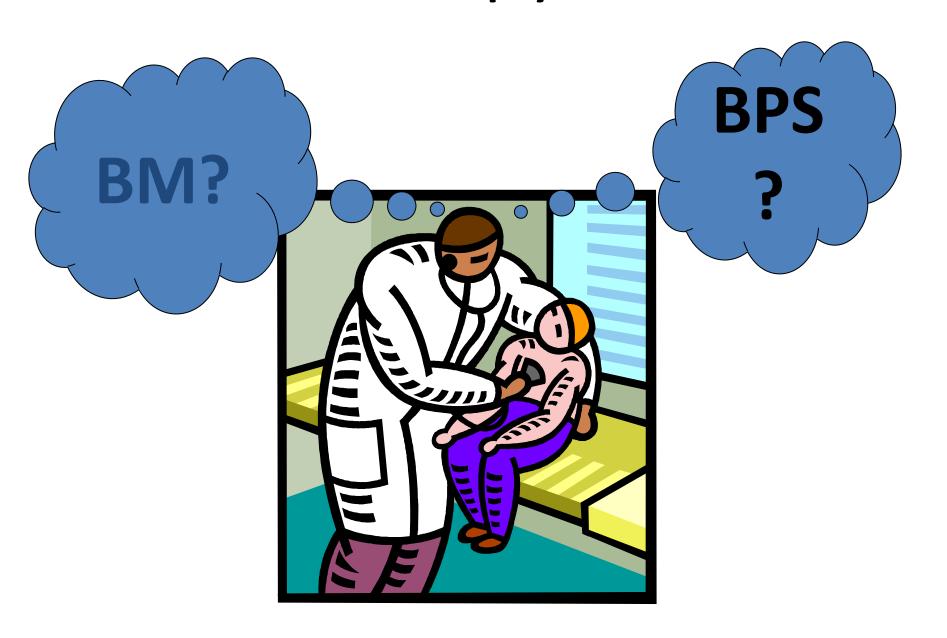
#### CHNOLA JumpStart Pain Program

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&

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#### Biomedical vs the Biopsychosocial Model



#### Disease

Objective anatomic abnormalities and/or pathophysiology

#### Illness

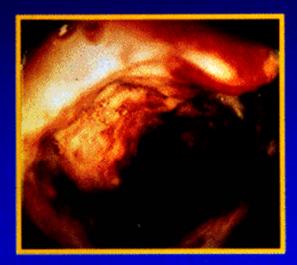
Suffering,
decreased
capacity for
functioning in
life's activity



## Medical Model

Disease

- pus
- blood



**Not Disease** 



## Medical Model

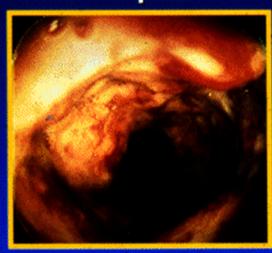
Disease

pus

blood

**Not Disease** 

Good patient



**Bad patient** 



#### Clinician's Response to Bad Patient

**Irritation** 

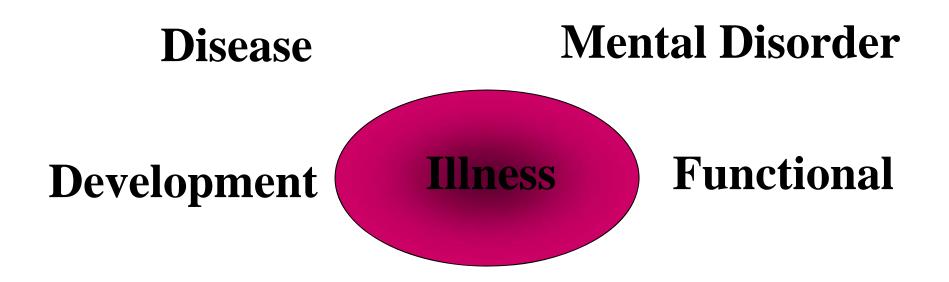
**Anxiety** 

Helplessness

**Anger** 

**Avoidance** 

#### **Biopsychosocial Model**



**Culture and Society** 

#### **Functional Gastrointestinal Disorders**

... Chronic or recurrent symptoms not

explained by structural, biochemical or

psychiatric abnormalities...

# CHRONIC FUNCTIONAL ABDOMINAL **PAIN** DISORDERS

- Irritable bowel syndrome
- Functional dyspepsia
- Functional abdominal pain
- Functional abdominal pain syndrome

Disability associated with functional gastrointestinal disorders is proportional to coexisting psychological distress.

## Psychological Issues are Common in **Disabled** Youth with FGIDs

- Anxiety
- Depression
- Sleep impairment



In preteens and teens with an FGID, disability is proportional to the patient's perception of their own academic or social incompetence.

#### FGIDs: IMPACT ON QOL

Impaired school and social life

Poor coping

Physical and psychological Severe

Modera

co-morbidity





## FGID TREATMENT HIERARCHY

- INTERdisciplinary approach
- Psychological treatments
- Rehabilitation
  - Manage stress
  - Pharmacotherapy

Moderate

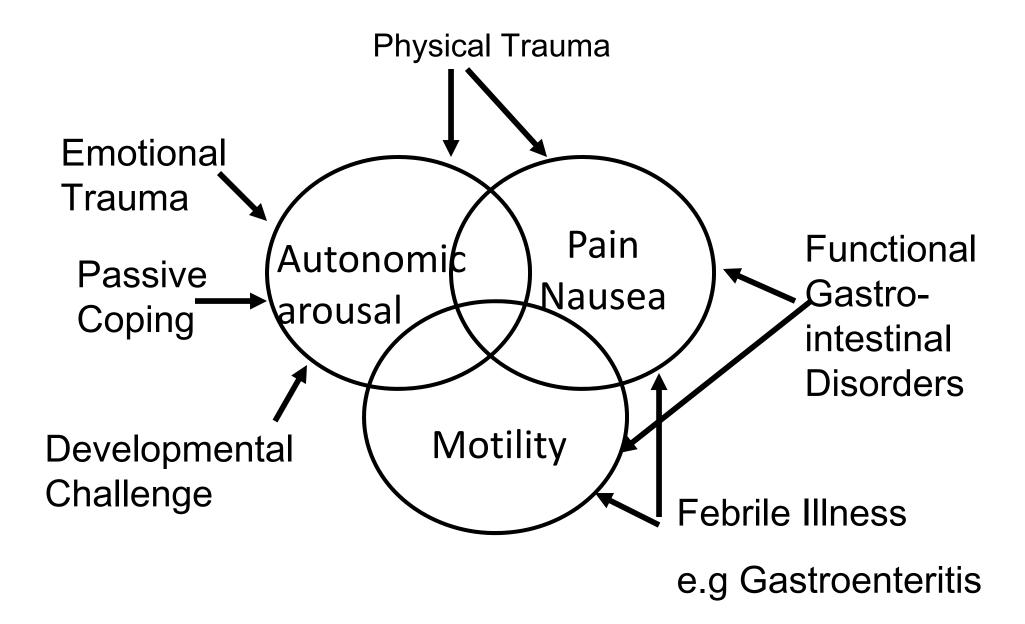
Severe



- Diet, lifestyle
- FGID diagnosis

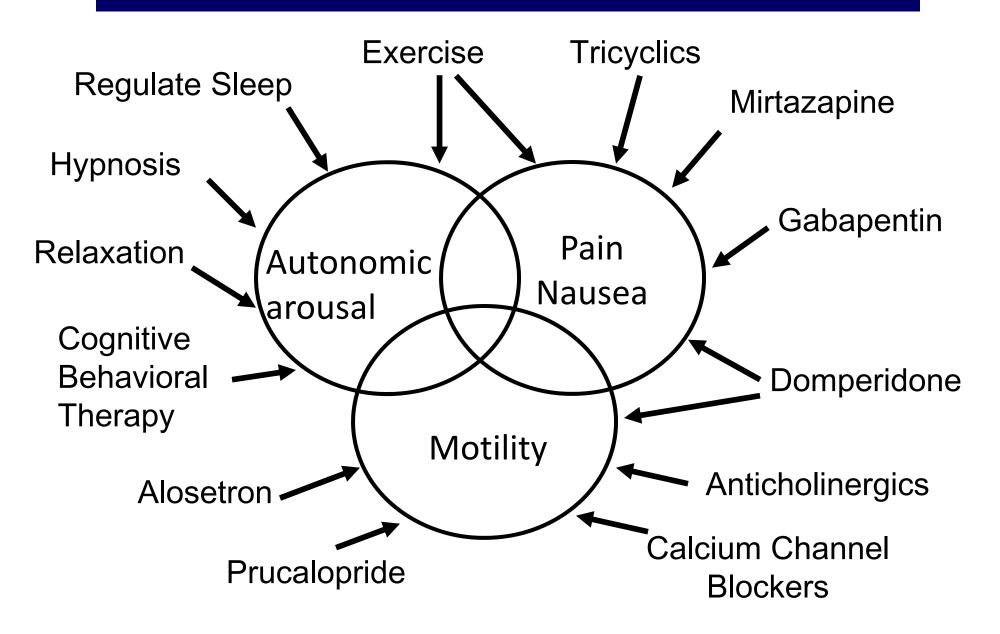


## Pathogenesis



For children disabled by a FGID, treatments such as CBT, hypnosis, and psychotropic drugs improve coping and resolve psychological distress and symptoms. Treatment targeting the CNS is often more successful than treatment targeting the GI tract.

#### **Treatment**



## Why JumpStart?

- Referral patterns for unexplained pain/nausea/vomiting lead to neurogastroenterologists like Dr Hyman
- We've acquired the requisite skills for a successful program after years of managing complex patients and families
- There is a need for this niche

#### JumpStart Pain Program Goals

- Change a family's expectation that a doctor will do something to cure the disease to a model in which the patient gets themselves better. We transition from an acute care model to rehab model.
- Shift the treatment goal from pain reduction to improved functioning in daily activities.
- Identify factors that cause or maintain symptoms and provide targeted treatment.
- Develop, and modify, an individualized plan based on patient's response during admission.

#### **Admission Criteria**

- Ages of 9 and 19 y
- Symptom-based diagnostic criteria for one or more functional gastrointestinal disorders
- Failed standard community care
- Family must express willingness to participate in treatment

#### **Exclusion Criteria**

- Malignant or inflammatory bowel disease
- Self injurious behavior or suicide attempts in the past three months
- Current substance abuse
- Current narcotics dependence
- Current eating disorder

#### JumpStart Pain Program: Personnel

- Neurogastroenterologist
- Clinical Psychologist
- Physical Therapist
- Occupational Therapist
- Child Life Specialist
- Family Therapy
- Inpatient Nursing
- GI Nurse Coordinator

#### JumpStart Pain Program: Outpatient Assessment

- Rigorous four hour pre-admission outpatient assessment
  - (medical, psychological, physical and occupational therapy)
- Education: Answer the 4 Questions:

What is wrong with my child? It's an FGID

Is it dangerous? No

Will it go away? Yes

What can we do about it? We'll show you!!!

#### Creating an Expectation for Success

- Signing a contract with child and family
- No testing necessary or desirable
- Absolutely no pain experiences
- No sleep interruptions; facilitating restful sleep
- Comfort a priority...they wear their own clothes
- Emphasis on improved functioning rather than reduction in pain

#### JumpStart Program Structure

- Staffing with team on week prior to admission
- 5 day inpatient hospitalization on our 3<sup>rd</sup> floor
- Scheduled treatments fill the day; patient participation is required
- Mid-week staffing
- Discharge meeting with family on Friday afternoon

#### What Does Dr Hyman Do?

- Meet with patient and family 30 min daily to answer questions ("Don't you think she needs a scope?" "No. We know what is wrong. No testing is necessary or desirable.")
- Assess and adjust medications to assure restful night of sleep
- Re-iteration the brains and guts are connected
- Prevent medicalization

#### What Does Dr Lewis Do?

- Meet with patient individually for 1 hour each day
- Cognitive behavioral therapy
- Exposure and response prevention
- Relaxation training
  - PMR, diaphragmatic breathing, imagery, hypnosis
- Coordinating care between team members
- Planning for transition home and to outpatient services
- Reinforce healthy behaviors, instill hope

#### Cognitive Behavioral Therapy

 Understanding and utilizing the relationships between thoughts, feelings, and behaviors to promote positive change

- Listen Listen and Listen some more
  - Why did your pain start?
  - What is causing your pain?
  - What will happen if you go to school hurting?
  - Is it possible for your pain to get better?

#### Cognitive Restructuring

All or nothing / black and white thinking

"My tummy hurts so bad, I CANNOT go to school"

"If my tummy hurts at school I can practice my breathing exercises. If that doesn't work I can take a 15 minute rest in the nurses office."

"Even if my tummy hurts, I am excited to go to school and see my friends. I am lonely staying at home."

"I noticed yesterday at grandma's birthday party I felt less bothered by my tummy when I was playing with my cousins. I think the same thing could happen when I am school with my friends."

## What Does Physical Therapy Do?

- 1.5 hours of daily therapy
- Improve endurance
- Increase strength and flexibility
- Moving your body regardless of pain
- Reinforce healthy behavior, instill hope

#### What Does Occupational Therapy Do?

- 1.5 hours of daily therapy
- Improve functioning in activities of daily living
- Activity planning and pacing
- Sensory desensitization
- Relaxation training

Reinforce healthy behaviors, instill hope

#### What Does Child Life Do?

- Meet with patient for 1 hour each day
- Provide opportunities to engage in enjoyable activities that promote independent functioning and improve self confidence
- Problem solve and provide rewards for progress
- Plan outings to practice skills in real life
- Reinforce healthy behaviors, instill hope

## What Does Family Therapist Do?

- Meet with parents, without patient, for 1 hour each day
- Reinforce tenants of treatment
- Uncover and problem solve stressors at home
- Trouble shoot financial barriers
- Plan for transition back to home and school
- Reinforce healthy behaviors, instill hope

#### What Does Nursing Do?

- Support the daily and nightly schedule
- Use our language
- Refrain from vitals & disturbing sleep
- Provide feedback to team on patient and family progress
- Reinforce healthy behavior, instill hope

## Case Example

- 11 y AA M with 24 y mother with SS disease, low income from rural Ms
- Abdominal pain, leg pain, progressive weakness, lack of appetite, insomnia and 10 kg weight loss beginning 3 m prior to admission
- No disease found after huge medical work-up and several hospitalizations

#### Case 1 Treatment week

- Day 1 & 2... Participated as requested; pain persisted
- Day 3 Mother disclosed belief that son's disability and pain was caused by voodoo curse by maternal grandmother
- Day 4 Hospital lawyers stated that we do not discriminate by religious preference; Mom was permitted counsel from a voodoo priestess.
- Day 5 Voodoo priestess works with family; child runs up 3 flights of stairs;

#### Case Resolution

- Mother and child felt wonderful after the JumpStart Treatment week.
- They recognized the biopsychosocial factors that lead to symptoms and symptom resolution.
- Staff felt proud about the outcome, and excited to take on the next challenging family

## **Next Steps**

- Follow-up on long term responses for JumpStart graduates
- Opportunity for prospective clinical research trials
- JumpStart day program for local kids with chronic pain

## Questions



Suggested Reading: <u>Conquering Your Child's Chronic Pain</u> Lonnie Zeltzer, MD