Channeling Rough Waters: Addressing Parent and Child Functioning in a Chronic Pain Rehabilitation Program

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Conflict of Interest Disclosure

• Authors Conflicts of Interest;
  – A. Andrea Ellingson, No Conflict of Interest
  – B. Connie Luedtke, No Conflict of Interest
  – C. Cindy Jasmin, No Conflict of Interest

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– Taken in part from "Do Being a Scientist: Responsible Conduct in Research". National Academies Press. 1995.

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Objectives

• Discuss 3 components of this comprehensive Pediatric Pain Rehabilitation Center (PPRC)
• Describe a correlation between parent distress and their child’s outcome in functioning.
• Identify 3 strategies for re-parenting children with chronic pain, POTS and other symptoms.
“Coast Guard”
Chronic Pain Rehabilitation Program

- 17 day out patient program
- Teens and parents
- Cognitive-Behavioral Therapy
- Teen program started 2008
- Adult program 1974
- Evidenced-based outcomes

The “Perfect Storm”
Patient/parent population with the PPRC

- Types of pain
  - Abdominal
  - Headache
  - Generalized
  - Back
- POTS
  - Any ANS dysfunction

The “Perfect Storm”
Patient/parent population with the PPRC

- Other diagnoses
  - Depression
  - Anxiety
  - PTSD
  - Disordered Eating
- General Demographics
  - 75% females
  - Mean age 15
  - 89% Caucasian
Distress Signal

• Parents of teens with chronic pain and Postural Orthostatic Tachycardia Syndrome (POTS) report distress about their children’s health and functioning.
• We will also review the correlation between parents’ level of distress and parenting styles with their children’s distress and functioning.

Demographics of this Group

• 33 adolescents/parents participated
• ages 12-18
• 76% female, 97% Caucasian
• Diagnosed with chronic pain and POTS
• 50% missed 4 or more days of school past month due to pain/symptoms
• 18.2% on opioids at time of admission to PPRC

Demographics of this Group

• Length of symptoms ranged from
  – 3 months to 12 years
  – Mean 2.5 years
• Pain Ratings
  – Range 0-10
  – Mean pain score was 5
  – Most reported score 7
Navigation/Compass
Review of Clinical Data

- Parent/adolescent depression
- Parent/adolescent anxiety
- Parent/adolescent pain catastrophizing
- Adolescent functional disability
- Parent worrisome and overinvolved behaviors
- Sense of parenting competency

Parent Score predicts change in teen

<table>
<thead>
<tr>
<th>Change in Parent Depression</th>
<th>F = 31.34, p &lt; .001</th>
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<tbody>
<tr>
<td>Change in Teen Anxiety</td>
<td>F = 11.07, p &lt; .001</td>
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<tr>
<td>Change in Teen Pain</td>
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<tr>
<td>Catastrophizing</td>
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<tr>
<td>Change in Teen</td>
<td>F = 9.93, p &lt; .01</td>
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<tr>
<td>Functional Disability</td>
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Parent Score predicts change in teen

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<thead>
<tr>
<th>Change in Parent Pain Catastrophizing</th>
<th>F = 4.35, p &lt; .05</th>
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<tbody>
<tr>
<td>Change in Teen Depression</td>
<td>F = 30.40, p &lt; .001</td>
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<tr>
<td>Change in Teen Anxiety</td>
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<tr>
<td>Change in Functional Disability</td>
<td>F = 12.06, p &lt; .001</td>
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<tr>
<td>Change in Pain Catastrophizing</td>
<td>F = 11.30, p &lt; .001</td>
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### Parent Score Predicts Change in Teen

<table>
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<tr>
<th>Parent Worrisome and Overinvolved Behaviors</th>
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<tr>
<td>Change in Teen Anxiety</td>
<td>F = 29.95 p &lt; .001</td>
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<tr>
<td>Change in Pain Catastrophizing</td>
<td>F = 11.80 p &lt; .001</td>
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<tr>
<td>Change in Functional Disability</td>
<td>F = 10.15 p &lt; .001</td>
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### Parent Score Predicts Change in Teen

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<th>Change in Sense of Parent Competency</th>
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<tr>
<td>Change in Teen Anxiety</td>
<td>F = 30.86 p &lt; .001</td>
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<tr>
<td>Change in Pain Catastrophizing</td>
<td>F = 12.10 p &lt; .001</td>
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<tr>
<td>Change in Functional Disability</td>
<td>F = 10.12 p &lt; .001</td>
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### Correlation
- Parents’ change of behaviors and responses to pain was significantly related to changes in adolescent functioning.
- Parent functioning is important to consider when conceptualizing and treating pediatric chronic pain.
Parent Programming

- Mandatory involvement of parent/delegate
- 2 hour Parenting Sessions 3 times a week
- 1 hour Group Session Daily for all parents/teens
- RN with parents between 15-60 minutes/day 5 days a week
- Psychologist meet with each set of parents ~ 60 minutes/week
- Some need more!

Topics of Parenting Session

- Establishing Rules
- Extreme reasons to “miss” anything
- Pain Behaviors
- Disrespectful behaviors
- Functioning despite behaviors
- Consequences
- Warm Neutrality
- Acute vs Chronic
- Symptom Substitution
- Decreasing reliance on health care system
- Learning how to function differently
- Home going plan

Examples

- Implement at least 3 daily chores despite their child’s level of pain.
- Implement consequences for not completing tasks and displaying disrespectful behaviors, as effective parenting may have been watered down by pain.
- Establish new expectations of their adolescent as a healthy teen, achieving developmental mile stones, and encouraging independence.
Topics of Combined Session

- Cycle of Pain
- Communication
- Diaphragmatic breathing
- Resilience
- Depression
- Sociogram: Family Portrait
- Chemical Awareness
- Autonomic Nervous System
- Managing the Bully
- Pain Sensitization
- Relapse Prevention
- Ask the Pharmacist
- Sleep Hygiene
- Humor
- Motivation/Passions

PPRC Goofing Off
Nurses are in strategic positions...

- To build trust with parents, family and teens and provide education on coping skills to manage symptom flares and fear of catastrophic illness.
- To establish individualized plan for restructuring the family unit and expectations within the home.

Nurses are in strategic positions...

- Set plans in motion to allow teens to be empowered to remain successful in managing their symptoms while returning to school and leisure activities
- Allowing parents to return to work, remove themselves from the caregiver role and back to being a parent, and give them their healthy family structure back.

Implications for Nursing

- There is hope
- Teens and their parents NEED HELP in breaking out of the cycle of medical work-ups, failed treatments, new symptoms, more work-ups...
- Parents need permission and guidance to become parents again
- Behavioral approach is very effective
Questions

References
