"But Doctor, it still hurts!"
Recognition, Belief, and Trust in Pediatric Chronic Pain

G. Allen Finley, MD FRCPC FAAP
Professor of Anesthesia and Psychology
Director, Centre for Pediatric Pain Research
Dr. Stewart Wenning Chair in Pediatric Pain Management
Dalhousie University & IWK Health Centre
www.pediatric-pain.ca www.childkindinternational.org

DALHOUSIE UNIVERSITY

Centre *for* Pediatric Pain Research
SCIENCE HELPING CHILDREN

IWK Health

What is pain for?


Francisco de Goya, 1791-2

Acute pain
- Warns of danger
- Teaches us to avoid future injury
- No pain sensation = burns, pressure sores, fractures, infections → death

Chronic pain
- Continues after tissue injury is over
- Serves no useful purpose
- Is a disease in its own right

Types of pain

Incident pain
- Procedures
- Immediate post-operative/trauma
- Post-operative/trauma (with movement, physical examination)

Continuing pain (from tissue injury)
- Post-operative (without movement)
- Disease related (cancer, etc.)

Chronic pain
- Complex biological/psychological/social interaction without tissue damage or inflammation

What is chronic pain?

Chronic pain in children is the result of a dynamic integration of biological processes, psychological factors, and sociocultural context considered within a developmental trajectory. This category of pain includes persistent (ongoing) and recurrent (episodic) pain with possible fluctuations in severity, quality, regularity, and predictability…

It is meaningless to dichotomize chronic pain as organic versus nonorganic, because all pain is associated with, *at minimum*, neurosensory changes…

American Pain Society Position Statement (revised 2006)

Scope of the problem

Affects up to 25% of children, 8% of total have "intense and frequent pain" (Netherlands)

Perquin et al. Pain 2000; 87: 51-8

Recurrent pain in 57%; chronic pain in 6%

van Dijk et al. Pain Res Manage 2006; 11(4): 234-240
Stanford et al. Pain 2008; 138(1): 11-21

Pain >3 months (Thailand): 14%

Siripul et al. WCP 2014

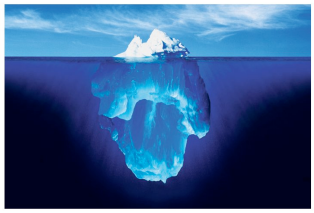
Statistics Canada (12-17 yrs): 2% of boys, 6% of girls

Ramage-Morin & Gilmour. Health Reports 2010;21(4):53.

Pain-related disability: 5%

Huguet & Miró. J Pain 2008;9(3): 226-36

Regional prevalence



Maritime Provinces of Canada

1.7 million x (~25% population < 19 years)

= 425,000 children & adolescents

x 2% with severe, disabling chronic pain

= 8500 children needing comprehensive care

Impact on families/society

Interferes with school, parents' employment: direct and indirect economic impact

Li & Balint. *Adv Pediatr* 2000;47:117-60

Societal cost of missed education in adolescence

Godfrey et al. Social Policy Research Unit, U. of York; 2002

May predispose to adult chronic pain and disability

Walker et al. *Pain* 2012; 153(9): 1798-806

Campo et al. Amer GI Assoc, 1999

Health service and family costs (UK)

- £8000 = €9858 per year
- £14000 = €17242 if idiopathic/non-rheumatological pain

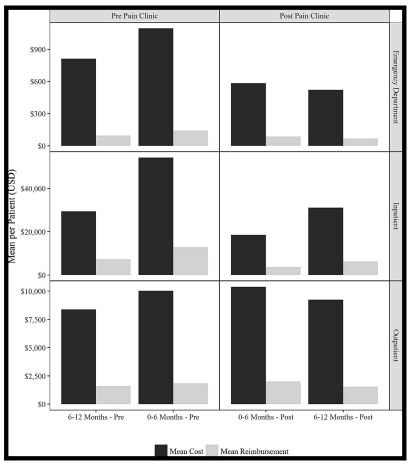
Sleed et al. *Pain* 2005; 119:183-90

Healthcare utilization & family burden (USA)

Multidisciplinary clinic treatment decreased:

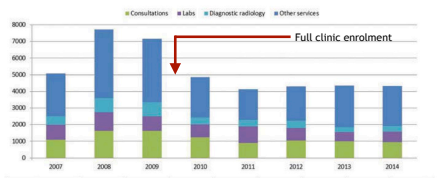
- Visits to specialists
- Visits to therapists (PT and others)
- Visits to psychologists
- Radiological investigations
- Outpatient costs ($) – decreased by 60%
- Inpatient costs ($) – decreased by > 90%
- Hours spent in medical appointments – decreased by 75%

Ho et al. *J Musculoskel Pain* 2008;16(3):155-164



"The findings of the current cost analysis of an outpatient individually-tailored interdisciplinary pain clinic supports that over the course of just 1 year, participation in such services can significantly reduce inpatient stays and ED visits and associated costs by more than the cost of the intervention itself."

Mahrer *et al. J Pain* 2018; 19(2): 158-165



SERVICE TYPE	2007	2008	2009	2010	2011	2012	2013	2014
Consultations/visits	22%	21%	23%	26%	22%	25%	23%	22%
Labs	17%	15%	12%	16%	24%	17%	13%	15%
Diagnostic radiology	10%	11%	12%	9%	9%	10%	7%	8%
Other services	51%	54%	53%	50%	45%	48%	57%	55%
TOTAL	100%	100%	100%	100%	100%	100%	100%	100%

Figure 2. Physician services by type and fiscal year.

Campbell et al. *Can J Pain* 2018; 2(1): 30-6

Range of problems

Fibromyalgia/Chronic widespread pain/Nociplastic

Specific peripheral neuralgia

Complex regional pain syndrome/RSD

"Weird neuropathies"

Joint pain (usually non-inflammatory)

Recurrent abdominal/visceral hyperalgesia/Crohn's

Back pain

Headache

Pelvic pain/endometriosis

Pain in cognitively-impaired/cerebral palsy/*etc.*

Patterns of chronic pain

Girls > boys (after puberty)

Usually (but not exclusively) adolescent

No particular psychological profile or predisposition

- May have associated anxiety

No particular family psychopathology

Family association for migraine, but not necessarily for other pains

How do we classify disability?

Constant or repeated pain

1. Continues school, activities, no obvious deficit
2. Continues school, drops activities/social; ± decreased school performance
3. Decreased or no school attendance, continues schoolwork at home; some physical activity
4. No schoolwork, minimal/no physical activity

No correlation with pain intensity

- Some patients have pain threshold for activity
- Reasonable to suggest that psychological factors modify disability, but not necessarily pain intensity

What happens if you do nothing?

School

- Missed classes, reduced performance
- Fewer options for careers, university

Costs

- Increased investigations, hospital visits
- Parent may have to miss work

Quality of life

- Affects friendships, socialization
- Impedes activities

Adulthood

- Children with chronic pain become adults with chronic pain → huge costs to society

First approach

Establish trust & a therapeutic relationship

Believe the patient

- Consequences of being wrong either way…

Don't hurt her more!

Offer reasonable hope

- "We don't promise to cure the pain."
- "We usually can improve the pain."
- "Almost always, we can improve your life."

Assessment

Pain history

Treatments attempted

Functional impairment

School attendance & performance

Family structure and pain history

Hobbies, sports, social activities

Other medical history

Beware of "professional ventriloquism"

What has the family been through?

The same questions over and over

Conflicting advice

Pain attributed to psychological causes (Melzack's "leap to the head")

Disbelief expressed by professionals, family, & friends (overt or insinuated)

Friends and family with "good suggestions"

Voices of families

"The hardest thing at the beginning I think, was feeling that we were being judged…and somehow found wanting…But the feeling was that…they wanted to find that there was a problem with the family or a problem with something and…that puts you under a great deal of stress and in some ways can be a self-fulfilling prophecy. …The fact that you're being analyzed, every step of the way. That really was the hardest thing to deal with" (Mother, interview)

Carter. *Qual Health Res* 2002; 12:28-41

The family is the patient

"I think also to remember you are dealing with a whole child and not just the spot that hurts plus a whole family that is also hurting."
(Mother, interview)

Carter. *Qual Health Res* 2002; 12:28-41

Listen to the family's views, but involve the child.

Support coping by the whole family, not just the child.

Voices of children

"Listen!!!!!…Listen to what the people [with chronic pain] have to say and take notice of it. Treat them as people no matter how young they are.…[Doctors] get really patronizing.…I just get really fed up with it." (Child, interview)

Carter. *Qual Health Res* 2002; 12:28-41

"Just because it's difficult to find out what's wrong...don't put us in the 'Can't Do Anything' box and make you feel you've been written off." (Mother, interview)

Carter. *Qual Health Res* 2002; 12:28-41

"I've had pain in my stomach for 2 years. It seems longer…One doctor told me that what she was seeing on examination and what she was being told were two different things. I was 11, and knew I was being accused of lying. This made me really angry, because it didn't help the pain (it actually got worse) and it really hurt me to be called a liar when the pain was very real." (Child, diary)

Carter. *Qual Health Res* 2002; 12:28-41

Taking charge of the pain

Multimodal approach: the 4 "M"s

- Mind
- Movement
- Medicines

→ **Motivation**

Presented as a single package

- Validates psychological treatments
- Synergistic effects
- Emphasizes self-management
- More efficient

Rehabilitation approach → takes time

Who's on the team?

Physician (anesthesiologist or pediatrician)
Clinical nurse specialist (CNS)/APN
Clinical psychologist
Physiotherapist
Support from:

- Psychiatry, Neurology, Rheumatology, GI, Rehab.
- Social work
- Occupational therapy
- Pharmacy

"The more negative you are the more it hurts."

"The kids in my class are a bit shocked that I get mad sometimes. It could be that I am thinking about it…so I almost snap at them."

Sällfors, et al. *Child: Care Health Devel* 2002; 28: 494-505

Psychology: Treatment

Cognitive behavioural therapy

- Goal: increase coping skills to improve function, QoL

Somatic/Pain management training

- Progressive muscle relaxation, diaphragmatic breathing, guided imagery

Cognitive restructuring

- Address negative thinking, enhance self-efficacy

Behavioural strategies

- Decrease avoidance, sleep hygiene

Motivational enhancement

"The worst thing was my pain was invisible… because I didn't have any bandages or anything."

Sällfors, et al. *Child: Care Health Devel* 2002; 28: 494-505

CNS: Clinical practice

Partner with patients and families

- Teach about pain, medications
- Problem-solve for flare-ups
  - When to seek other medical attention
- Strategize to increase function, decrease sick role behaviour
- Navigating the health-care system
- Managing school
- Managing friendships, peer relationships

"It's like being exhausted all the time. Because it's very tiring…always being in pain."

"And that's what you get so tired from… mentally tired…Not knowing what it is and why."

Sällfors, et al. *Child: Care Health Devel* 2002; 28: 494-505

Physiotherapy

PAIN EDUCATION

- "Hurt does not equal harm"
- Decrease threat
- Most important component of treatment

Loew et al. Arch Phys Med Rehabil 2011; 92:2041-56
van Oosterwijck et al. Clin J Pain 2013; 29: 873-82

Brain training

- Normalize cortical representation
- Graded motor imagery
  - laterality reconstruction
  - motor imagery
  - mirror therapy

Physiotherapy

Neural modulation

- Movement without moving (mirror/GMI, Recognise™ app)
- Selective tensioning/movement of nerves
- Gentle passive non-threatening movement, then active movement

Pacing and graded exposure

- Progressive increase in activity
  - Consider anxiety, fear, sense of safety
- Goal setting
  - Patient-directed
  - PT as coach/mentor
  - "Always do more today than you did yesterday, but not much more."

Drugs

Goals

- Decrease current pain
- Reduce central sensitization
- Facilitate physiotherapy/rehabilitation

May include:

- NSAIDs (or coxibs)
- Anticonvulsants (gabapentin, pregabalin)
- Tricyclic antidepressants (*e.g.* amitriptyline)/SNRIs
- Opioids (IR/SR, transdermal) — very rarely
- Ketamine (IV, oral); Lidocaine IV

Nerve blocks used very rarely

- Epidural, peripheral nerve, trigger point, etc.

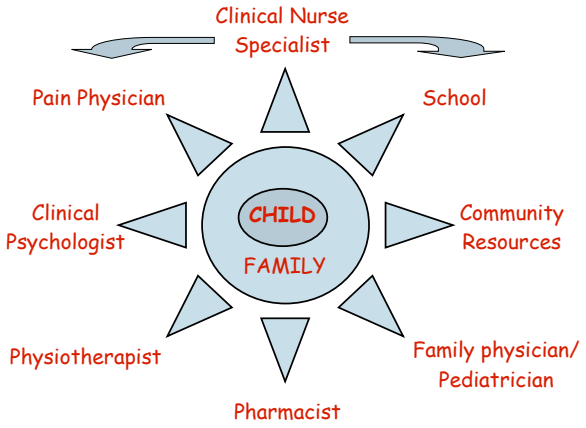
Opioids

Used very infrequently
- Rarely effective in neuropathic pain
- Indicated only if **improved function**

Dosage strategies
- Regular stable dose to control constant pain

and/or
- Intermittent targeted doses for specific exacerbations

Monitor for change in pattern of use



IWK Pediatric Complex Pain Clinic

Physicians
Allen Finley, MD FPCPC FAAP – Medical Director
Stuart Wright, MD PhD FRCPC
Jane Seviour, MD FRCPC

Physiotherapists
Michael Sangster, BSc(Physio) MBA DPT
Allison Lerette, BSc(Physio)
Alexis Nickerson, RN BN MSc(Physio)

Clinical Nurse Specialists
Lori Campbell, RN MN
Shelley Lowther, RN MN

Clinical Psychologists
Lindsay Uman, PhD
Ayala Gorodzinsky, PhD

902.470.7708
902.470.6208
fax 902.470.7911