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

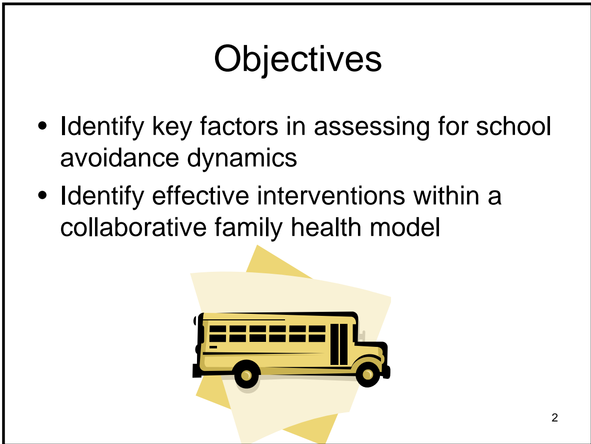
Michelle L. Czarnecki, MSN, RN-BC, CPNP
Caroline O. Madormo, BSN, RN, CPN
Renee J. Ladwig, MSN, CNS, BC, LMFT

Jane B. Pettit Pain and Palliative Care Center,
Children's Hospital of Wisconsin

1

Objectives

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



2

Meet our Patients

- Patient A
- 13 yo female
- H/A, dizziness, fatigue
- 5 day inpatient stay
- Chronic pain clinic 1 month later

- Patient B
- 12 yo female
- Abdominal pain (worse after fatty meal)
- Numerous ER visits
- Admitted - 2 day stay
- Admitted 4 days later for 5 days (ex lap/appy)
- Pain clinic 10 days later
- Admitted 1 day stay ERCP 1 month later
- No further admissions

3

Meet our Inpatient & Outpatient Pain Teams

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

(414) 266-2775
www.chw.org/painmanagement

4

Patient A (Headaches) 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 or feelings of anxiety or depressed mood

5

Patient B (abdimonal 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

6

Patient A (Headaches) Inpatient Stay

- Presented to ER with HA
- Multiple unsuccessful medication trials
- Admitted to hospital
- Withdrawn from friends, physical and recreational activities
- Discharged home after 5 days with PRN Hydromorphone and referral to Pain Clinic
- 1 month later – presented to ER with HA
- Pain Clinic evaluation next day

7

Patient B (abdominal pain) Inpatient Stay

- Sudden onset of abdominal pain
- 1 month later – evaluated in GI Clinic
- 2 months after GI clinic – presented to ER, admitted
- Discharged home after 2 days
- Admitted 4 days later
- Discharged home after 5 days
- Pain Clinic evaluation 10 days later

8

Patient A (headaches) 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 HA will never go away.

9

Patient B (abdominal pain) Further Assessment in Pain Clinic

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

10

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

11

School Avoidance (SA) Definition

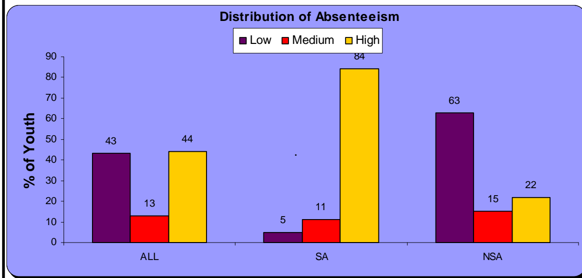
- High rates of absenteeism or inability to attend full day
- Difficulty attending school is associated with:
  - Emotional and physical distress
  - Avoidant coping
  - Functional disability
- Difficulty attending school is <u>not</u> associated with:
  - Serious misconduct or antisocial behaviors
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

School Avoidance Prevalence

- Affects 1-5% of all school age children (Burke & Silverman, 1987)
- Occurs equally in boys and girls, across all socioeconomic & age groups
- 66% of youth with SA present with somatic symptoms (Stickney & 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

13

School Absenteeism Patterns
(CHW Pain Clinic)



Low < 10% Medium 10-29% High > 29%

14

Escalating Functional Disability
(CHW Pain Clinic)

- Overwhelmed with school work
  - Difficulty concentrating in school (68% vs 29%)*
  - Unable to keep up with school work (56% vs 14%)*
- Socially out of the loop
  - Loss of friends (46% vs 13%)*
  - History of peer rejection (40% vs 14%)*
  - Feels isolated (57% vs 19%)*
  - Restricted time with friends (71% vs 37%)*
- Withdrawal from activities
  - No fun, no exercise, pull out of daily routine

Significance p< 0.05%

15

Assessment: Disproportional Symptom Severity

- Often previously healthy/well-functioning
- Child and parent report of severe symptoms; miserable
- Real symptoms, not feigned
- Medical findings don't explain severity
- Escalating symptom severity and functional disability despite treatment
- Frequently no identified psychosocial stressors

16

Assessment: Unexpected Treatment Response

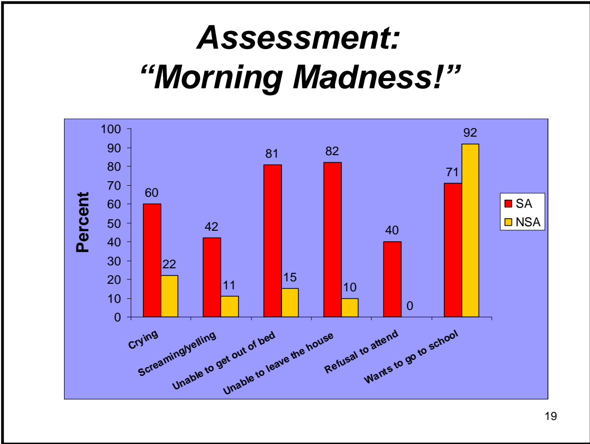
- "Failed" medical interventions
  - Escalating symptom and functional disability Medication trials may not be valid
- Medication response
  - No response
  - Brief response
  - Unusual side affects
- Shifting symptoms

17

Assessment: Symptom Onset and Course

- Onset
  - Start of school year
  - New school
  - Return from vacation and holidays
  - Acute illness
  - Following stressful event
- Timing of intensification
  - Daily/weekly/monthly variation
  - Acute to chronic trajectory

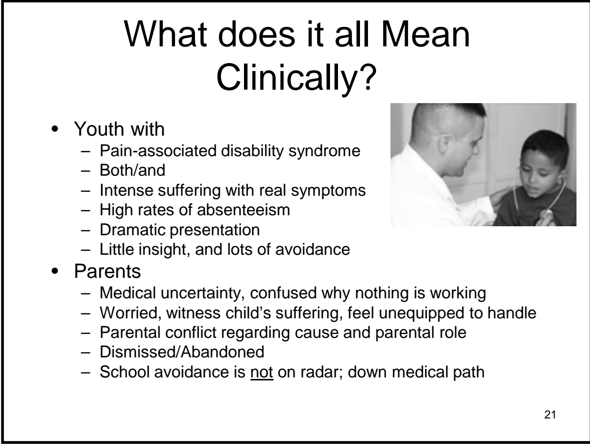
18



Assessment:
High-stress Temperament

- Intense temperament
  - Capable/competent
  - High performance expectations/perfectionist
  - Deny emotional stress, physical manifestation
- Anxious temperament
  - Worrier, difficulty with separation or new situations
  - Eager to please, timid
- Avoidance/Denial
- Present more stressed/anxious than depressed

20



"Just Make Him Go to School…."

- Simple, but is not practical because the parents have no context with which to understand or accept this recommendation
- Minimizes magnitude of the problem
- Sets parents and child up to fail
- Leaves parents feeling inadequate, judged, helpless, ashamed, and angry

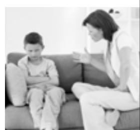
School Avoidance Treatment

- Provide parents, youth, healthcare providers with a *context* to understand the:
  - Impact of school avoidance on pain and disability
  - Constellation of signs and symptoms
  - Rational for treatment strategies

23

Blame and Shame Phrases

- "This is all in his head/psychological."
- "There is no reason for her to have pain."
- "She just doesn't want to go to school."
- "I don't think the pain is real."
- "He's faking."
- "He is making himself sick."



School Avoidance "Frame"

- Common occurrence/Good kids/Good parents
- Severe physical symptoms/Medical findings minimal
- Subconscious level the body is rescuing child by producing symptoms/Sx 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

25

School Avoidance "Frame"

- 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: AM 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

26

School Avoidance Treatment

- Practical, integrated plan to improve pain and functioning
  - Treatment for underlying medical condition
  - Improve child coping skills
  - Return to school plan
  - Management of pain and behavioral symptoms at home and at school

27

Treatment Considerations

- PCP and parent
- PCP/local mental health/school
- Referral to the Chronic Pain Clinic

  (if pain is primary symptom)

28

Effective Mental Health Referrals: Psychotherapist Qualifications

- Works with children/adolescents
- Willing to communicate with the PMP
- Trained in Cognitive-behavioral therapy (CBT) and/or Family Therapy (traditional talk therapy is <u>NOT</u> indicated)

29

Cognitive-behavioral Therapy

- Cognitive-Behavioral skills for managing pain symptoms, anxiety & enhancing sense of control
  - Shifting beliefs and behaviors
  - Build individual coping skills
    - Decatastophizing/Positive Self talk
    - Deep breathing/Relaxation strategies
  - Desensitization/exposure
  - Reinforcing successes in skill development

30

Effective Mental Health Referrals: Collaboration and Parent Education

- Collaboration with therapist
  - Medical perspective
  - "The frame"
- Parent education
  - Treatment goals
  - Insurance
  - Cognitive-Behavioral therapy
  - Roles
    - Psychiatrist - MD
    - Psychologist -PhD
    - Psychotherapist – Masters prepared
  - Goodness of "fit"

31

Effective Mental Health Referral: Language

"Your child has a complex pain problem that has affected all areas of his life and needs to be address 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."

32

Referral to the Chronic Pain Program: When, How & What

- When to refer:
  - Primary symptom is **pain**
  - Severe symptoms and functional impairment
  - Tx/Management challenges
- 1½ hour interdisciplinary evaluation
  - Joint interview with MD and mental health provider
  - Written biopsychosocial treatment plan
- Medical management, mental health treatment, school plan coordination; collaboration with local providers

33

Referral to the Chronic Pain Program: Words are Important

"Despite treatment, your child still suffers from pain. The pain has clearly impacted his/her ability to engage in normal activities. I think your child would benefit from an evaluation by a multidisciplinary team specializing in complex pain problems. They will treat the pain and address the affect the pain has had on your child's life.

34

Patients A and B Medical Treatment

- Thoughtful consideration of medical symptoms, prior evaluation and treatment
- Introduced and maintain the "frame"
- Management of pain symptoms
  - Treat symptoms, but "do no harm"
- Remained medically engaged

35

Patients A and B CBT Interventions with Parents

- Reframe
- Uncouple somatic symptoms, school attendance, and play
- Mother-Father team approach
  - Present as confident, unified front
  - KIND BUT FIRM
  - Non-negotiable attendance expectations
- Predicting behavioral/emotional challenges

36

Patients A and B
School Interventions

- Avoid homebound tutoring!
- Supportive school environment
- Phone contact and school letter
  - Set Frame – medical/vulnerable
  - Request accommodations
  - Behavior/symptom management
- Facilitate parent/school communication
- Act as resource

37

Patients A and B
CBT Goals & Interventions

- Trust in “adult team”
- Relaxation skills/Positive self-talk
- Family therapy (parents and patient)
- Return to school plan
  - Manageable goals and expectations
    - Make-up work, explanations to peers, social reintegration, symptom management at school, grades

38

Patient A (headaches) Outcome

- Family did not follow up with mental health treatment after initial visit
- Symptoms continued to escalate; numerous calls to clinic nurse
- 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
- Pt finished 2nd semester attending school daily
- June – Pain resolved; stopped all pain meds

39

Patient B (abdominal pain) Outcome

- Family accepted school avoidance frame and began working with family therapist
- 1 week later – pt attending school 2 hours/day; pt began complaining of back pain
- February – attending school 3h/d, decreased pain complaints
- May – attending school fulltime; when asked, pt endorses pain, but no longer complains of pain; pt states the pain does not interfere with any activities

40

Factors Limiting Positive Outcomes

- Limited parental buy-in
- Limited parental power
  - Oppositional/defiant child
  - Older adolescents
  - Parent mental illness/role strain
- Extreme physical symptoms
- Chronic problematic absenteeism

41

School Avoidance Summary

- **Subgroup** of pediatric chronic pain patients
- May **affect** pain-associated disability
- Often requires **multi-systemic intervention**
- PCP can assess for and treat school avoidance
- Provide a **context** for understanding the interaction between pain/disability and school avoidance
- Treatment **resources** are available for complicated cases

42

References

- Ladwig, R., & Khan, K. (2007). School avoidance: Implications for school nurses. Journal for Specialists in Pediatric Nursing. 12(3), 210-212.
- Sato, A.F., Hainsworth, K.R., Khan, K.A., Ladwig, R.J., Weisman, S.J., & Davies, W.H. (2007). School Absenteeism in Pediatric Chronic Pain: Identifying Lessons Learned from the General School Absenteeism Literature. Children's Health Care.
- Kearney, C.A. (2001). School refusal behavior in youth. Washington, DC: American Psychological Association.

43