Getting Back in the Game: Treating Chronic Pain in Adolescents

Helen Gutin, APRN, CPNP
Carrie Kreuer, APRN,CPNP FCNC
Pediatric Pain Rehabilitation Program
Cleveland Clinic Children's Hospital for Rehabilitation

Speaker Introductions
- Helen Gutin is a certified pediatric nurse practitioner that works in the Cleveland Clinic Children's Hospital for Rehabilitation, a multidisciplinary in-patient/patient three week program which helps adolescents and older school age children with significant impairment in their normal daily activities due to chronic pain return to normal functioning. Ms. Gutin has been a CPNP for 35 years, working in the chronic pain program for six years. She helped start a pediatric palliative care program and was the coordinator of a pediatric sickle cell program for 36 years, along with NP jobs in neurology and primary care in her early career.
- Carrie Kreuer has been a CPNP for 14 years and has worked as an NP in neurosurgery, PICU and hospital medicine. She has been with the chronic pain program for three years. Ms. Kreuer has kind, energetic and hilarious boys ages 6 and 7 that make her laugh every day.

Tame the Beast
- [https://www.youtube.com/watch?v=IktUvGph724](https://www.youtube.com/watch?v=IktUvGph724)

Disclosures
No conflict of interest or financial disclosures
This talk will focus on chronic pain which continues after specific conditions have been treated or ruled out.

Learning Objectives
- Discuss chronic pain prevalence and epidemiology in children
- Understand the cycle of chronic pain and the most common pediatric chronic pain conditions
- Review role of pharmacotherapy in chronic pain in children
- Evaluate when to treat chronic pain in primary care practice and when to refer to subspecialists
- Acknowledge importance of rehabilitative, Multidisciplinary team approach in chronic pain

Epidemiology of Pediatric Chronic Pain
- 20% of youth are affected by chronic pain in the United States [Exley, Sola, Eax, Norman, 2018]
- More prevalent in girls, with peak incidence at 14-15 years
- Pain may be the primary problem or occur in the context of chronic health problem
Clinical significance

• 5-10% report significant impact or disability associated with pain
  • Lost school days, lower grades
  • Fewer social interactions
  • Less involvement in sports & other activities
  • Sleep & emotional/behavior difficulties

Chronic Pain is a Significant Pediatric Health Problem

• Total cost to society incurred to care for children with moderate to severe chronic pain extrapolated to $19.5 Billion in US (Kong et al., 2011)

• Untreated chronic pain in children incurs a high risk for subsequent development of chronic pain into adulthood (80%) (Hassett, et al., 2013)

• Chronic pain in adolescence associated with higher rates of anxiety (21.1% vs 12.4%) and depression (24.5% vs 14.1%) in adulthood

What is Chronic Pain?

CHRONIC/FUNCTIONAL PAIN:

• Results from malfunction or injury in the nervous system.
• May or may not be due to nervous system damage
• Persists because pain signals still sent to brain after tissue has healed
• Doesn’t respond as well to standard pain killers, but can respond to antidepressants and anticonvulsants, other meds
• Lasts > 3 months, continuous or in flare-ups
• Source of the pain can’t be removed

COMORBIDITIES and RESULTS OF CHRONIC PAIN

• Depression and/or Anxiety
• Failure to achieve developmental milestones/academic failure/school avoidance
• Family conflict and dysfunction
• Disordered sleep
• Social isolation
• Chronic Fatigue can occur with any of the chronic pain syndromes
• Motivation
• Secondary gain

Variety of Pain Conditions Treated

• Complex regional pain syndrome (CRPS)
• Headache/Migraine
• Abdominal Pain
• Amplified Muscular Skeletal Pain Syndrome (AMPS)
• Postural Orthostatic Tolerance Syndrome (POTS)
• Ehler-Danlos Syndrome (EDS)
3 most common chronic pediatric pain disorders

- Chronic recurrent musculoskeletal and joint pain
- Primary headaches
- Abdominal pain syndromes

**Complex Regional Pain Syndrome**

- Abnormal autonomic nervous system response
- Initiating event such as injury or immobilization or no known such event
- Continuing pain, allodynia (sensitive to even light touch), or hyperalgesia which is disproportionate to any triggering event
- Pain when burning or sharp
- Muscle atrophy from disuse
- Edema, temperature and or color changes
- Abnormal motor activity such as tremors in area of pain
- If untreated it typically spreads
- Most kids miss about 25% of school days

**What should the PCP Do?**

Take a good History!
Has a new injury occurred?
Is this a chronic or acute problem?

**Treatment for CRPS in children/adolescents**

- Education about the condition and what can be done to make it better or worse
-Modifier essential to use, head, or extremity affected
- Lying down in the room with the hands on the patient and turning off the brain messages
- Sometimes it gets worse before it gets better.
- Key point: if your face pain improves it does not mean it is causing more injury.

When would you refer and who would you refer to?

**Pharmacology for CRPS**

- Anticonvulsants:
  - Gabapentin and pregabalin bind to the voltage-gated calcium channels at the alpha 2-delta subunit and inhibit neurotransmitter release. They are proven efficacy versus placebo in several neuropathic pain conditions (Dworkin et al. 2007)
  - Side effects that we see with these meds, drowsiness, "brainfog"

**Pharmacology for CRPS continued**

- If fear of pain has caused anxiety or depression that is getting in the way of treatment
  - Treat anxiety with SSRI, SNRI, benzodiazepine or hydroxyzine
  - Selective serotonin reuptake inhibitors (SSRI) and serotonin-norepinephrine reuptake inhibitors (SNRIs) are effective in the treatment of generalized anxiety disorder (GAD) and PTSD.
  - Benzodiazepines exert their principal antianxiety effect via central nervous system (CNS) receptors, potentially in the region of neurotransmitters such as GABA and dopamine.
  - Side effects of benzodiazepines include dizziness, drowsiness, oversedation, and hypotension. Lower doses are recommended for older adults and patients with liver disease.
  - Hydroxyzine is a benzo diazepine, antihistamine.
  - Oral: 5-30mcg/kg four to six times, maximum dose is age-dependent: Age <5 years: 12.5 mg/day; age 6-12 years: 25 mg/day
  - Sedative effects
Pharmacology continued

- For sleep disturbance in children and adolescents with chronic pain
  - Melatonin is a hormone secreted by the pineal gland in response to decreased light. The mechanism of action is not completely understood, immediate-release melatonin is to supplement the endogenous Pineal hormone.
  - Widely used in children and adults, 3 mg in children, 5 mg in adolescents, given 30 minutes before bedtime.
  - Tranquilizers: Antidepressants, Serotonin Reuptake Inhibitors (SSRIs), Antipsychotics. Used at bedtime.
  - Non-habit forming: Alprazolam, clonazepam, eszopiclone, zaleplon, zolpidem.

Headaches—often a combination

- Chronic Daily Headaches
  - Gaps in sleep patterns or sleep disorders, tension headache, prior headache, depression, fibromyalgia, Raynaud’s disease, migraine, cluster headache.
  - Daily; persistent headache, not relieved by aspirin, NSAIDs, triptans, other headache medication.

New Daily Persistent Headaches (NDPH)
- New daily persistent headache is one that first occurs after age 50 yrs, often worse in the morning, no lasting headache associated with other medical conditions.
- New daily persistent headache can be a sign of brain tumor, stroke, or other serious conditions.
- Chronic daily headache with new daily persistent headache is a type of another headache, not a new headache.

- Migraine Headaches
  - Can be accompanied by nausea, vomiting, and sensitivity to light (photophobia).
  - Can cause severe headaches that last for days or weeks, usually on one side of the head.
  - Can be relieved by over-the-counter pain relievers, such as ibuprofen or acetaminophen.

- Cluster Headaches
  - Occur in clusters of attacks over a period of weeks or months.
  - Can cause severe, one-sided headaches that last for hours or days.
  - Can be relieved by over-the-counter pain relievers, such as ibuprofen or acetaminophen.

HA Pharmacology

- Topamax: Anticonvulsant, Miscellaneous
  - Used to treat chronic daily headache.
  - Prescribed for patients with intractable headache, chronic daily headache.
  - Used as an adjunctive therapy to other medications for treatment of chronic daily headache.

- Migraine: OTC supplements: Includes Vitamin B12, Riboflavin, Magnesium, Coenzyme Q10, PA-Free Butterbur.
  - Does one tab once or twice per day
  - HA rescue protocol: This protocol may be used at most 2 days per week.

- Functional Abdominal Pain
  - Diffuse symptoms
  - Irritable bowel syndrome
  - Migraine
  - Fatigue
  - Generalized weakness
  - Abdominal pain
  - Abdominal bloating
  - Gas
  - Diarrhea
  - Constipation
  - Headache
  - Mood swings
  - Insomnia, weight loss
  - Nausea
  - Unexplained fever

Chronic abdominal pain

- Most common children’s chronic pain
  - 10 children/10 yrs, usually organic cause
  - Children > 2 yrs old: functional

Functional Abdominal Pain Rome III Criteria 2006

- At least 12 weeks for > 2 months episodic or continuous abdominal pain
- Insufficient criteria for other functional GI disorders (e.g., irritable bowel syndrome, functional dyspepsia, functional constipation, chronic pain syndrome, etc.)
- No evidence of an inflammatory, infective, metabolic or neoplastic process that explains patient’s symptoms.
Functional abdominal pain pharmacology
- Am triptyline or nortriptyline: Antidepressant, Tricyclic
  - Irritable bowel syndrome (off-label use): Oral: Initial: 10 to 25 mg once daily at bedtime; may gradually increase dose based on response and tolerability up to 75 mg/day (Balagopalan 1999; Yahoudi 2008).
- Antispasmodics: Anticholinergic Agent
  - Dicyclomine/Bentyl
    - Children 25 years Oral: 10 mg 3 to 4 times daily
    - Adolescents/Adults: 30 to 20 mg 3 to 4 times daily. If efficacy not achieved in 3 weeks, therapy should be discontinued.
  - Phenergan/Meatrizin
    - Levodopa 0.25 to 0.5 mg every 4 hours or as needed; maximal: 1.5 mg/day

PNPs role in treatment of chronic pain
- Red flags
  - Falling behind in school
  - Missing activities
  - Frustration with day to day tasks
  - Initially out of social opportunities
  - Starting family activities
- Do the minimal workup that will assure organic causes are ruled out.

- A chronic pain patient’s initial treatment plan should include physical therapy, occupational therapy and psychology. “Early intervention is critical in managing chronic pain. Taking action right away can help many kids prevent the physical, psychological and social issues that decrease their functioning long term.” (Kemp et al., 2010)

The ideal approach: Multidisciplinary care of children with chronic pain
- Education
- Physical Therapy
- Psychological Interventions
- Complementary & Alternative Therapies
- Pharmacological

Multidisciplinary rehabilitation approach with goal to return to normal functioning
- Shift away from finding a cure (teach acceptance and management of the pain)
- Teach Mind Body Connection
- Emphasize return of normal daily functioning (go out to play, do sports, do things with friends, participate in family fun)
- Patient and family are ACTIVE participants in recovery
- Refocus on the “little wins” & reduce unscheduled hospital visits
- Educate family and child; child is capable, strong and competent (not passive, helpless, fragile)
- Success: Return to school, social and recreational activities, parents return to work

When to refer to mental health specialist
- When normal functioning is affected (missing school, not participating in friends/family)
- Signs of depression or anxiety
- A stressful situation is making pain worse
- When developing mind body skills would be useful to manage pain

When to refer to PT/OT
- Goals of returning to sport or activities
- Not participating in gym class
- Signs of weakness, poor balance, poor endurance, abnormal movement patterns or weakness or poor posture, etc.
- Diagnoses associated with abnormal movement patterns or weakness: e.g. Ehlers-Danlos syndrome (joint hypermobility), CHS, chronic headaches (posture, shoulder tension), abdominal pain and back pain-posture
PARENT ROLE IN CARING FOR CHILD IN PAIN

- Natural role of parenting is to help and protect child
- Parents often hypervigilant to pain
- Parents experiences with pain may influence child's pain beliefs and behaviors.

*Parent coaching key component in treating chronic pain

Parent Toolbox

- Parent self care
- Target behaviors to increase functioning (school, relaxation, chores)
- Attention and praise
- Set up reward system
- Encourage positive coping skills
- Make school plan (including 504)
- Get other adults and school personnel on your "team"
- Model coping skills

Commonly used Integrative Modalities

- Aromatherapy
- Biofeedback
- Exercise
- Mental imagery
- Massage therapy and healing touch
- Stress management (Mind Body Skills)
- Yoga
- Music and Recreation Therapy
- Acupuncture

Treatment of Chronic Pain - "Rules of Engagement"

- Primary focus return to normal functioning
- Program is treatment-focused, not evaluative or diagnostic
- Active participation, both child and parent, is critical
- Stay active despite pain
- Long-term commitment to lifestyle changes is essential

- In bed by 10:30p and awake by 7a
- Eat three meals daily and stay hydrated
- Be active outside rooms
- Complete PIVOT, mind-body, & school homework nightly
- Parents are expected to participate in educational, school re- Entry, & other meetings

Take Home Messages

- Do the correct action to make sure there is any pathology that is causing symptoms that can be treated to relieve pain.
- Once chronic pain is diagnosed, education is key.
- Pain is what the patient says it is
- A well-functioning team is everything. Communicate and back each other up to avoid splitting
- When chronic pain becomes a disability, refer to Pain Specialist

Case Study
Pediatric Chronic Pain Programs

Although each program has the primary goal of functional improvement, disparities exist in the format, organization, and balance of treatment modalities.

- Inpatient versus day hospital treatment modalities.
- The Cleveland Clinic Children’s Hospital pain rehabilitation program combines inpatient and day hospital treatments for some of the patients based on individual needs.
- Other differences include length of stay and activities of patients by cohort versus a rolling admission process. For instance, the Mayo Clinic and AHN programs have fixed, 2-week admissions with a group treatment emphasis.
- In contrast, programs such as those at Boston Children’s Hospital and Shriners Hospitals for Children have more flexible lengths of stay based on the individual needs and progress of the patient.
- The amount of each therapy a patient receives also varies across programs and across patients within some programs.

Follow-up

- If you have a patient with chronic pain that has finished a multidisciplinary program and they continue to have issues with pain.
- Long-term problem with ups and downs (be reassured you are doing great)
- Remember to use your skills (stretching, mind-body skills)
- Are you following thru with your plan of care?
- PT/OT, Psychology, psychiatry, attending referral
- Contact the pain program for additional support, most times the patient and family just need reassurance that this is normal

Great Resources- Books (for providers and families)


Great Resources- Video’s

- Understanding Pain: https://www.youtube.com/watch?v=8lTFT1L_2Y
- Understanding Pain in Less that 5 minutes: https://www.youtube.com/watch?v=PIWqEe09g5
- Chronic Pain: Tame the Beast: https://www.youtube.com/watch?v=Kw9Ylw-FKQ
- Elliot Krane: The mystery of chronic pain: https://www.youtube.com/watch?v=O-KMcjCI

References


Cleveland Clinic Children’s Hospital for Rehabilitation

- MD’s (PM&R and Pediatric Hospitalists), APRN’s, dedicated RNs, Psychologists (and their trainees both Fellows and Residents), Physical Therapist, Occupational Therapist, Social Worker, Social Worker (LISV)

To schedule an evaluation for the Pediatric Pain Rehabilitation Assessment, Call 330-448-6603.
End

- Picture of the kids quotes that Rick has them write at the end of the program
- Read a few good ones
- "Be a fountain not a drain"
- Throw kindness around like confetti!
- Be so good they can’t ignore you- Steve Martin
- Reads emails