Somatic Symptom Disorder: An Evidence-based, Multi-disciplinary, Inpatient Rehab Approach

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About Our Presenter

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Learning Objectives

• Identify 3 or more key principles important for providing optimal care for patients with SSD,
• Discuss effective treatment settings for patients with SSD,
• Utilize strategies to address problematic behaviors commonly experienced with this population,
• Appreciate the challenges and advantages of Clinical Practice Guideline development in busy clinical practice,
• Understand the state of the literature on this topic,
• Recognize the interdisciplinary components of an effective treatment plan for individuals with SSD (pain subtype) or Functional Neurologic Disorder (Conversion Disorder).
Presentation Overview

- Brief description of the process used to develop and update the CPG (5 minutes)
- Summary of literature review (15 minutes)
- Description of protocol (25 minutes)
- Time for discussion, questions, sharing ideas
DEVELOPMENT OF CLINICAL PRACTICE GUIDELINE
Clinical Practice Guideline Development

Helping kids realize what they can achieve
Clinical Practice Guideline Development

- Defend specific treatment paradigms to payers
- Promote best practice
- Support outcome measurement
- Provide base for comprehensive patient education
Clinical Practice Guideline Development

• Because these patients were really challenging!
• Stress/distress to the team
• Sort of similar to other rehab inpatients
• Sort of exactly the opposite
Clinical Practice Guideline Development

Who?

- Physician
  - Angela Sinner, DO
- Psychologists
  - Emily Gale, PhD LP ABPP
  - Nancy Wagner, PhD, LP
- Therapeutic Recreation
  - Tammy Larson, CTRS
- Nurses
  - Elizabeth Potratz, MA RN
  - Karla Ross, CRRN
- Rehabilitation Therapists
  - Amy Schulz, PT
  - Lisa Rounds, MS OTR/L
  - JM Farber, DPT, PCS, ATP

Helping kids realize what they can achieve
Clinical Practice Guideline Development

• 2014
  – Information gathering
  – Literature review
  – Synthesis
  – Presentation to team
  – Revision based on feedback
  – Education

• 2016
  – Updated literature review
  – Review of feedback gathered during first year
  – Development of educational materials
  – Consensus
  – Rewrite
  – AGREE II review
LITERATURE REVIEW - BRIEF SUMMARY
Methods

• First literature search (2014)
  – Conversion, somatoform disorder, somatoform illness AND
  – Pediatric, children, adolescent AND
  – Treatment, protocol
  – No publication dates older than 10 years
  – 151 titles retrieved, 30 selected, 24 read closely
  – 32 additional references
    • Older
    • Personal communications
Methods

• Revision (2016)
  – Conversion disorder, conversion reaction, amplified pain, reflex neurovascular dystrophy, reflex sympathetic dystrophy, chronic regional pain syndrome, psychogenic movement disorder, somatoform disorder AND
  – Treatment, intervention, prognosis, diagnosis
  – 2014 and after
  – 1,898 titles, 102 pulled, 42 additional through citations, 119 in total reviewed
Methods and Results

• Mostly level 4 and level 5 evidence
  – Level 4: case series, case control
  – Level 5: expert opinion

• Lit review form
  – Articles distributed
  – Area of expertise
  – Available time
Nomenclature

- DSM-5²
  - Somatic Symptom Disorder – pain subtype (SSD-PS)
  - Functional Neurological Disorder (FND)
- Need to acknowledge mind-body connection ⁶⁷, ¹⁰⁵
- Potentially increases effectiveness of treatment ⁹⁸, ¹²⁴
- Biopsychosocial condition
Etiology and Epidemiology

• Prevalence 2->11% \(^{141}\)
• SSD may be the third most common psychiatric diagnosis \(^{141}\)
• SSD-PS and FND \(\sim\) 30% of all SSD diagnoses \(^{141}\)
• \(\frac{3}{4}\) of children with SSD have concurrent medical diagnosis \(^{18}\)
• Girls > Boys \(^{18,94}\)
Etiology and Epidemiology

• Bio:
  – More common when ADHD, alcoholism present\textsuperscript{54,116}
  – Evidence of significant structural brain changes \textsuperscript{139}
  – Genetics may play a role\textsuperscript{38}

• Psycho:
  – Insecure attachment style\textsuperscript{14}
  – Impaired emotional awareness \textsuperscript{140}
  – Anxiety and/or depression not uncommon but not universal \textsuperscript{107}
  – History of trauma in about 30% adolescents \textsuperscript{127}
Etiology and Epidemiology

• Social:
  – Symptom modeling \(^{54, 99}\)
  – Positive correlation between family conflict and intensity of symptoms \(^{13}\)
    • Bidirectional influence \(^{13}\)

• Prognosis
  – Evidence limited, maybe better for children \(^{115, 122}\)
  – 20% adults complete remission \(^{47}\)
  – Chronic diagnosis, requires long term management \(^{68}\)
Somatic Symptom Disorder – Pain Subtype

• Criteria
  – One or more somatic symptom significantly disrupts life
  – Thoughts, feeling, behaviors
  – Persistent (> 6 months)
  – Predominantly pain

• Bio:
  – Significant somatosensory cortical reorganization
  – Resolves with resolution of symptoms
  – “Maladaptive neuroplasticity”
Somatic Symptom Disorder – Pain Subtype

• Psycho:
  – Brain areas activated with pain are the same as those activated with emotions and emotional pain\textsuperscript{63}
  – Negative emotional states influence how pain is experienced\textsuperscript{63}

• Social:
  – Miss significant amount of school, re-entry needs to be part of any program\textsuperscript{64}
  – Cultural and spiritual influences on symptoms\textsuperscript{63}
Functional Neurological Disorder

• Commonly called “Conversion Disorder”
• Criteria:
  – 1+ symptoms of altered voluntary motor or sensory function
  – Incompatibility between symptoms and known disease
  – Not better explained by another diagnosis
  – Causes significant distress and/or impairment¹
• Presence of a medical diagnosis does not rule out diagnosis of FND¹, ¹²⁰
Functional Neurological Disorder

• Bio:
  – Incidence higher with history of brain damage\textsuperscript{72, 117}
  – Brain changes on MRI\textsuperscript{3, 38, 133}
  – Unclear if changes are a result or a marker\textsuperscript{134}
  – MRI evidence that habituation to fearful stimuli does not occur\textsuperscript{4}
  – Autonomic dysfunction compared to age-matched peers\textsuperscript{65}

• Psycho:
  – Some suggest that symptoms are, in part, maintained through classic operant conditioning\textsuperscript{120}
  – Early trauma, stressful events, parenting styles\textsuperscript{38}
  – As many as 39% do not have concurrent psychological diagnosis\textsuperscript{131}
Functional Neurological Disorder

• Social:
  – Rejection in interpersonal relationships\(^9\)\(^3\)
  – Poor emotional regulation and recognition together with unexplained medical symptoms associated with insecure attachment\(^6\)\(^0\)

• Considerations
  – Hoover sign, abduction sign, finger abduction sign, spinal injury test all demonstrate good specificity and sensitivity to confirm FND diagnosis\(^3\)\(^5\)
  – FND and SSD-PS are not mutually exclusive diagnoses\(^5\)\(^9\)
Sharing the Diagnosis

• In order to be successful with intervention, diagnosis needs to be shared with both patient and family\textsuperscript{5, 6, 20, 115}

• But shared with care and compassion, avoiding terms like “hysterical” and “psychogenic”, and avoiding the appearance of judgment or blame\textsuperscript{87, 108, 116}

• Highlight and emphasize that it is normal that the mind affects the body and vice versa\textsuperscript{64, 116}
Common Components of Treatment

• Multidisciplinary team most effective\textsuperscript{22,24,36,90,95,120,126}
  – “entrenched patterns of pain ...or disability [that cannot be] removed by purely psychosocial interventions... Conversely, the exclusive application of a medical model may escalate symptoms...” \textsuperscript{24}
• Team needs to be cohesive, with unified message\textsuperscript{5,6,46}
• Family should not be present during treatment\textsuperscript{5,6,16,73,115}
• But should work on making changes to dynamics that will benefit the child\textsuperscript{64}
• Primary focus: reduction of symptoms, restoration of function, learning coping skills\textsuperscript{37,77}
Common Components of Treatment

• Bio:
  – Engage patient’s senses in a safe environment and in a step-wise fashion to “prove” that normal movement is possible\(^{23,80,118}\)
  – Initiate and maintain regular physical fitness\(^{23,52}\)

• Psycho:
  – Cognitive behavior therapy (CBT) helpful for any type of pain of long standing, not just SSD\(^{28}\)
  – CBT recognized as effective component\(^{11,54,102}\)
  – Increased awareness of mind body connection\(^{21,24,76,104}\)
Common Components of Treatment

• Social:
  – Family needs to be involved (function of child cannot be separated from function of family)\textsuperscript{27, 103}
  – SSD in children associated with mental illness in family or marital discord \textsuperscript{18, 109}
Treatment Specific to SSD - Pain Subtype

• Functional and social impairment, sleep disturbance, missing school as bad or worse than children with chronic disease and cancer\textsuperscript{61}

• Bio:
  – Graded motor imagery may increase longevity of effect and decrease resistance to therapy\textsuperscript{23,80}
  – Brain changes and laterality training\textsuperscript{58,80}
  – Pain exposure training effective in treating chronic pain\textsuperscript{8}
Treatment Specific to SSD - Pain Subtype

• Psycho:
  – CBT, diaphragmatic breathing, acceptance and commitment theory based approaches have all been shown effective\textsuperscript{33,79}

• Social:
  – People with SSD-PS see negative expression in faces more than those without\textsuperscript{112}

• Intervention principles:
  – Emphasize that function returns before pain resolves\textsuperscript{5,24}
  – Intensive exercise programs (homework)\textsuperscript{33,79,115}
Treatment Specific to Functional Neurological Disorder

• Bio:
  – Learning to ___ programs\textsuperscript{56, 90, 120, 128}
  – In general, remove assistive devices as soon as possible, avoid giving new ones\textsuperscript{16, 25, 56, 73, 90, 120}

• Psycho:
  – Work to improve implicit to explicit emotional processing effective\textsuperscript{19}

• Social:
  – Modeling of illness behavior and enabling are common in social circles and should be addressed\textsuperscript{54, 99, 115}
Outcome Measures

- Functional Disability Inventory, Child Health Questionnaire $^{61, 70, 95}$
- Children’s Somatization Inventory $^{54, 61, 135}$
- Reporting on objective outcome measure very limited in the literature
Helping kids realize what they **can** achieve

Clinical Expertise

Best Research Evidence ➔ EBP ➔ Patient Values & Preferences

Gillette Children’s
Specialty Healthcare
THE PROTOCOL
<table>
<thead>
<tr>
<th>Inclusion</th>
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<tbody>
<tr>
<td>• Children 10-18</td>
<td>• Diagnosed moderate to severe psychiatric disorder</td>
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<tr>
<td>• Diagnosed with FND or SSD-pain subtype</td>
<td>• Severe untreated mental illness (anxiety, depression)</td>
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<tr>
<td>• Diagnosis explicitly shared with patient and family</td>
<td>• Worker’s comp or litigation</td>
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<tr>
<td>• OP therapy has not been effective</td>
<td>• Contagious illness</td>
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<tr>
<td>• Significant loss of function</td>
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Protocol – Before Admission

• Will recommend outpatient therapy first
• Need to be sure diagnosis is shared with child and family explicitly
• Admission planning meeting
  – One to two weeks before admission
  – Explain parameters of program
  – Expectations on both sides, contract
  – Information gathering and sharing with team
Protocol – Treating Team

- Attending Physiatrist and/or Fellow
- Child’s Psychologist
- Family Education Psychologist
- Physical Therapist
- Occupational Therapist
- Therapeutic Recreation Specialist
- Rehab Nurses (champions each shift)
- School Teacher
- Child Life Specialist
- Potentially: Music Therapist, Speech Language Pathologist
Protocol – Day of Admission

• Always on a Monday
• Maximize team consistency
• No more than 2 on unit at any one time
• Set schedule
  – Admission to unit, orientation
  – Arena evaluation
  – Team meeting
  – Family meeting
Protocol – History at Evaluation

• Child’s past medical history
  – History of prolonged illness or disability in family
• Psychiatric history, patient and family
• Primary problems per patient and family
• Previous interventions
• Level of function home, school, and community before symptom onset
• Activities that have been discontinued because of symptoms
• Patient and family goals
Protocol – Typical Frequency

- Child’s psych 4-5 times per week
- PT, OT twice a day plus once a day Saturday
- Therapeutic rec 5 times per week
- Family education psychologist meets with family 2 times per week or more
- Music, child life, school as indicated
Protocol –
Use of Assistive Devices (AD)

• In general, avoid introduction of new AD
• Considerations-
  – Patient safety
  – Staff safety
  – Potential for secondary gain
  – Time
• Decisions made as a team, never use AD as a temporary measure
Protocol – Team Communication

• Note to team describing pre-admission meeting
• Weekly team meetings
• All changes communicated through rounds notes
  – Back up plan for changes made after notes are sent
• Expectation that all staff who work with patient review all written communication
• In person hand off from primary therapist to evening shift nurse
Protocol –
Team Communication

• Nurse champion on each shift
  – Provided in depth review of CPG
  – Assists with in the moment problem solving
  – Close communication with CPG team

• Goal cards
  – Reviewed before session/shift
  – Progress assessed by patient and by staff

• “Learning to __” progression, when appropriate

• Debriefing after discharge
Protocol –
Communication with Family

• Family not present during the day
• Questions funneled to attending/fellow
• Phone call each day to report progress, answer questions
• Family conference weekly, team meeting first fifteen minutes
• Potential observation of therapies
Protocol – Communication with Patient

- Avoid direct confrontation
- Don’t reinforce non-functional behaviors
- Careful with non-verbal communication
- Reassurance that the team has expertise
- Create expectation for recovery
Protocol – Patient/Family Agreement

• Parent does not stay overnight, is not present during therapy day
• Only family may visit, only during specified hours
• Communication will be through physician
• No electronic devices
• Homework can be completed in room (not bed)
  – Otherwise, in common areas during down time
• Lights out by 10:30 p.m.
Protocol – Patient/Family Agreement

• Up and ready to go by 8:30 a.m.
• Follow all hospital rules
• No social media sites set up around admission
• No day or overnight passes; possible therapeutic rec outing
• Family participates in education at least twice per week
Protocol -

Intervention SSD - Pain Subtype

- Pain neuroscience education

- Graded motor imagery
  - Increase time
  - Static to more dynamic

- Laterality practice → mirror therapy
  - Recognise App ®

- Initiation of aerobic exercise

- Sensory discrimination practice

- Pain exposure therapy
Protocol-Intervention Treatment Specific to Functional Neurological Disorder

• Functional limitation is identified
• Use task analysis to develop step-wise progression
• Initiate “Learning to ___” program
• Or dual task paradigm
• Negative reinforcement or deep rest
Protocol - Day of Discharge

• Discharge teaching session with PT/OT/ psych, patient and family
• Family education psychologist meets with family before family conference
• Family conference
Protocol - Discharge Plan

• Functional improvement is expected by discharge, but not complete resolution of symptoms
• Strategies taught for lifelong management of symptoms
• Likely recommendation for ongoing therapies
  – Family counselling
  – Psychology
  – PT or OT, tapering quickly
Protocol – Outcome Measures

• Admission and one year follow up
  – Canadian Occupational Performance Measure
  – Multidimensional Anxiety Scale for Children – 2\textsuperscript{nd} ed
  – Children’s Somatization Inventory
  – Children’s Depression Inventory, if indicated
  – Beck Depression Inventory, if indicated
Protocol – Outcome Measures

• Admission and discharge
  – Neuropathic Pain Scale
  – Ten meter walk test
  – Six minute walk
  – Recognise App (SSD-PS)
  – WeeFIM (also every week)
Protocol – Key Points

• Communication
  – Transparent
  – Complete, then a little more
  – Unified

• Consistent team

• Good preparation

• Education for child and family
CEUs for Occupational Therapists

• IPRC thanks our partners at WeeFIM for sponsoring today’s CEUs.

• To obtain CEUs for today’s event, each participant must have attended the full presentation and complete an online evaluation to receive a certificate.

• An evaluation link and instructions will be emailed to all registrants. Please share with all attendees.
Survey & Certificates of Attendance

• IPRC values your opinion. Following the webinar, a survey link will be emailed to all registrants. Please share with all attendees.

• A certificate of attendance for today’s presentation may be requested via the survey.

surveymonkey.com/r/IPRCwebinarsurvey
Questions
Group Discussion Questions (Optional)

1. How can our program improve the way we deliver care to individuals with SSD?
2. Who are the key contributors from our rehab team involved in the care of individuals with SSD? Do we need to seek additional resources?
3. How do we measure progress/success with this population? How do we track this over time?
4. How can we improve the quality of our communication with the patients and families impacted by this diagnosis?
Citations


Helping kids realize what they can achieve
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