Integrated Care for Children and Youth who Experience Distress Through Physical Symptoms (Somatization)

ANU CHAHUVER, MSW, RSW
JOEY LATINO, MD, FRCPC
HANA SAAB, PHD
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Consultation Liaison Psychiatry Program, The Hospital for Sick Children

The Department of Social Work, The Hospital for Sick Children

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No disclosures
Welcome

Hopes for the talk today?

What are your experiences working with this population?
Objectives

1. Understand a child/youth’s somatic symptoms within a biopsychosocial framework and the 4 phase model for somatization

2. Review evidence based interventions and resources for somatization

3. Apply targeted interventions to cases based on the phase of somatization and the setting
Distressing physical symptoms are common and can be impairing

Affects up to 40% of kids/teens:
- Headaches, nausea, recurrent abdominal pain, fatigue
- School Absenteeism
- More common & complicated in medically ill

Increased use of health services
- Repeat Doctor and ER visits
- Unnecessary medical investigations
- Increased hospitalizations

Stigma - Risk of unrecognized medical illness

Maisami et al 1987; Offord et al, 87; Kreipe 2006; Geist et al 2008
Terminology

- Somatization
- Medically unexplained symptoms
- Psychosomatic complaints
- Functional/Non-organic
- Somatic Symptom Disorder
- Conversion Disorder
  (Functional neurological symptom disorder)
Somatic Symptom Disorder

1+ somatic (physical) symptoms – distressing / impairing
++ associated thoughts, feelings and/or behaviour
Persistent

Specifiers:
- With predominant pain
- Persistent
- Severity: mild / moderate / severe
Conversion Disorder
(Functional neurological symptom disorder)

1+ symptoms of altered motor / sensory function
Incompatibility between symptom & neurological / medical condition
Significant distress / impairment / requires medical evaluation

Specifiers:
◦ With weakness / paralysis; abnormal movement, swallowing symptoms; speech symptom; attacks/seizures; sensory loss; special sensory symptom; mixed
◦ Acute / persistent
◦ With / without psychological stressor

DSM 5
Somatic symptom as “body language” for an “unspeakable dilemma” → Sick Role

- Mood
- Issues/conflicts
- Behaviour
- Interpersonal

Stressors → Emotional predisposition

Physiological factors
Family factors
System factors

Broom, 1997; Maisami et al 1987; Griffith et al 1998
Mind-Body Connection: Brain-Body

**Biopsychosocial stressor**

**Weak**

**Strong**

**Hippocampus**
Regulates memory and emotions.

**Amygdala**
Turns on fight or flight, and stores memories of the event.

**Prefrontal Cortex**
Thinking/logic/what to do/evaluation.

**Fight-or-Flight Response**

**Immune System**
- Is suppressed

**Heart**
- Beats faster
- Pumps more blood
- Blood pressure rises
- Blood increases to muscles
- Blood decreases to organs

**Endocrine System**
- Pumps out adrenaline, noradrenaline & cortisol
- Noradrenaline constricts blood vessels
- Releases less growth hormone
- Produces fewer sex hormones

**Lungs**
- Breathing becomes faster & shallower
- Consume more oxygen
- Expel more carbon dioxide

**Skin**
- Sweating begins

**Pancreas**
- Pumps out glucagon
- Produces less insulin
- Blood sugar level rises
Collaborating to understand

- Biological (medical)
- Psychological (individual)
- Social (Family, peers, school)
Individual Factors

- Medical illness, injury
- Somatosensory amplification; sensitivity to pain
- Stressors/Losses → stress, fear, shame, embarrassment, anger
  - Examples: related to academics, activities, bullying, relationships, family, deaths, trauma, abuse
- Anxiety, Depression
- Perfectionistic
- Minimizes stress
- Learning disability, difficulty labeling feelings

Wynick et al 1997; Maisami et al 1987; Middleton et al 2008; Shaw and DeMaso 2006; Griffith et al 1998; Kozlowska et al 2009
Family Factors

- Perception of child/teen – vulnerable, sick, fragile
- Perception of illness – scary, life threatening
- Family illness, disability, somatization
- Family stress
- Communication breakdown
- Perception of / response to emotional expression of distress

DSM5; Shaw et al 2006; Campo et al 2001, Geist et al 2008
Community Factors

- Attention
- Expectations
- Response

- Physical Complaint
- Sick Role
- School Avoidance

- Comfort
- Altered Expectations / Interactions
Medical System Factors

**Biomedical approach: mind-body dichotomy**

- **Focus on Somatic Complaint**
  - Investigations to search for underlying physical cause

- **FP**
  - Pain

- **FN**
  - Anxiety
  - Complications

**Kreipe 2006**
“Body Talk: Stories of Somatization”

https://www.youtube.com/watch?v=Dt36kZyN5wg

Stories of Somatization - Part 1

http://keltymentalhealth.ca/Somatization-Disorders
4 Phases → Pathway → Targeted Intervention

Phase 1: Confusion
Family searching for medical Dx / Rx;
Patient/ family does not acknowledge stress/stressors

Phase 2: Connections
Family open to mind-body discussion / education
patient/family acknowledges stress / stressors

Phase 3: Integrated Care
Family is engaged in integrated & coordinated treatment (medical / mental health / rehab)

Phase 4: Recovery
Patient/family addressing stressors, using strategies

Pirlot, Chapman and De Souza 2017
Targeting Interventions to the 4 Phases

**Phase 1: Confusion**
- Integrated Mind Body Connection (iMBC) Clinic
- Paediatric Consultation Clinic

**Phase 2: Connections**
- CL Psychiatry clinic (interdisciplinary)
- Mind Body Connection (MBC) Parent Education Night
- Individual, family therapy
- Mind Body Connection (MBC) group therapy
- Brief Therapy clinic

**Phase 3: Integrated Treatment**
- Treatment (physician, rehab, individual and family therapy)
- Care plans & School letter template
- Tuning In Group therapy
- Family Therapy treatment seminar

**Phase 4: Recovery**
- Follow-up as needed
- Children’s mental health
- Primary care
PHASE 1: Confusion
Family searching for Medical Diagnosis & Treatment
Patient/Family does not acknowledge stress/stressors

Approach:
- Assessment through a biopsychosocial lens
- Coordinated & integrated with defined roles and consistent language

Strategy:
- Outpatient: Paediatric Consultation Clinic → Integrated Mind-Body Connection Clinic (iMBC) Clinic - An Integrated Pediatric & Consultation Psychiatry Clinic
The Integrated Mind-Body Connection Clinic is an interdisciplinary clinic for children and adolescents with distressing and impairing physical symptoms. The clinic aims to provide families with a biopsychosocial understanding of the nature and impact of the symptoms as well as an integrated management plan. The clinic incorporates an interdisciplinary approach to care that includes consultants from medical, mental health and rehabilitation fields.

**When:** Monday afternoons, starting January 8th, 2018  
**Where:** The Hospital for Sick Children, Clinic 7A – Main floor  
**How:** Referral to Paediatric Medicine Consultation: Integrated Mind Body Connection Clinic  
**Referral route:** Medical inpatients; Subspecialties (e.g. Neurology, GI); Emergency Dept; Community Physicians
iMBC Clinic

Interdisciplinary Clinic
(medical, mental health, rehab)

Biopsychosocial & Integrated Approach

For distressing and impairing physical symptoms

Mind-Body Connection

Understanding

Diagnosis

Integrated Treatment

communication

For Phase 1 Somatization

Mind - Body Connection

Understanding

Diagnosis

Integrated Treatment

communication
PHASE 2: Parent Education Night

Understanding the Mind and Body Connection
A talk for parents and others affected by distressing and impairing physical symptoms
Offered twice a year
Provide information about how to understand somatic symptoms, how parents can cope, and strategies to support their child to improve functioning
Interdisciplinary Education to Families

- **Offer hope**
  - Normalize symptoms & team’s experience

- **Discuss treatment principles**
  - Normalize routine, emphasis on improving functioning / coping / ability
  - Strategies using a biopsychosocial approach

- **Review collaborative interdisciplinary approach**
  - Roles of team members (medical / mental health / rehab)
  - Monitoring / plan for follow-up
  - Communication

- **Discuss resources**
Mind Body Connection Group

Background & Description

• Developed by BC Children’s Hospital and is currently being run out of Sick Kids, Alberta Children’s Hospital, CHEO…
• Psychoeducational group for parents and caregivers
• Learn about connection between the mind & body
• Assists with recognizing, accepting, and responding to emotional experiences and improvement of physical symptoms
• Caregivers learn how to coach their child to use skills that are taught and how to meet their emotional needs
• Peer connection & mutual aid
Mind Body Connection Group

Group Structure
• Manualized 6 session program, occurs weekly
• Consistent session structure
• Caregivers and youth start each session in the same room
  • Introductory information
  • Review of previous week utilizing a fun activity i.e. charades, Pictionary, game show
  • Videos
• Break out into separate groups – latency age (8-13), teen group (14-18), caregiver group
  • Content same in all groups, modifications for latency age group
  • 1:1 format provided to non-English speaking caregivers with a translator
• Caregivers/Youth end each session together
  • One-word check out
PHASE 3: Integrated Treatment

*Family is engaged in integrated & coordinated treatment (medical / mental health / rehab)*

Setting: Out-patient, (Community)

Approach: Medical / mental health / rehab follow-up

Strategy:

- Clinical - CL Psychiatry treatment – complexity / severity determines type, location and duration of treatment and required disciplines: OT, PT, BT, APN, case manager, SW, Psychology, Psychiatry
  - Care plans
  - School support – school letter template
  - Family therapy treatment seminar
  - *Tuning In* Group therapy
- Mental health professional education
  - CL / Community education sessions
Individual & Family Therapy Treatment

**Clinical treatment**

- Psychotherapy: individually for the Patient and as a family
- Strengths-based Approach: focused on Gradually returning to functioning – school, seeing friends, etc.
- Collaborating with Patient & family to identify areas of strength as well as times when physical symptoms are not present or are less impairing

**Treatment Interventions:**

- Identifying emotions and physical symptoms / body cues
- Notice the situation / stressors
- Identify the thoughts and notice actions / behaviour
- Developing coping strategies and ways to shift unhelpful thoughts and beliefs
- FOCUSING ON VALUES, SKILLS AND ABILITIES
- EXTERNALIZING PROBLEMS AND SYMPTOMS
- DEVELOPING IDENTITY OUTSIDE OF SICK ROLE
Group Therapy: Tuning In—10 week group intervention

**Tuning in: Parent Group**
- Psychoeducation
- Supportive
- Strategy
- Mutual Aid

**Tuning in: Teen Group**
- Psychotherapeutic group
- Focus on support and facilitating emotional expression in teens
- Promoting mutual aid and understanding amongst parents
Teen Group Session Outline

Mindfulness Moment
Check-in
Review
Group Activity
Check out
Key components in early stage of group

Development of safety, use of humour, opportunities to connection outside of scope of illness, sharing food

Providing psycho-education, normalizing experience

Naming and recognizing common stressors / triggers

Building toward emotional expression
Components in middle stage of group work

Creating opportunities for non-verbal expression of emotions, thoughts and experiences

Presenting metaphor of internal vs external

Use of art allows for creative expression, development of insight
Outside/Inside Exercise
Movie: Inside Out

https://www.youtube.com/watch?v=QT6FdhKriB8
Trajectory of symptoms vs emotional expression
Components of ending phase of group work

Consolidation of learning – through messages to self, parents, peers and health care providers

Advocacy – discussion of next steps

Constructive feedback within group and to group leaders

Reinforcing the progress, future planning

Ending, goodbyes, focus on hope
Stewing Pot Exercise

Teens individually write down stressors

Group members take turns picking from the stewing pot and discussing for themselves and with the group messages to

- Family
- Peers
- Self
- Health Care Providers
Themes of symptoms, pain & emotions from teens

Pain can be invisible.
The pain affects my mood.
Why would I want this
I’m not faking it – the pain, the symptoms
Don’t push me.
Even what looks like small strides are really big => require huge effort.
Physical symptoms/pain can look like a ‘real illness’, you have to ask.
When I am not able to express my emotions, my symptoms increase.
It is as real as a physical illness
Don’t be so overprotective
Stop asking me if I’m okay
Themes about self: From teens

Don’t walk on eggshells around me
I am my own person. I have my own thoughts, feelings and beliefs.
I’m more than just a good dancer/good student/good athlete (what you idealize or intend me to be).
You can’t speed up my journey
Be proud of me.
Please understand I am working hard.
Don’t get mad when I don’t meet the expectations you set for me.
I’m proud of what I’m able to do and I wish you could recognize my effort.
Be empathic toward me
Stop treating me like a baby
I’m still the same person I was before
Giving Voice: hard feedback from teens to parents

Why did you dismiss what has happened / what I’m going through regarding my diagnosis?

Why weren’t you supportive?

Your upset feelings and anger shut me down.

Just shut up! (listen to me without interrupting)

Just because you feel something doesn’t mean I will feel the same way.

The fear of your negative reactions steals my voice.

You don’t realize that the fear of being shut down or of a negative response causes me to have more symptoms.
Parent group

STRUCTURE OF SESSION
Check in
Activity/Discussion
Education
Check out

THEMES EXPLORED
Sharing experiences
Understanding symptoms
The family context
Family dilemmas
Teen’s perspective

Each session had specific purpose and goal and the education and discussion was developed to address the purpose.
Process of parent group

Developed as a psycho-educational and mutual aid/support group.

Incorporating psycho-education in order to assist parents in helping teen cope with somatization symptoms

To enable parents to offer support to each other as this is an isolating experience for many families
Messages from parents to themselves

Our teens are really smart & will figure it out.
Be good to yourself; be easier on yourself
Be patient with yourself & your teen
Take care of yourself – so you can take care of others.
Seek help if you’re stressed
It’s ok to talk about it to other people.
Get rid of the guilt
Don’t blame yourself.
We’re not alone.
It’s common.
There’s hope.
People are open to talking about it.
There are good resources – keltymentalhealth.ca
Messages from Parents to Teens

We’re trying – keep telling us.
We’re not perfect – we make mistakes.
We want you to feel comfortable talking with us – how you feel...
We’re there for you.
We don’t know what it’s like to be you – help us understand.
Don’t push others away.
Let us know if you think we’re wrong.
Please forgive us if we’re wrong.
We know you’re trying.
We don’t see you as a burden.
We’re hopeful that we / you will get well.
We look forward to things getting better.
Parents’ Suggested Strategies

Try to understand what it’s like for teen
Find opportunities to talk with teen about stress
Coordinate / tag team
Give control – offer choices
Set limits, consequences
Manage own concerns, expectations, behaviour
Refuel (self-care)
Create a support system
Parents’ take home messages

• We are not alone
• We are more than our teens’ diagnoses
• We can get through this
• There is hope
• We accept the peaks & valleys as part of the norm
• Celebrate all our successes

• Don’t be too hard on ourselves; It’s ok to fail
• We have to take care of ourselves so that we can support teens
• You have to have patience
• We (parents & teens) each may have our own path with the shared goal of teens being successful, happy and healthy
Parent group feedback

- Very helpful to know others have similar symptoms
- Helpful to gain perspective from other parents with similar struggles
- Relief to have a place to discuss this otherwise taboo topic
- Relief that we’re not alone
- Feel like we have to walk on egg shells with the teens
- Unsure how much to push the teen
- Recognized importance for teens to talk about their issues with other teens
- Catalyzed conversations after

- Medical system – has failed a number of people
- Doctors walking on egg shells
- Doctors need to say what next steps are
- Would like to create a website – see progress
- Create a family network
Parents’ feedback to healthcare professionals

Families feel misunderstood & in distress (home, community, hospital)

Parents feel worried, helpless, frustrated, useless, blamed

Varied terms / diagnoses used are confusing

Parents seek understanding, support & strategies

What parents want from health care system:

- Explanation
- Approach for symptoms
- Education for clinicians to counter “there’s nothing wrong / faking
Teen Messages to Health Care Providers

Use consistent language

Use the words somatic symptom disorder and or conversion disorder

Educate others about these symptoms

Provide accurate information about my symptoms and allow me to talk about difficult subjects

Just because you haven’t seen my symptoms before doesn’t mean they aren’t real

I’m not faking!
PHASE 4: Recovery

*Patient/family addressing stressors, using strategies*

- **Setting:** Community (Out-patient)
- **Approach:** Reinforcing skills & transition to community (primary care, mental health)
- **Clinical Strategy:**
  - Periodic integrated follow-up: Reinforcing what’s been learned
- **Education**
  - CL/Community education sessions
  - TeleLink education for community mental health / primary care
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<tr>
<th>OUTCOME</th>
<th>Patient 1 Not Accessing Pathway</th>
<th>Patient 2 Accessing Pathway</th>
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<tbody>
<tr>
<td>Access to right care</td>
<td>Delay with increased healthcare utilization</td>
<td>Expedited with decreased healthcare utilization</td>
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<tr>
<td>Cost</td>
<td>Increased</td>
<td>Decreased</td>
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<tr>
<td>Duration of symptoms</td>
<td>Increased</td>
<td>Decreased</td>
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<tr>
<td>Impairment</td>
<td>Increased</td>
<td>Decreased</td>
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<tr>
<td>Collaboration</td>
<td>Fragmented</td>
<td>Enhanced, coordinated</td>
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<td>System capacity</td>
<td>Impacted</td>
<td>Enhanced</td>
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<tr>
<td>Team satisfaction</td>
<td>Decreased</td>
<td>Improved</td>
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<tr>
<td>Patient/family satisfaction</td>
<td>Decreased</td>
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Micro-level: Pre and post assessment of patient and family outcomes
Micro-level: Evaluation of the Integrated Mind Body Connection (iMBC) Clinic

Patient & Family-level Outcomes:

• Quality of Life measure-KIDSCREEN (pre-visit, at 3, and 9 months).
• Functional Disability Inventory (pre-visit, at 3, and 9 months).
• Beliefs About Somatic Symptoms (BASS; pre-visit, 3 and 9 months)
• Patient disposition (engagement in treatment; 3 and 9 months)
• Patient and family Satisfaction with the iMBC clinic (at 3 months).
Micro-level: Evaluation of the Integrated Mind Body Connection Groups

Pre-Intervention Measures:
- Parent information sheet (parents only)
- Children’s Somatization Inventory 24 (CSI-24)
- Functional Disability Inventory (FDI)
- Pain Stages of Change Questionnaire (PSOCQ)

Post-Intervention Measures (immediately after the 6th & final session):
- Children’s Somatization Inventory 24 (CSI-24)
- Functional Disability Inventory (FDI)
- Pain Stages of Change Questionnaire (PSOCQ)

Post-Intervention Interview (2-4 weeks after the 6th & final session):
- To gather information about the patient and family experience and their satisfaction with the MBC Group intervention
Micro-level: Evaluation of the Tuning In Group

**Quantitative Outcomes:**
- Understanding Somatic Symptoms and Coping Rating Scale
  - Developed by tuning-in group facilitators
  - Responders indicate how they feel in areas of symptom interference, understanding of symptoms, coping strategies, and use of coping strategies
- Outcome Rating Scale
  - Used by therapists to assess psychological outcomes individually, interpersonally, socially, and overall

**Qualitative Outcomes:**
- Adolescents: participants were asked to discuss what they would like to communicate to their family, friends/peers, health care team, and to themselves
- Parents: parents participated in interviews that asked about the impact of the group, logistics of the group, feedback, and suggestions for future group sessions.
Evaluation of the Tuning-In Group: Results

Quantitative Outcomes:

- Adolescent participants reported significant improvements in:
  - their understanding of somatic symptoms ($Z = -2.09, p=0.03$)
  - their overall sense of personal well-being ($Z = -1.98, p=0.04$)
## Evaluation of the Tuning-In Group: Results

### Qualitative Outcomes (Adolescents):

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<tr>
<th>Theme</th>
<th>Representative quotations</th>
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| **The importance of feeling supported by family and peers/friends** | “I just want your support”  
“‘I appreciate it when you ‘have my back’”                                                                                                                                                                      |
| **The importance of having symptoms taken seriously** | “Why did you dismiss what has happened or what I’m going through regarding my diagnosis?”  
“‘It’s not something I do for attention or to be dramatic’”                                                                                                           |
| **The need to express one’s emotions and be accepted** | “The fear of your negative reactions steals my voice”  
“When I am not able to express my emotions, my symptoms increase”                                                                                                       |
| **Daily challenges of somatic symptom disorder and conversion disorder** | “I know that I water down what I tell you about the pain but if I could be there (at school/with friends) I would”  
“It’s really difficult getting up and going to school with my symptoms”                                                                                     |
| **The importance of family taking pride in the adolescents’ accomplishments** | “I’m proud of what I’m able to do and I wish you [parent] could recognize my effort”  
“Please understand that I am working hard”                                                                                                                        |
| **Wanting to maintain a sense of normalcy**     | “I don’t want people to walk on eggshells around me”  
“I want to be treated normally”                                                                                                                                     |
Evaluation of the Tuning-In Group: Results

**Qualitative Outcomes (Parents):**

• Better understanding of child’s physical and emotional symptoms as a result of the group

• Parents noted various positive changes in their children including communicating more with friends and seeking support from friends

• Parents expressed that the group felt like a safe space to vocalize their thoughts and concerns and had their feelings validated by other members of the group

• Parents expressed wanting more practical tips or suggestions about how to parent a child with somatic symptom disorder
Meso-level: Evaluation of the Somatization Strategy at SickKids

**Outpatients**

Effectiveness of the iMBC clinic at improving healthcare system efficiencies by:

- Reducing direct and indirect hospital costs
- Repeat visits to SickKids after referral to community resources (9 months after initial visit).
- Admission rates and healthcare use for patients before and after engagement with the iMBC clinic

**Inpatients**

Effectiveness of the somatization strategy at improving healthcare system efficiencies by:

- Reducing Length of Stay
- Reducing resource use (Resource Intensity Weight)*
- Reducing unplanned readmissions

*A relative value that describes the expected resource consumption of an average patient*
Macro-level: Determine the Burden of Somatization at the Provincial Level

33,272 Children and youth, ages 4 to 24 with a confirmed diagnosis of somatization between Jan. 1 2008 & March 31 2015

A 2 year lookback to explore:
• Demographic characteristics: Age, gender, urban/rural, income diagnostic & healthcare characteristics)
• Health service use and costs 2 years prior to somatization diagnosis

A 1 year look forward to explore: Health service use and costs after establishing diagnosis
Why a Multilevel Evaluation Framework?

• To improve our understanding of who the somatization patient population is?

• To highlight the healthcare burden of somatization

• To triangulate information and data from multiple sources to strengthen claims about findings
Thank you!