

Stigma & Social Consequences of Chronic Pain

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No Conflicts of Interest
No Support from Private
Industry

Objectives

- Define stigma
- Define discrimination
- Discuss research findings & stigma for adults with chronic pain
- Discuss research findings & stigma for children & teens with chronic pain
- Consequences to social roles
- Clinical & Research implications

Stigma

- Process through which the reaction of others spoils normal identity
- Situation of the individual who is disqualified from full social acceptance

Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity*.

Discrimination

- Legal term
- Prejudicial treatment of an individual based on their membership in a certain group or category
- Involves actual behaviors
 - i.e. excluding or restricting members of one group from opportunities available to another group.

Charter of Rights & Freedoms

15. (1)

Every individual is equal before and under the law and has the right to the equal protection and equal benefit of the law without discrimination and, in particular, without discrimination based on race, national or ethnic origin, colour, religion, sex, age or mental or **physical disability**.

Why is chronic pain stigmatized?

- Pain that is not understood, especially if it has unusual presentation is assumed to be of psychological origin.
- A “Leap to the head” Patrick Wall (1964)

- Mental health problems and chronic pain
 - Blamed on the person with the problem
 - “She would be fine if only she ...
 - Didn't give in to her pain
 - Didn't allow herself to be depressed
 - Wasn't so negative

Pain Without Known Cause

- May be most stigmatized
- Pain with disease or following serious injury may provide legitimacy
- Pain without known etiology seen as the patient's fault
 - A sign of weakness
 - A sign of mental illness

- Society
 - Lack of understanding about chronic pain
 - Lack of understanding about opioids
 - Highlight the negative of opioids
 - Blame the sufferer
- Health Care providers
 - Lack of understanding about chronic pain
 - Lack of understanding about pain treatment
 - Assumption that patients are drug seekers

Challenges in Social Situations

- Social situations create challenges for discreditable person (someone with a stigma that is not necessarily detectable upon meeting)
- Constantly aware they may disclose information separating them from the 'normals' in the society
- Once discredited may be subjected to stigmatizing responses

- Goffman, 1963

Discrimination

- 2095 Asian Americans (Chinese, Filipino, Vietnamese, Other [Japanese, East Indian, Korean])
- Surveyed about chronic illness (1 of which was pain)
 - 32% of total sample reported chronic pain
 - Self-perceived daily discrimination (9 questions)
 - You receive poorer service than others in restaurants or stores
 - You are called names or insulted
 - People act as if they think you are not smart
- Daily discrimination was a significant predictor of pain—total sample (OR = 1.7)
 - Vietnamese (OR = 2.1); Filipinos (OR = 1.5); Chinese non-significant

Stigma, even if not
discrimination, is
damaging to those with
chronic pain

Adults with Chronic Pain & Stigma

- Adults with low back pain described being subjected to negative reactions of others
- Negative reactions = feeling intimidated, judged, blamed, guilty, and disbelieved about their pain
- Contributed to negative views of self

- 151 women surveyed with TMJ pain = negative views of chronic pain sufferers contribute to their feelings of stigmatization

Marbach, et al. 1990 J of Behavioral Med

Health Professionals & Adults

- By the time adults with chronic pain attend a pain clinic, they had been subjected to subtle & overt forms of stigmatization by many individuals including health professionals
- Being the recipient of subtle and overt forms of stigmatization may affect one's attitudes & behaviors towards those offering pain care

Holloway et al. (2007) Disability & Rehab

Stigma & Treatment

- Societies focus on opioid abuse—in numbers = outliers, at least in opioid naïve patients
 - Legitimate patients made to feel like addicts
 - Patients come with a concern about addiction based on biased reporting in the media
 - Regulations, professional practice guidelines inhibit some to care for patient requiring opioids

McGee et al. (2011) Pain Medicine

- Methadone more challenging
 - 124 pain physicians surveyed; 59% stated less than 20% of patients on methadone, stigma of the methadone one of the major reasons for patient refusal

Shah & Diwan (2010) Pain Physician

- Minimal use of analgesia especially challenging in the ED
 - stigma of opioids & transient relationship between ED doc & pt.

Fosnocht et al. (2005). Emerg Med Clin North Am.

Stigmatization of Children and Teens with Chronic Pain

School was identified as the greatest source of stress by adolescents with chronic pain.

Forgeron & McGrath (2008) J. Pain Manag

School as a site for stigma

- Maybe subjected to more bullying
 - Children with non-specific abd. pain are subjected to more overt & relational victimization

Greco, et al. (2007) J of Ped Pscych

- Pain may interfere with friendships
 - Girls with fibromyalgia are less liked, less popular, selected less often as friends, selected less often as best friend

Kashikar-Zuck (2007) Arthritis & Rheumatism

Teachers

This one teacher calls me the elevator mafia, And it doesn't matter how many times I talk to him or that the guidance counselor talks to him, like he thinks he's being funny and like that's great and wonderful, but you have to be able to differentiate funny from mean. Like I don't want to hear it. But it's annoying to have to say that to yourself, like – I do care what people think, I do care, because kids kind of look at me, why are you on the elevator?

Joanne, age 16

Classroom Discrimination

- When I went back to school they were giving me different work, like from the time that I missed, and **I was physically separated** from the class [off in a corner] **I felt horrible**. [The teacher] **she chose** to separate me from the class, and make me do different work, and I felt like she was treating me different because of the pain.

Lisa, age 16

Teens & Work

One of the managers pretty much told me, like, you can do this, you can't do this, why can't you just go on cash for 10 minutes? **And then I was like, I have pain, & she goes, well how do I even know you have pain?** She made it seem like I didn't, & I actually broke down, I was so frustrated. Then she felt really bad, & apologized to me later that night. But it takes something like that—crying. I haven't had the same relationship with her since she said that to me either.

Kelly age 16

Non-stigma Social Consequences

Changes in Social Roles

Adults:

- Spouse
- Parent
- Leisure/sport activities
- Friend
- Peer group
- Employer/employee

Children/Teens:

- Student
- Leisure/sport activities
- Friend
- Peer group
- School & part-time work
- Romantic friends

Adult Social Roles

- Family Life
 - Irritable with children
 - Unable to participate in children's activities
 - Children may worry about their parent
- Romantic relationships
 - Change partnership from equality to dependent relationship (transfer of household chores, financial dependence)
 - Change in sexual relationship

- Social avoidance

- Changing personality of the chronic pain sufferer (willingness to engage with others and/or need to express their distress to others)
- Perception of other people's discomfort about the amount of pain the sufferer is experiencing
- Easier to manage how one feels in the presence of others by avoiding social situations

Snelling (1994) J of Adv Nsg

Osborn & Smith (2007) Psychology & Health



Peer Relationships & Friendship

- Facilitate sense of personal identity, increase independence, & contributes to positive self-worth

Dusek, 1991; Ginseber, Gottman and Parker, 1986

- Positive friendship outcomes
 - less lonely
 - less depressed
 - positive school adjustment
 - offset negative adjustment effects for peer-victimized children

Parker & Asher (1993) Dev Psych; Ladd, et al. (1997) Child Dev;
Hodges, et al., (1999) Dev Pscyh; Gauze et al. (1996) Child Dev

Pediatric Chronic Pain

- Feel isolated as they do not know a peer with a similar pain experience

Sällfors et al. (2002) Child: Care, Health & Develop

- 50% of teen with pain rated themselves behind peers on social development

- strong peer relationships associated with more positive comparison on social development

Eccleston et al. (2008) European J of Pain

- Reported fewer friends, subject to more peer victimization, viewed as more isolated & less likeable than healthy peers

Forgeron et al. (2010) Pain & Research Manag

Pain & Friendships

“It’s very hard to keep close friends when you can’t go out every weekend, and you can’t really make friends in advance, and you have to take pills all the time. And you can tell that people are kind of like, uneasy around it or they don’t fully understand. They want to ask, but they don’t, and sometimes I’ll sort of bring it up to answer their questions. But it always kind of seems like a downer, and it’s always about the pain.”

Joanne, age 16

Changes in Friendships

- Teens developed new friendship needs; friends might not feel skilled in providing these needs
- Non- supportive social situations may be particularly challenging
- Internalizing behaviours did not account for the findings despite group differences.
- Small differences may have large impact if teens refrain from engaging with friends.
- Friends impact pain and pain impacts friendships.

- Forgeron, et al. (2011) Dissertation

Consequences of Stigma & Impaired Social Roles

- Loneliness
- Depressed mood
- Decreased self-worth
- Isolation
- Possible decrease in physical functioning (staying home, disengaging from social engagement & activities)

Physical & Social Pain

- neuroimaging studies suggest overlap in underlying neural circuitry & computational processes

Eisenberger et al. 2003, Science; (2004) Trends in Cog. Science

- social rejection & pain task
 - participants more distressed by exclusion in social task groups reported greater unpleasantness to same heat stimuli post task even after controlling for neuroticism

Eisenberger et al. (2006) Pain

Implication social rejection may hurt

Clinical Implications

- Don't label chronic pain as psychogenic
 - No advantage
- Recognize the impact of chronic pain on social function & relationships
- Improve patients understanding of chronic pain
- Encourage patients to maintain &/or initiate social contact
- Work & school accommodations to aid in engagement

- Friends & family may not know how to help
 - Need new forms of support
 - Balance to ensure not promoting illness behaviors
- Communication strategies with friends, family, employers
- Clinicians/Researchers advocacy for chronic pain patients & treatment

Research Limitations

- Qualitative findings—
 - Unable to generalize
 - Don't know the prevalence of stigmatization
 - Are certain subgroups more stigmatized
- Stigma vs. discrimination
- Research needed on social interventions & pain coping/function

Questions?