hours of pain mgmt education in 4 years of med school; veterinarians get 87 hours
- *Dearth of Effective Treatment Options* – no cure & very few, if any treatments to dramatically reduce severe chronic pain



What Are Root Causes of Inadequate Pain Care in the US?

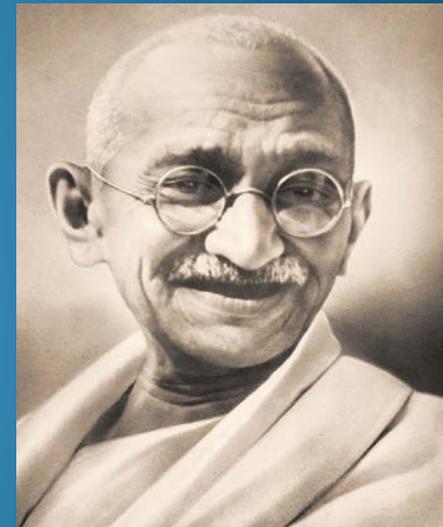
- **Lack Epidemiological Data on Pain** – We do not collect regular data on pain; lack precise data on trends, types of pain, severity, etc.
- **Lack of Public Awareness of the Scope, Severity & Impact** – hidden epidemic; our nation's biggest public health problem yet that is not generally known; devastation is causes not understood
- **Stigma, Misinformation, Hyperbole & Access Restrictions Regarding Opioids** – not for everyone but they can be a lifeline for some pain sufferers, vast majority use them safely & legitimately; people w/ pain often treated as drug-seekers, marginalized, not believed, some dropped from care
- **Insurer Practices that Limit Access to Treatment** – Pharmacy benefit mgmt practices limit access to certain pharmacological treatments; many complementary & alternative treatments are not covered



"You must be the change you wish to see in the world."

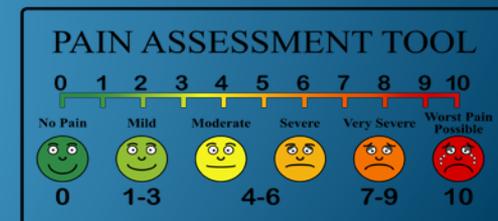
Mahatma Gandhi

- I have found inspiration from great advocacy leaders
- Strong belief that if you don't like something, work to change it
- After my own experience searching for help & that of my pain group members, decided to focus all my efforts on improving pain care in this country
- I have devoted my life's work to trying to do that, primarily through policy change at the state & federal level
- Largely because policy has the ability to affect many more lives than I can w/ my support group



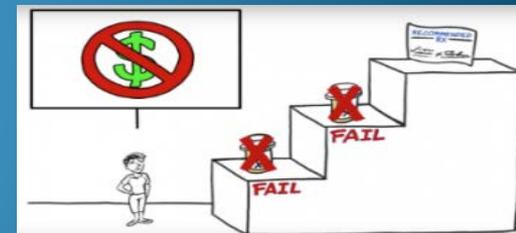
Advocacy In Action: State Policy Activities

- **Licensing Boards Adopt Policy Rulings on Pain Mgmt in MA (Nursing, Pharmacy, Dental & Physicians Asst), 2009**
 - Professionals responsible for acquiring specified knowledge & skills in pain mgmt, for practicing according to specified standards
 - *Addresses: Lack of Pain Education for Health Care Professionals*
- **Passed Law Requiring Continuing Pain Education for Doctors in MA, 2010**
 - Doctors must take 3 hours of pain mgmt CEU's every 2 years
 - *Addresses: Lack of Pain Education for Physicians*
- **Introduced Bill I Drafted Requiring Pain Assessment & Mgmt in All H/C Facilities in MA, 2013**
 - Has not passed but has gotten thru many steps & will be reintroduced
 - *Addresses: Lack of Awareness of Scope, Severity & Impact*



Advocacy In Action: State Policy Activities

- **Passed Law Limiting the Practice of Step Therapy in CT, 2014**
 - Insurer practice of requiring patients to fail 1 or more medications before covering medication originally prescribed by patient's doctor
 - Law limits to 60 days & establishes overrides for past or expected ineffectiveness, adverse reactions or when not in best interest of insured
 - *Addresses: Insurer Practices Limiting Access to Treatment*
- **Passed Law w/ Key Pain Exception & 2 Pain Commissions in MA, 2016**
 - Governor's proposed 3-day limit for initial opioid script changed to 7-day limit w/ exceptions for chronic pain, cancer pain, palliative care
 - Added Special Commission to study referral system to increase access to pain mgmt specialists & ways to "ensure a full spectrum of pain mgmt interventions are covered by insurers"
 - Added Special Commission to "study the incorporation of safe and effective pain treatment and prescribing practices into the professional training of students"
 - *Addresses: Extreme Access Restrictions on Opioids, Lack of Trained Physicians, Lack of Pain Education for H/C Providers, Dearth of Effective Treatment Options*



Advocacy In Action: State Policy Activities

- **Appointed By MA Governor Baker to Opioid Working Group 2015**
 - One of his first acts as Governor was to appoint this 17 member working group; I was the only one representing pain; chaired by HHS Secretary
 - Came up with 65 recommendations to address opioid crisis without restricting legitimate access
 - *Addresses: Extreme Access Restrictions*
- **Appointed to MA Drug Formulary Commission**
 - Commission tasked by the legislature with developing a formulary of ADF opioids that can be substituted for non-ADF opioids
 - Also tasked with annually producing a list of non-opioid pharmacological treatments for pain that is sent to all prescribers in MA
 - *Addresses: Extreme Access Restrictions*

Advocacy In Action: Federal Policy Activities

- Participation on Interagency Pain Research Coordinating Committee (IPRCC), term began in 2015
 - Oversee, coordinate & identify gaps in pain research across gov't;
 - *Addresses: Understanding Pain in Human Body, Dearth of Treatment Options*
- Participation in National Pain Strategy Workgroup, 2016
 - Comprehensive national plan to address pain population research, public awareness, professional education, care & prevention, disparities, reimbursement & service delivery
 - 80 experts served on 6 working groups; I served on Care & Prevention Working Group;
 - *Addresses: Lack Epidemiological Data on Pain, Lack of Public Awareness, Lack of Education of H/C Providers*



How To Manage Life with Chronic Pain

- *Accept there is no cure, no magic bullet*
 - Must learn to cope w/a chronic illness
 - This may not be the life you planned, but most pain can be managed so you can still have a quality life
- *Recognize great individual variability in response to treatments*
 - Essential to expose every pain sufferer to as many treatments as necessary to find what helps them; still trial and error
- *Multimodal treatment is essential; find the right combination that reduces your pain to manageable levels*
 - Unlikely that any individual treatment will be so dramatically effective that it will take away most of the pain
 - If each therapy that helps you reduces pain by 15%, 20% & 30% that adds up to a 65% reduction which is huge!



How To Manage Life with Chronic Pain

- *Most successful therapeutic outcome is when doctor partners with patient*
 - Conveys the message, “we will work together to solve this”, you are not alone”
 - Doctor is the captain of the team
 - Recommends therapies to try and asks patient to report back on what is helpful and what is not and they make adjustments together
 - All therapeutic options do not have to be within that practice but doctor needs to have a network of providers he knows & trusts

The Doctor Who Finally Helped Me

- An osteopath specializing in pain management
- What did he do? No miraculous cure; even tried things that hurt & didn't help
- Empathic, listened, believed me, sought to understand how the pain affected my life
- “I will work w/ you. You are not alone.”; a partner
- Pain may never go away completely but we can manage it
- Said I had to give up my career & try medication & other treatments
- Walked away from a successful career I loved; one of the hardest things I have ever done



How To Manage Life with Chronic Pain

- *Successful pain management requires long-term support*
 - This is a lifelong, life-limiting illness
 - There will be ups and downs, relapses, improvements, set-backs
 - If we were to establish grants for a wide network of support groups like mine that are cheap, we would save healthcare \$ in the long run
 - I volunteer my time, my group is free but how many people will do that?
- *Successful pain management requires pacing & some limitations on activities*
 - Limits are all different (ie. position, time engaged in activity, amount of rest time, etc)
 - Essential to learn your own limits and live within them

My Research Wishes & Suggestions

- *Closer working relationship between researchers & patients*

- Value in hearing directly from patients about the characteristics of the disease; what make it better or worse, what side effects are tolerable and what are not, etc.

Partnership with people like me could inform research

- My recommendations were remarkably similar to findings reported here; I knew those 10 years ago but no one asked

My Research Wishes & Suggestions

- *Plea for more and better epidemiologic study, analysis and reporting on pain*
 - Data we have is imprecise, lacks specificity
 - Longitudinal comparisons of pain data needed to identify trends, subpopulations at risk, and the health consequences of pain in terms of morbidity, mortality and disability
 - incidence and prevalence of various pain syndromes differentiated by patient age; comorbidities; socio-economic status; race and gender
 - Resource utilization data of medical and social services including direct healthcare costs of pain treatment, both traditional and complementary; and indirect costs, i.e. missed work, public and private disability, reductions in productivity

My Research Wishes & Suggestions

- *Study people with debilitating pain who have had successful outcomes*
 - What do they do? What has worked for them?
 - What personal skills and characteristics have helped them be successful?
- *Intrigued with how aggregate patient experience data is helping patients find treatments (ie. Patients Like Me)*
 - Can we leverage big data to find better treatments?

Thank You's

- *To Linda Porter*

For leading two extraordinary accomplishments – **The National Pain Strategy & the Federal Pain Research Strategy**
And for her tireless work & dedication to pain research

- *To Allan Basbaum*

For co-leading the **Federal Pain Research Strategy** that has been greatly anticipated

- *To all the pain researchers here today*

Thank you for investing your time, energy and working life in pain research and please know that it is much appreciated by the millions of Americans who struggle to live with this disease every day.

Thank You for listening!

A blackboard with white chalk writing that says "ANY QUESTIONS?". The text is written in a casual, hand-drawn style. The word "ANY" is on the top line, "QUESTIONS" is on the second line, and a question mark "?" is on the third line. The blackboard is set against a dark background.

ANY
QUESTIONS
?