Pediatric Chronic Pain and School Avoidance: What’s a Team to Do?

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Objectives

- Verbalize an understanding of school avoidance dynamics
- Identify key factors in assessing for school avoidance dynamics
- Identify effective interventions within a collaborative family health model

School Anxiety

- 80% of children have difficulty adjusting to school at some point
- Fleeting anxiety episodes at start of the school year
- May test parents’ resolve by occasionally acting out to stay home from school
- Usually managed successfully by parents and teachers

Kearney, 2001
School Avoidance (SA)

- High rates of absenteeism or inability to attend full day
- Difficulty attending school is associated with:
  - Emotional and physical distress
  - Avoidant coping
  - Functional disability
- Difficulty attending school is not associated with:
  - Serious misconduct or antisocial behaviors
  - Truancy

SA Prevalence

- Affects 1-5% of all school age children (Burke & Silverman, 1987)
- Occurs equally across genders, ages, & socioeconomic groups
- 66% of youth with SA present with somatic symptoms (Stickley & Miltenberger, 1998; Bernstein et al., 2001)
  - Dizziness, sweating, headaches, shakiness/trembling, chest pain, palpitations, blurred vision, SOB, weakness, fatigue
  - Abdominal pain, nausea, vomiting, diarrhea
  - Back pain, joint pain, difficulty walking

Common Themes Seen with SA

- Escalating functional disability
- Disproportional symptom severity
- Unexpected treatment response
- Symptom onset and course
- High stress temperament
Meet our Inpatient and Outpatient Pain Teams

- Acute, Chronic, Palliative Care Programs
- Medical & mental health integration
- Work collaboratively with families, HCPs, schools
- Dedicated team of pain experts includes:
  - Pediatric anesthesiologists
  - Psychologist
  - Family therapist
  - Advance Practice Nurses, clinic nurse, research nurse
  - Social worker
  - Physical & occupational therapists
  - Research psychologist

Model of Pediatric Chronic Pain Management

- Assess
- Diagnose/Plan
- Intervene
- Evaluate
- Intervene
- Evaluate
- Refer….
Meet Patient A: Headache

- Hx: H/A 1 year PTA, possible pseudo-tumor
- No H/A x 6 months
- 9 day PTA, severe unrelenting H/A, taken to outside hospital
  - MRA/MRI x 2; questionable mild chairi malformation
- Amitriptyline, depakote, hydromorphone PCA, 5-day course methylprednisolone
- Transfer to CHW

Patient A (H/A) Inpatient Stay

- Assess:
  - Throbbing, entire head, can be sharp
  - n/v, photophobia
  - + dizziness, overall weakness, tingling legs
  - Mom: + migraines
- Intervene:
  - D/C PCA basal & decrease dose
  - Change depakote to ER, increase amitriptyline dose
  - Start diclofenac tid pm; tramadol bid pm

Evaluate: Patient A Day 1
Inpatient Stay

- Intervene:
  - D/C PCA; start oral hydromorphone
- Evaluate:
  - Pain decreased to 3/10
- Intervene:
  - Patient D/c'd
  - F/u in chronic pain clinic

Evaluate: Patient A Day 2

Evaluate: Patient A Day 3
Evaluate: Patient A Day 4 (discharge)

Acute Pain Service Impression....

Meet Patient B: Abdominal pain

- 12 yo female
- Abdominal pain
- Numerous ER visits
- Admitted - 2 day stay
- Admitted - 4 days after d/c (ex lap/appy)
- Pain clinic 10 days later
- Admitted 1 day stay ERCP 1 month later
- No further admissions

Patient B: Inpatient APS Consult

- Assess:
  - CC: abdominal pain
  - HPI: 12 yo w/abd pain of unclear etiology. W/U to date has not revealed a source
  - ROS: As above; labs wnl
  - PE: Deferred
  - Current medications: None
  - VS: T: 36, BP: 108/55 HR 77 RR 24
  - Pain scores: 7-8/10; sedation 4-5
  - No relief w/amitriptyline, tramadol, roxicet
**What Should be in an Assessment or Consult?**

- Place: ___________________________
- Amount: ___________________________
- Intensifiers: ___________________________
- Nullifiers: ___________________________
- Effects: ___________________________
- Description: ___________________________


**Compare, Contrast, Critique**

- Hx: H/A 1 year PTA, possible pseudo-tumor
- No H/A x 6 months
- 9 day PTA, severe unrelenting H/A, taken to outside hospital
  - MRA/MRI x 2; questionable mild chain malformation
- Amitriptyline, depakote, hydromorphone PCA, 5day course methylprednisolone
- Transfer to CHW
- CC: abdominal pain
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**RN Admission Note**

- 12 yo admitted from EDTC with chronic abdominal pain
- 3 mo hx RUQ ‘under ribs’ that on a good day is 5-6/10; otherwise mostly 10/10
- 11 pound weight loss, has an appetite, but eats less
- Endoscopy & colonoscopy results pending
- Tramadol taken without relief; distraction helps sometimes
- Has missed 2 weeks of school over 3 months
- Currently pain 7/10, tender to touch, BS +
- Declined meds, child life consult ordered, MD aware of pain scores
- Mom voicing concerns about not getting answers & doesn’t want to leave without knowing a cause
Intervene

- Begin gabapentin 200mg tid and increase to 300mg tid by d/c if tolerated, then to a max of 600mg tid in 100mg increments
- 2mg diazepam and/or 100mg tramadol PRN anxiety/pain
- Sleep aid tonight as sleep trial
- Comprehensive outpatient pain appointment made for 8 days from now

Evaluate: Patient B

- Day 1
  - Pain scores 6 – 9/10, mostly 9
- Day 2
  - Pain scores 7-10/10 (mostly 10)
  - Valium & tramadol 1-2 times per day
- APS:
  - Patient slept overnight which was one of our goals. Continue current regimen. Going for nuclear med test
  - Called at night, increased gabapentin

Evaluate: Patient B

- Day 3
  - APS met with mom & patient re: discharge planning
  - Called in prescription for gabapentin
  - Encouraged good sleep, exercise, eating habits
  - F/U in chronic pain clinic
Patient B: Admit 2

- Assess: APS consult:
  - Worsening abd pain; extensive w/u negative
  - Per mom: pain started in October, worsened at the end of 2009; frequent school absences; admitted 1/4, has not attended school this year (1/12/10)
  - Took her to school yesterday, but pain worsened so couldn’t go
  - Pain has profoundly affected her ability to function
  - Current medications: Amitriptyline 20mg; gabapentin 400mg tid; ambien 10mg hs; tramadol 100mg q6h prn; diazepam 2mg q6h prn

Evaluate: Patient B, 2nd Admission

- Pain Scores
  - 9 – 9.5 – 10
- Intervene:
  - Increase gabapentin to 600mg tid
  - Keep appt with chronic pain clinic tomorrow
  - Diagnostic Lap

General Course Admit 2

- Pain scores stayed 5-10
- 3 - 6/10 after exploratory lap
- 0 - 2/10 day of d/c

- ERCP to be done as outpatient

- Acute Pain Service Impression...
Inpatient Treatment Patients A & B

- Assessment (varying in depth)
- Interventions to decrease pain
- No psychiatry or psychology consult
- Possible child life consult for distraction/relaxation
- Referral to chronic pain clinic

Symptoms Resulting in Referral

- Patient A
  - Mismatch of pain scores and activity
  - Many after school activities
  - Timing of admission (1/23)
  - Sudden improvement without reason
  - Mom with chronic condition
  - “Intuition” by APS chronic pain MD

- Patient B
  - 3 month history
  - Timing of admissions (1/4, 1/12)
  - 2 admissions within a week of each other
  - Mismatch of pain scores and activity
  - School absences/timing
  - Tried to go to school…pain got so much worse

General Cues for Referral

- Individual factors:
  - Anxiety/Depression/Learning disability
  - Challenging temperament
  - Impaired social functioning

- Family factors:
  - Medical/mental illness in family
  - Marital, work, or financial strains
  - Poor insight

- Impact of illness/Pain
  - Sig. school absences
  - Major family accommodation
  - Somatic focus

- Medical history:
  - Shifting medical problems
  - Unexpected treatment responses
  - Multiple referrals
Inpatient Medical Assessment/Management

- Biomedical
- Dichotomizing
- Focus on area of specialty
- Initially very superficial psychosocial assessment
- Insufficient experience with presentation of biopsychosocial pain problems
- May have had past negative experience when addressing psychosocial
- Psych consult is seen as the intervention

HCP Mistaken Beliefs/Conclusions

- Medical work-up first, then look at psychosocial:
  - But they seem so nice, provider bias
- Tunnel Vision:
  - She has gastritis, that explains EVERYTHING (i.e. there can’t be anything more to it)
- Leave no stone unturned:
  - When in doubt...
- Underlying issue:
  - Medical team is not always skilled or comfortable with assessing or addressing psychosocial possibilities

Challenges for Addressing Psychosocial Factors Inpatient

- Hard to shift from all medical to psychosocial
  - Family is expecting a medical diagnosis and preparing for the worst
  - "All the tests are negative, and she can go home" sounds like a dismissal and abandonment
- Often families hear, "It's all in her head"
What We've Learned

- Family may not be ready to hear, understand, or believe there’s psychological factors making the child vulnerable & the body is responding in a physical manner.
- Symptoms are always real…but in response to stress related factors by generating pain (for example).
- Always “and”, not “or” (physical and psychological, not or).
- Medical system assists families down the medical tract.
- Most families have insight, question psychological factors…but if no one asks, it seems irrelevant and unimportant.

Inpatient Phrasing for Families & HCPs

- Pain is real.
- Psychosocial factors may be impacting the pain.
- There may be psychological factors making the child vulnerable & the body is responding in a physical manner.
- Our goal is to help the patient manage the pain while working on what’s causing the pain….
- Onward to the chronic pain clinic.
- 95% of patients/families accept this, unless they’ve heard “it’s all in your head”.
- Anxiety, “I see you’re a bit anxious and I think it’s impacting your pain….”

Onward to the Chronic Pain clinic.
Chronic Pain Referral

- Medical history
- Psychosocial history
- Inpatient course
- Acute pain team’s assessment
- “Where is the family?”

Multidisciplinary team evaluation

- 1½ hour interdisciplinary evaluation
  - Joint interview with MD and mental health provider
  - OT/PT when applicable
  - Written biopsychosocial treatment plan
- Medical management, mental health treatment, school plan coordination; collaboration with local providers

Patient A (H/A) Psychosocial History

- Lives with mother and father
  - Parents both work outside the home
  - Father recently had a heart attack
- School/Social functioning
  - Good student – A/B; Grades have now dropped
  - Well-liked by peers
  - Involved in: violin lessons, 3 dance classes, theater class, religious education
  - Likes school; verbalizes desire to attend
  - Denies stressors, feelings of anxiety, depressed mood
Patient A (H/A) 
Further Assessment in Pain Clinic

- Recently withdrew from activities (violin, dance, theater)
- Patient stated, "my brain is telling me to cut some of the activities out"
- Mother and patient both become very anxious and worry the H/A will never go away

Patient B (abd pain) 
Psychosocial History

- Lives with mother, father, and older sister
  - Parents both work outside the home
  - Sister diagnosed with fibromyalgia
- School/Social functioning
  - New school this year; grades B's and C's
  - Has made new friends at school
  - Likes school; verbalizes desire to attend
  - Denies stressors or feelings of anxiety or depressed mood

Patient B (abd pain) 
Further Assessment in Pain Clinic

- Parents describe patient as laid back, not much of a worrier
- Mother does believe patient has anxiety about returning to school
- Difficulty sleeping before school; symptoms peak in the mornings
- As return to school was discussed during the appt, patient became noticeably "fidgety".
- Team identified School Avoidance Pattern
School Avoidance “Frame”

- Common occurrence/Good kids/Good parents
- Severe physical symptoms/Medical findings minimal
- Subconsciously, the body is rescuing child by producing symptoms/symptoms that are real, not feigned
- Previously doing well in school/Often deny stress and emphasize the desire to return to school/previous activities, but physical symptoms prevent him/her from doing so
- Miss a lot of school/Functionally disabled/Suffer terribly
- Confused about what is going on

Once SA begins, it takes on a life of its own
- Takes child down and out/Lost sense of competence
- SA complicates symptoms presentation/SA generates symptoms
- Common patterns: Morning desperation, windups, no medical explanation for severity of symptoms
- Will be very hard work for youth and parent
- Coordinated plan between parents, school, team, and child is crucial

Outcomes of Patients A & B
Team Assessments

- Change medications
- Meet with a mental health provider for pain and stress management
- Pain team will contact school
- F/U in 1-2 months
- Call with questions
Nursing Role: Supporting the Frame

- Telephone triage
- Reinforcement of cognitive-behavioral therapy
- Collaboration of medication management

Telephone Triage

- Clinic RN is available M-F, 0800 – 1630
- Answer questions, provide support, reinforce treatment plan
- 721 calls, ranging from 2 – 103 min in length
- Most common call reasons: Increased pain, Medication side effect, School excuse request
- Overall call volume was more than 2x greater during the winter months (Jan-Mar, n=259) than in the summer months (Jun-Aug, n=106)

Cognitive-behavioral Therapy

“is a form of psychotherapy that emphasizes the important role of thinking in how we feel and what we do”

National Association of Cognitive-Behavioral Therapists
http://nacbt.org/whatiscbt.htm
Applying CBT Principles to the Nursing Role

- Education and provision of information
- Reassurance and reduction of anxiety
- Cognitive restructuring
- Problem solving
- Goal setting

Richardson 2006

Education and Provision of Information

- Information can improve coping skills by decreasing anxiety (Richardson, 2006)
- Parents often have questions after initial intake appointment
- RN provides information on child’s pain problem, treatment & rationale, and medications

Reassurance and Reduction of Anxiety

- Parental role uncertainty
- The anxious caller
- LISTEN
- Normalize feelings of anxiety
  - “This is a stressful situation”
  - “You are having a very normal reaction to an abnormal situation”
Cognitive Restructuring

- Identify maladaptive coping behaviors and encourage coping skills
- Challenge parents’ beliefs
  - “What makes you think the medical team is missing something?”
  - “I’m hearing that the school day was very difficult for her, BUT she made it through the day!”

Problem Solving

- Parents call feeling stressed and overwhelmed
- Break down pain treatment plan piece by piece
  - “Try giving her the pain medication about a half hour before physical therapy”
  - “Have him try to eat something now, and then take him to school for the afternoon”

Goal Setting

- Pain team’s overall goal: Increased function, decreased pain
- RN can work with parents to develop shorter goals
  - “Tomorrow she will attend school for at least 2 hours”
- Always acknowledge progress, praise parents
  - “I know the morning must have been difficult, but you did everything we asked of you, and he made it to school”
Patients A and B Phone Calls

- Patient A (H/A)
  - Mom called 3 times before initial intake
  - Mom called 2 – 3 times/week from initial intake to 1st f/u visit (2 months)
  - Average length of call: 13 minutes
  - Total time: 170 minutes

- Patient B (abd pain)
  - No calls to clinic
  - Total time: 0 minutes
Phone Call Tips

- “Tell me what’s going on.”
- “Do you see a stress component to his pain?”
- “It is very common to have a difficult time returning to school after a break.”
- “This has been a pattern for her in the past, and we know that the sooner she gets back to school, the better she will feel.”
- “I will call tomorrow to see how the morning went.”
- “What questions do you have?”

Patient A (H/A) Outcome

- Family did not F/U with mental health after initial visit
- Symptoms continued to escalate; numerous calls to clinic
- Physical therapy, massage therapy and acupuncture-minimally helpful
- 2 weeks pain-free, followed by 10/10 HA
- Family accepted school avoidance frame; began working with therapist and sending pt to school
- Patient finished 2nd semester attending school daily
- June – Pain resolved; stopped all pain meds

Patient B (abd pain) Outcome

- Family accepted school avoidance frame & began working with family therapist
- 1 week later – attending school 2 hours/day; began complaining of back pain
- February – attending school 3h/d, decreased pain complaints
- May – attending school fulltime; when asked, patient endorses pain, but no longer reports pain; patient states the pain does not interfere with any activities
Effective Mental Health Language for Families

"Your child has a complex pain problem that has affected all areas of his life and needs to be addressed from a rehabilitation standpoint. In addition to medical treatment, I would like to refer your child to a therapist to address the impact of the pain on your child’s life and to help him/her learn skills to better manage the pain and challenges of rehabilitation in efforts to restore functioning. The therapist will teach your child stress management and relaxation skills."

Summary

- **Subgroup** of pediatric chronic pain patients
- Requires **interdisciplinary** approach
- Inpatient is just the beginning
- Provide the **context**
- **AND**, not **OR**
- Nurses have the skills to utilize CBT

References