



STOLLERY
CHILDREN'S
HOSPITAL

Stigma in Children and Adolescents with Chronic Pain

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Overview

- Factors associated with stigma
- Stigma in adults with chronic pain
- Perceived stigma – CPSS
- Stigma in children and teens with chronic pain
- Development of the Children’s CPSS
- What can we do?



Stigma

- Goffman (1963):
- “...reduces the stigmatized individual from a whole and usual person to a tainted, discounted one.”
- *Stigma* originates from ancient Greece
- Body markings were used to discredit the moral status of a marked person.
- The blemished person was to be avoided.

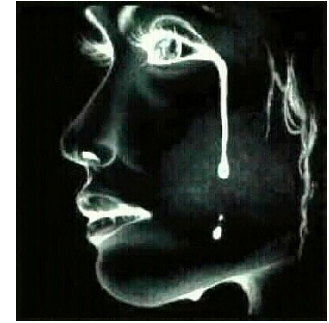


Stigma

- Lerner & Simmons (1966):
- *Just world hypothesis*: people get what they deserve
- Attribution theory (Weiner, 1986)
 - Blame the victim
 - Decreases own anxiety
 - Increases sense of control that one can avoid a similar fate



Associated Factors



- **Depression** (Fife & Wright, 2000)
- **Decreased self-esteem** (Berger et al., 1998)
- **Strained interpersonal relationships** (Govier et al., 1994)
- **Lower QOL** (Asbring & Narvanen, 2002)
- **These factors can affect medical outcomes and illness adjustment**



Stigma (Reed, 2005)

- Level consistently affected by:
- Attribution to psychological cause
- Perceived controllability
- Severity of illness
 - **Chronic pain includes all of the above**
- Labelling by physicians pointed to as strong predictor of perceived stigma
 - Marbach et al. (1990)



Commonly Stigmatized Diagnoses

- Fibromyalgia
- Irritable Bowel Syndrome
- Functional Abdominal Pain
- Pain Amplification Syndrome
- Chronic Daily Headache

- Anything treated with opioids...
 - Peppin (2009) / Gardner & Sandhu (2007)



Åsbring & Närvänen (2002)

- Fibromyalgia & Chronic Fatigue Syndrome
- Stigmatization reported to be worse before formal diagnosis provided
- Associated with questioning of honesty, morality and accuracy of person
- Psychologizing of symptoms stigmatizing



The person's experience

- 'It's all in your head'
- Common terms:
- Non-organic, functional, psychosomatic, idiopathic
- 'Clinical diagnoses'
- Many terms used pejoratively



Looper & Kirmayer (2004)

- Compared perceived stigma in:
 - Functional Somatic Syndromes (FSS)
 - CFS
 - FM
 - IBS
- VS.
- Validated medical diagnoses:
 - MS
 - RA
 - IBD
-
- **Higher perceived stigma in FSS**



The face of stigma in chronic pain

- S/he can do X but not Y...
- Children who keep playing while reporting high levels of pain (distraction)
- Recreational activities, hobbies, family
- ANY, even remote psychosocial events may be linked to pain syndrome



Stigma in adults with chronic pain

- Reed (2005)
- Chronic Pain Stigma Scale (CPSS)
- 30-item Likert scale

- 3 domains:
 - General public
 - Physicians
 - Family



Chronic Pain Stigma Scale (CPSS)

- **Dimensions of chronic pain stigma:**
- Estrangement
- Attribution to psychological cause
- Malingering
- Bias against opioid analgesics
- General negative attitudes



Chronic Pain Stigma Scale (CPSS)

- N = 150 (62% male)
- OA & LBP
- Good internal consistency for entire scale and subscales
- Good discriminant validity (compared to measure of impairment)
- Moderate positive correlation with depression
- Moderate negative correlation with QOL

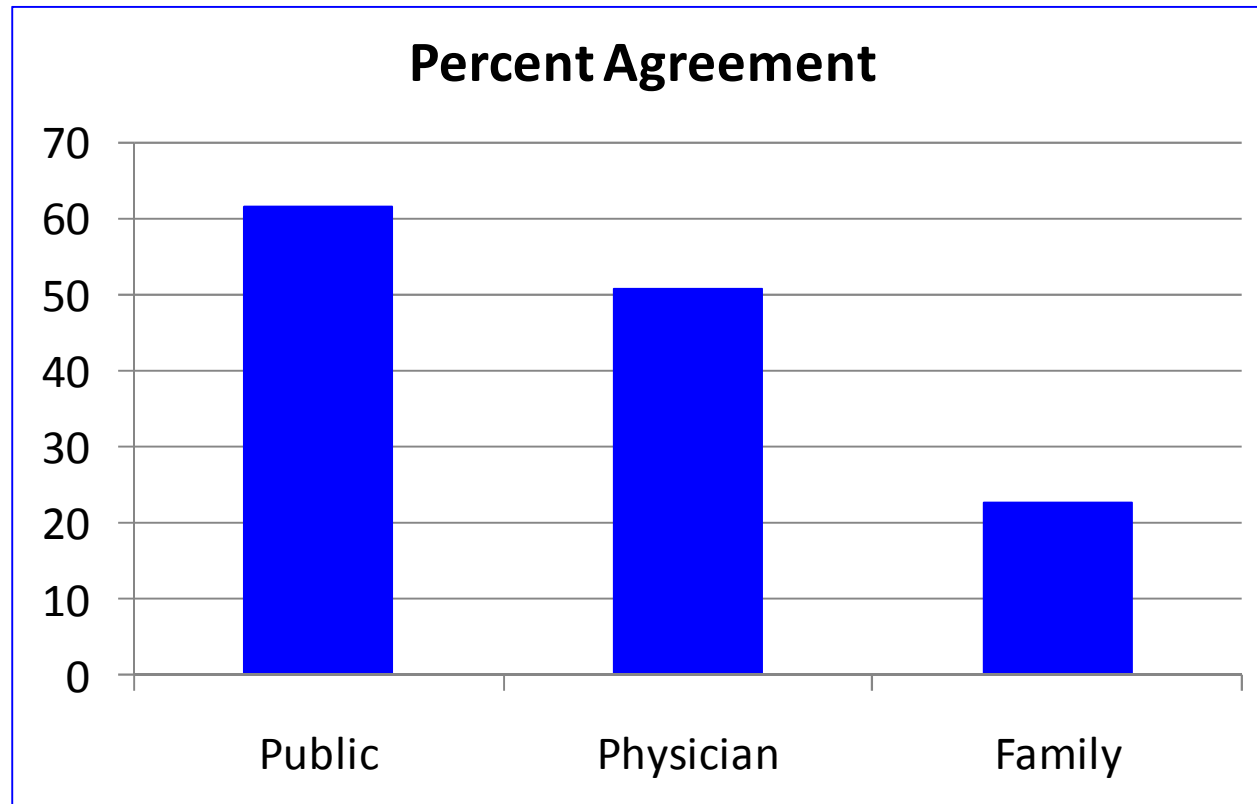


Chronic Pain Stigma Scale (CPSS)

- 79% reported stigma due to pain-related unemployment
- 57% reported physicians believe chronic pain mostly a mental/emotional problem
- 49% reported perception that physicians would prefer not to treat chronic pain
- 35% reported that family members respect them less because of chronic pain



Chronic Pain Stigma Scale (CPSS)



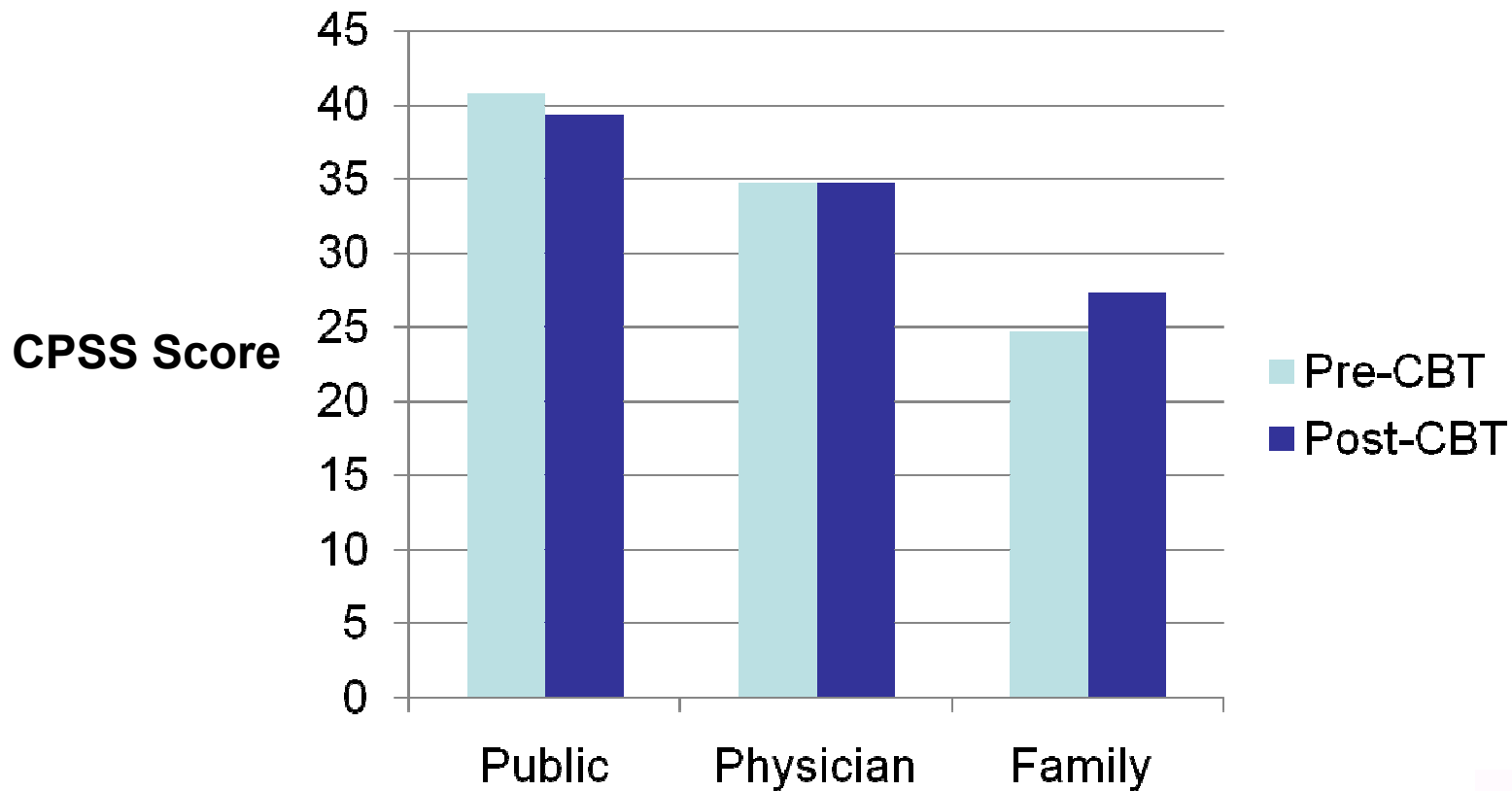
- High endorsement of stigma related to use of analgesics, especially opioids

Chronic Pain Stigma Scale (CPSS)

- Dr. Pravesh Vallabh
- Explore level of perceived stigma in our Multidisciplinary Pain Centre
- Does CBT reduce perceived stigma in adults with chronic pain?
- 3 experimental groups:
 - 1) Group CBT with no family member
 - 2) Group CBT with family member
 - 3) Wait-list control group



CPSS Preliminary data



CPSS Preliminary data



- Anxiety associated with CPSS Full Score
 - $r = .83, p = .021$
- Quality of life inversely related to CPSS Full Score
 - $r = -.87, p = .012$



Stigma in children and teens with chronic pain

- Pediatric stigma research less common in the literature
- **HIV/Aids** (Yan, Xiao, Zhou, & Tang, 2008)
- **Epilepsy** (Austin et al., 2004)
 - Perceived stigma associated with poorer self-concept and increased depression
- **Obesity** (Swaye Macdermott, 2008; Puhl & Latner, 2007)
- **Mental illness** (Hanrahan, 2008; Perry et al., 2007)



Stigma in children and teens with chronic pain

- Dell'Api et al. (2007)
- Negative outcomes often reported in interactions between children with chronic pain and their physicians
- Psychological causes often ascribed by physicians when no organic cause discovered
- Therapeutic alliance affected



Stigma in children and teens with chronic pain

- Logan et al. (2007)
- Teacher's perceptions of children with chronic pain
- Almost 2/3 of respondents held dualistic rather than biopsychosocial view
- Increased sympathy when physical cause for pain perceived



Stigma in children and teens with chronic pain

- Alex Baloukov
- Preliminary validation of Children's Chronic Pain Stigma Scale
- Language of items made 'child friendly'
- Added Teacher subscale



Stigma in children and teens with chronic pain

- Sample from Stollery Pediatric Chronic Pain Clinic
- MSK pain, chronic headache, abdominal pain, CRPS, Fibromyalgia, various other dx.
- Ages 11 – 17 years
- Predominantly adolescent females

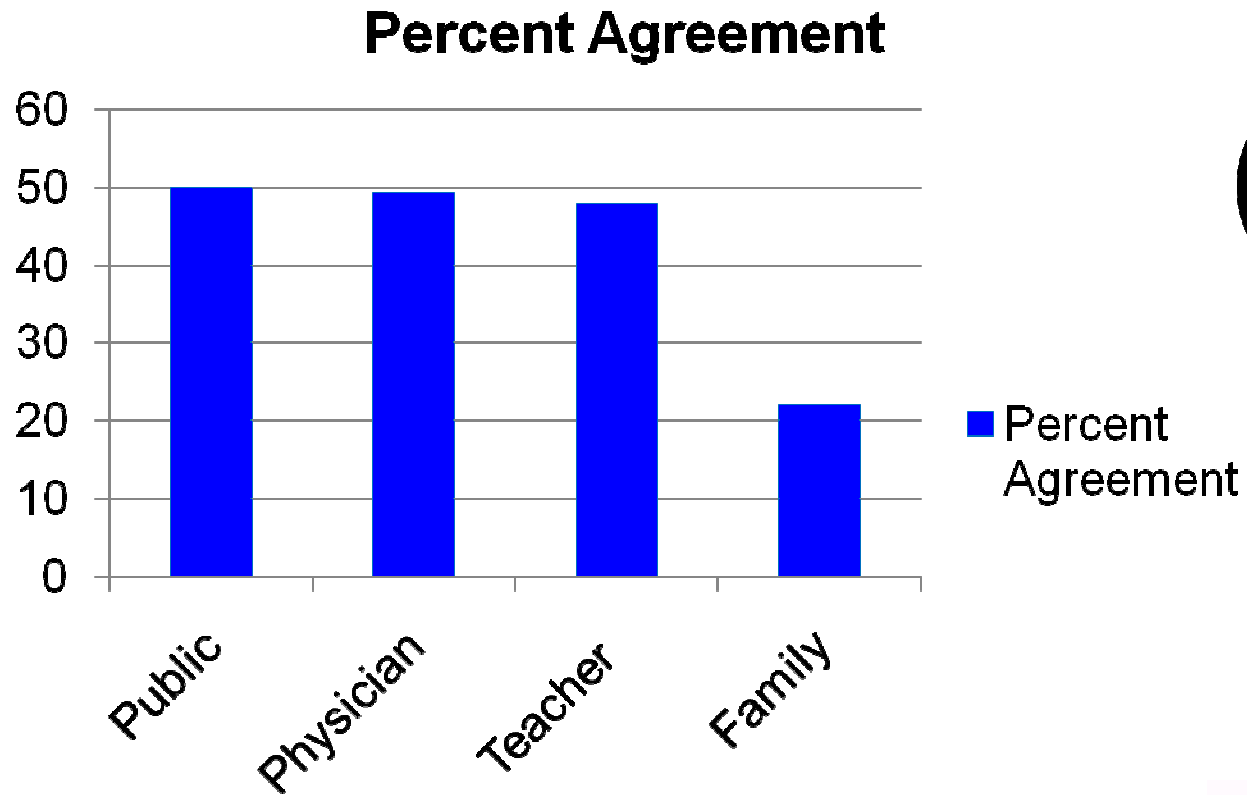


Development of CCPSS

- Demographics and medical history
- Child Attitude Toward Illness Scale (CATIS)
 - Higher score = more positive attitude
- Children's Depression Inventory (CDI)
- Multidimensional Anxiety Scale for Children (MASC)



CCPSS Preliminary data



CCPSS Preliminary data

- Depression and anxiety not significantly correlated with CPSS Full Score
- Attitude toward illness inversely related to CPSS Full Score
 - $r = -.59, p = .047$



Holloway et al. (2007)

- Stigma from family, friends, public, health providers
- People feel stigmatized by the time they attend pain clinics
- This perception may affect attitudes and interactions with health care providers
- Treatment programs need to address this reality in a practical way



What can we do?

- Normalize life
- Encourage activities & hobbies
- Educate ourselves and others
- Support & Encourage
- Cognitive and behavioural strategies to cope with stigma
- Life Despite Pain (program & philosophy)



Life Despite Pain

Multidisciplinary Pain Centre
University of Alberta Hospital

Summary

- Factors associated with stigma
- Stigma in adults with chronic pain
- Perceived stigma – CPSS
- Stigma in children and teens with chronic pain
- Development of the CCPSS - Perceived stigma in children

- **How we can make a difference**

