Managing pain in children with developmental disabilities

# Therapeutic Failure:

## Why do things go wrong even when you are doing everything right

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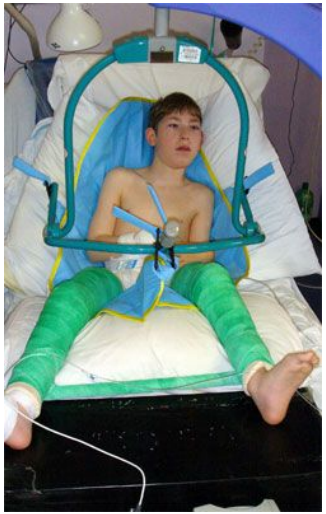
No conflict of interests

# LEARNING OBJECTIVES

- Describe pain in children with developmental disabilities
- Establish an approach to getting started with pain assessment & management
- Develop an approach to ‘therapeutic failure’ (what to do when nothing works?)

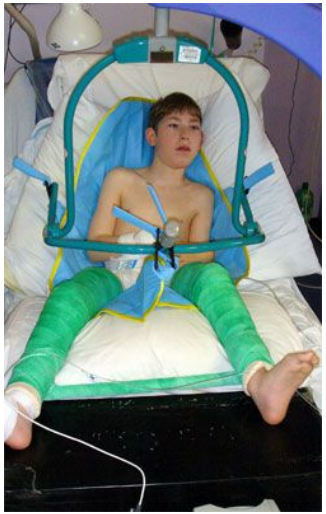


# Clinical Vignette

12-year-old with choreoathetoid cerebral palsy

- Presenting Issues:
  - poorly controlled movement disorder & significant weight loss
  - increased frequency and intensity of arousal/irritability & crying
  - irritability of unknown origin ? Pain

- CNS:
  - movement disorder/spasticity
  - seizure disorder
  - history of thought and mood disorders
  - cognitive ability - borderline (~70)



# Clinical Vignette

- MSK:
  - dislocated hips & chronic bilateral hip and chronic knee pain
- GI:
  - fed orally & via  gastrostomy tube
  - gastroesophageal reflux
- Social/emotional:
  - family disorder – birth mother's poor mental health & foster mother's pregnancy
- Communication:
  - variety of monosyllabic words, facial expressions, and body movements.

# Clinical Vignette

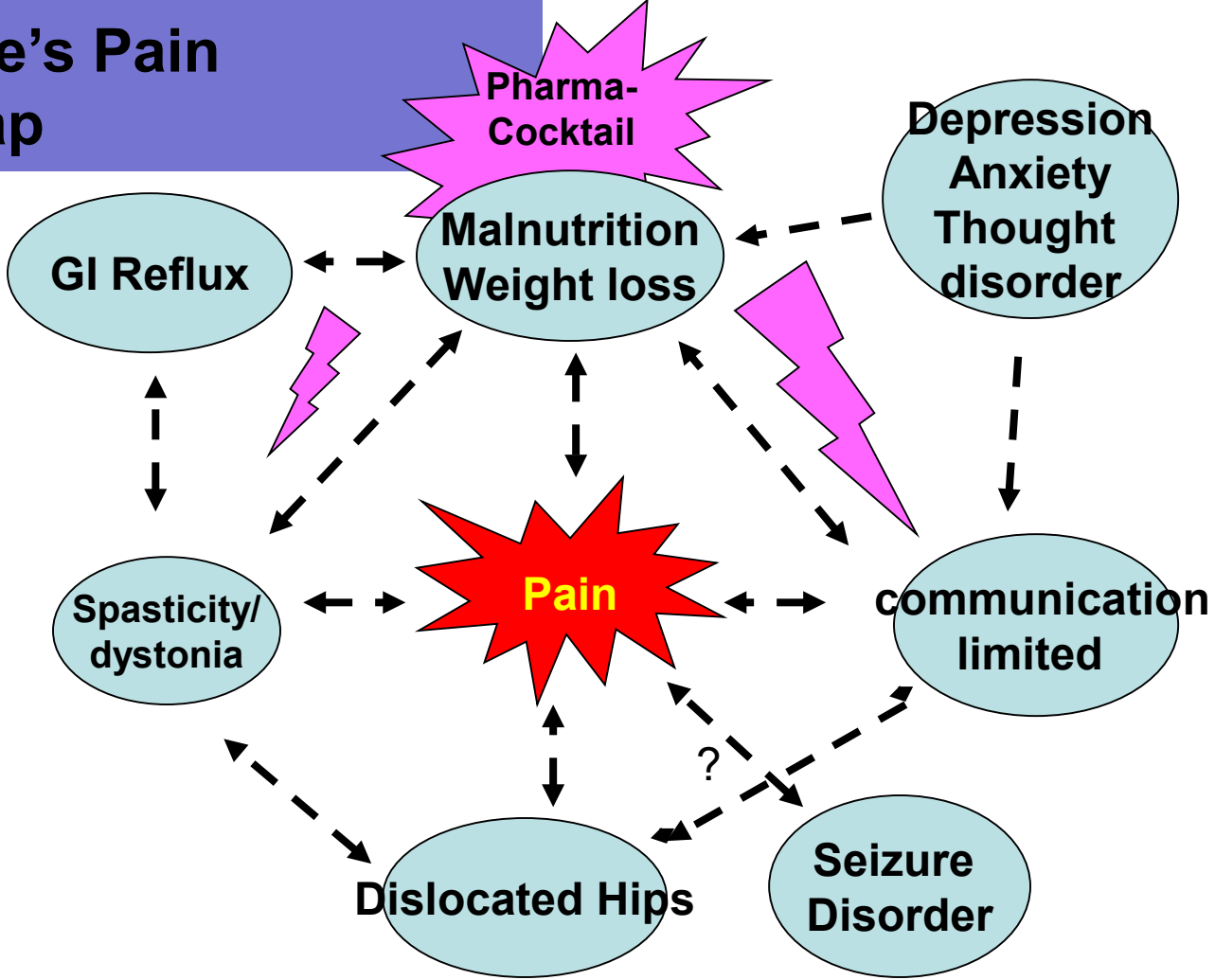
- Medications
  - Baclofen, clonazepam, erythromycin
  - phenytoin, omeprazole, chlorpromazine, paroxetine, salbutamol
- “prn” ibuprofen & acetaminophen + codeine
- Meperidine then added: no pain relief

- Impact of chronic irritability:
  - *limited* participation in activities of daily living (dressing, school, social function),
  - *reduced* appetite & increased weight loss
  - *disrupted* sleep, mood, and mobility
  - *increased* his rigidity, muscle tone, GI refux

# Clinical Vignette

- Joe's care:
  - Multiple professionals
    - family physician, pediatrician, psychiatrist, orthopaedic surgeon, community nurses, social workers
  - Spread across multiple locations
  - No common venue for communication or case coordination.
- All increasingly concerned about pain, its impact & frustrated with apparent  therapeutic failure

# Joe's Pain Map



# Take Home Message

- Pain in children with a developmental disability:
  - common every day problem
  - adds to existing disability
  - challenging to recognize and manage
- Pain management may fail and contribute to further pain and suffering
  - particularly pharmacological approaches
- Easy to get onto the *"calamity cascade"*
- Mind set counts:
  - long-term perspective, multidisciplinary processes

# 5 Reasons for Therapeutic Failure

## Why do things go wrong even when you are doing everything right

1. Limited knowledge & bias
2. Limited access to the pain experience
   - is pain assessment possible?
3. Diagnosis is in doubt…
4. Right drug, but….
   - wrong dose, route, pharmacokinetic, metabolic, genetic factors, etc
5. Context:
   - Mismatch between caregiving environment, communication and expectations

# 1. Limited Knowledge & Bias

“An unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage….

….The inability to communicate in no way negates the possibility that an individual is experiencing pain and is in need of appropriate pain relieving treatment.” *

(http://www.iasp-pain.org/terms-p.html, 2001)

* May still fail to recognize that individuals who lack self report often communicate very effectively using non verbal behavior – K. Craig

VIEWPOINT

# Pain in Children With Severe Neurologic Impairment
## Undoing Assumptions

"Does a child with severe impairment of the CNS experience pain?"

**Julie M. Hauer, MD**
Division of General Pediatrics, Boston Children's Hospital, Harvard Medical School, Boston, Massachusetts.

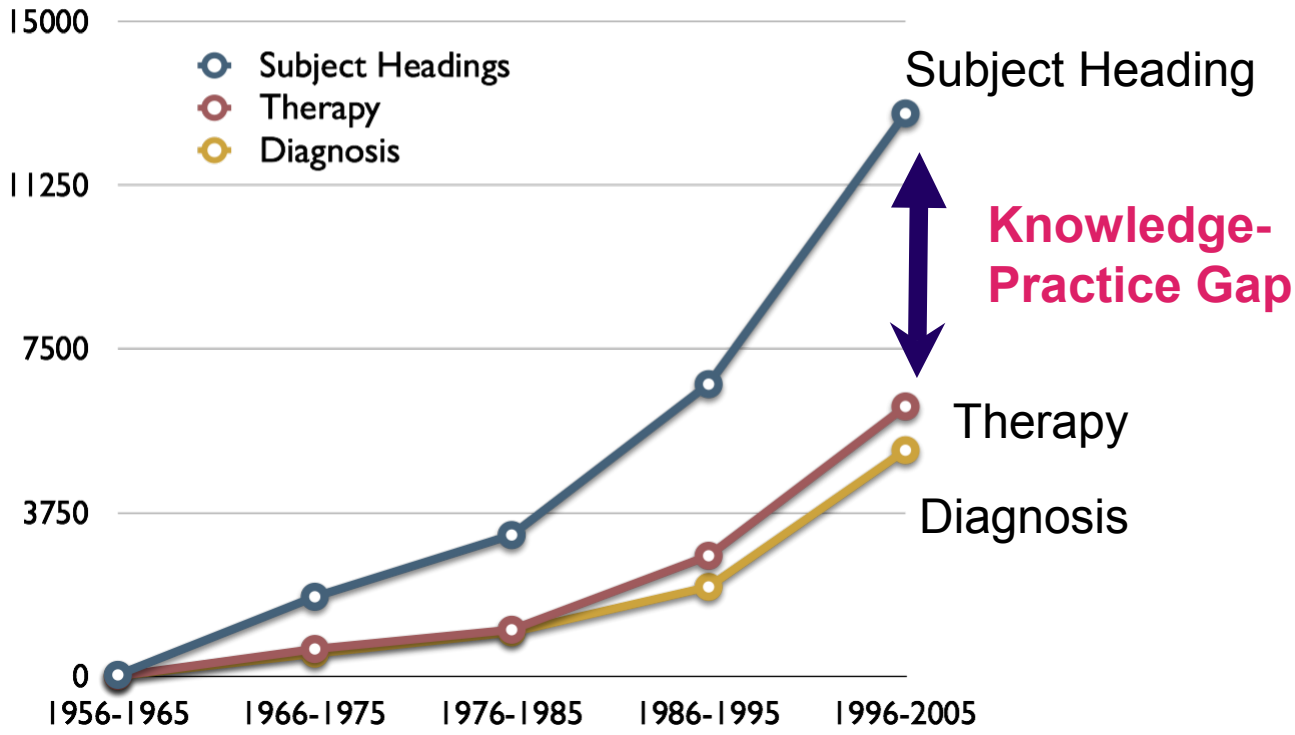
**I encountered 2 similar comments** this week: "we don't think she experiences pain" and "there remains uncertainty... whether [she] has sufficient awareness to *experience* the burdens associated with pain." The first comment was shared by a colleague at another institution involved in the care of a child with severe impairment of the central nervous system (CNS) with pain features who was looking for suggestions about how to

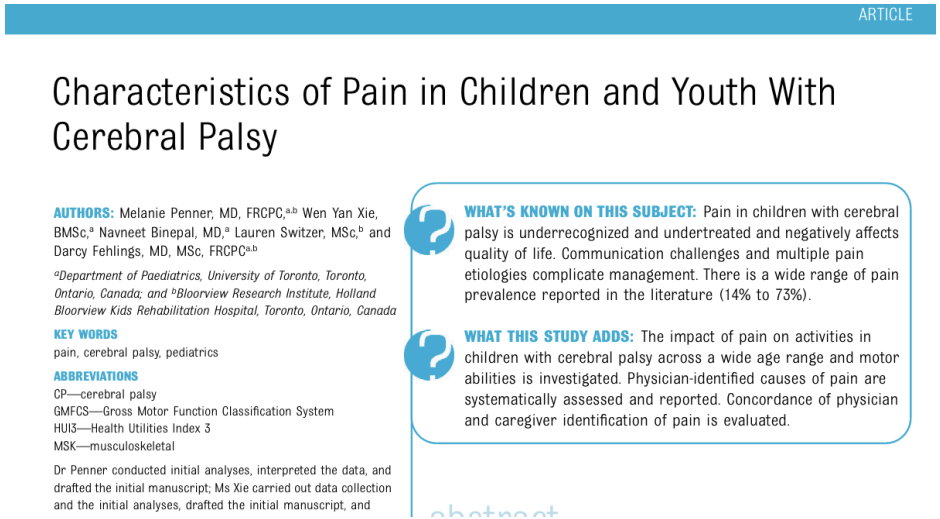
pain; (2) acute new pain that is an expected manifestation of a new cause of tissue injury or inflammation (ie, nociceptive pain); and (3) chronic pain with intermittent breakthrough symptoms. There is a need to better define chronic vs acute pain.[4] Chronic pain in children with SNI is more complicated because it can be caused by sources for which there are no tests, such as central neuropathic pain and autonomic dysfunction. In addition, new pain episodes when

- The wrong question to ask (we can never prove that such a child does not feel pain)
- Misconception that experiencing pain requires consciousness with a functional cortex
- Thalamocortical projections that relay sensory transmissions from the spinothalamic tract to the thalamus and then the cortex
  - present at 30 weeks' gestation.
- Example: parents of children with hydranencephaly were asked whether their child felt pain
  - 96% said yes
- No reason to believe that physiologic stress response (increased catecholamines, cortisol etc) associated with untreated pain is any less harmful to children with SNI

Hauer JM. Pain in Children With Severe Neurologic Impairment Undoing Assumptions. *JAMA Pediatr.*2018;172(10):899–900

# Childhood Pain Citations (Medline)





ARTICLE

# Characteristics of Pain in Children and Youth With Cerebral Palsy

**AUTHORS:** Melanie Penner, MD, FRCPC,[a,b] Wen Yan Xie, BMSc,[a] Navneet Binepal, MD,[a] Lauren Switzer, MSc,[b] and Darcy Fehlings, MD, MSc, FRCPC[a,b]

*[a]Department of Paediatrics, University of Toronto, Toronto, Ontario, Canada; and [b]Bloorview Research Institute, Holland Bloorview Kids Rehabilitation Hospital, Toronto, Ontario, Canada*

**KEY WORDS**
pain, cerebral palsy, pediatrics

**ABBREVIATIONS**
CP—cerebral palsy
GMFCS—Gross Motor Function Classification System
HUI3—Health Utilities Index 3
MSK—musculoskeletal

Dr Penner conducted initial analyses, interpreted the data, and drafted the initial manuscript; Ms Xie carried out data collection and the initial analyses, drafted the initial manuscript, and

**WHAT'S KNOWN ON THIS SUBJECT:** Pain in children with cerebral palsy is underrecognized and undertreated and negatively affects quality of life. Communication challenges and multiple pain etiologies complicate management. There is a wide range of pain prevalence reported in the literature (14% to 73%).

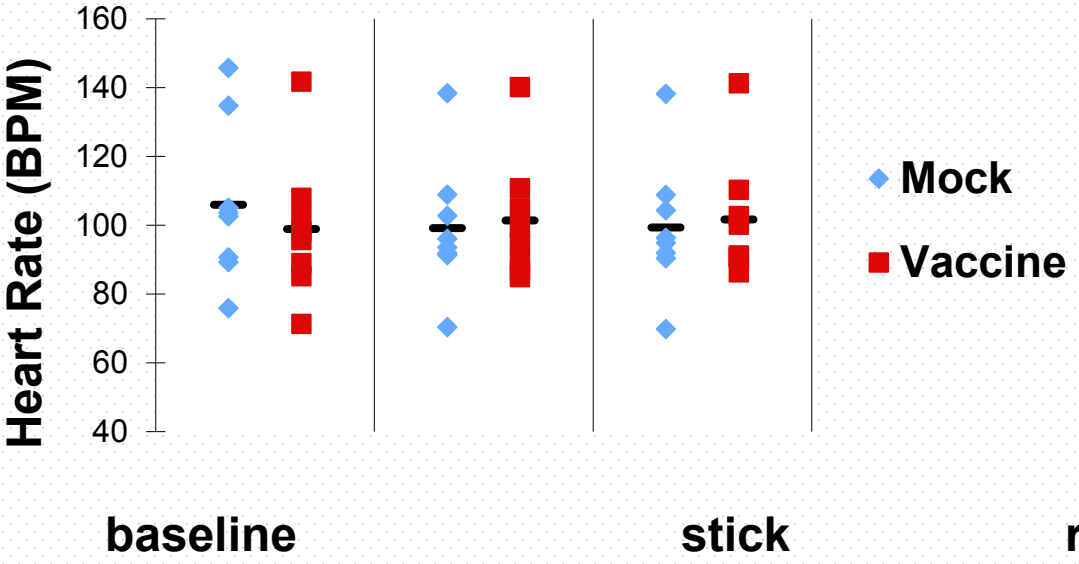
**WHAT THIS STUDY ADDS:** The impact of pain on activities in children with cerebral palsy across a wide age range and motor abilities is investigated. Physician-identified causes of pain are systematically assessed and reported. Concordance of physician and caregiver identification of pain is evaluated.

abstract

- children & youth 3 -19 years across all levels of severity of CP
- 54.8% reported pain
- 38.7% physicians reported daily pain
- 24.4% of caregivers reported pain limited activities and participation
- hip dislocation/subluxation, dystonia, & constipation frequent causes

Pediatrics 2013;132: e407–e413

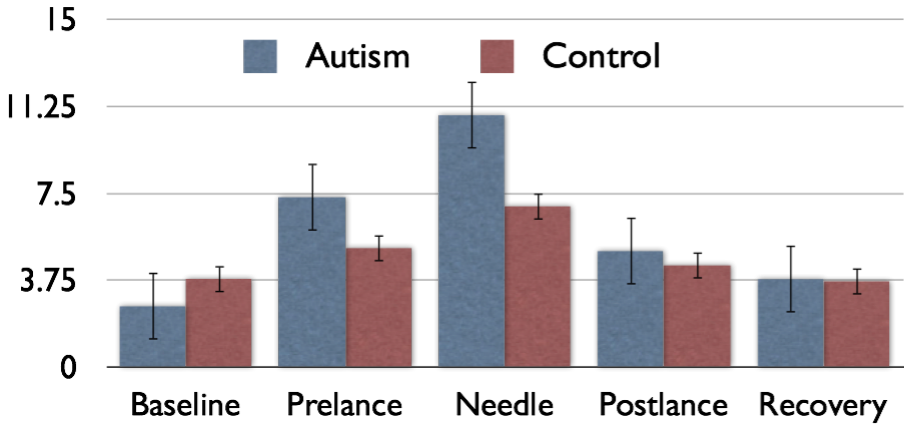
# HR responses to vaccine in youth with CP



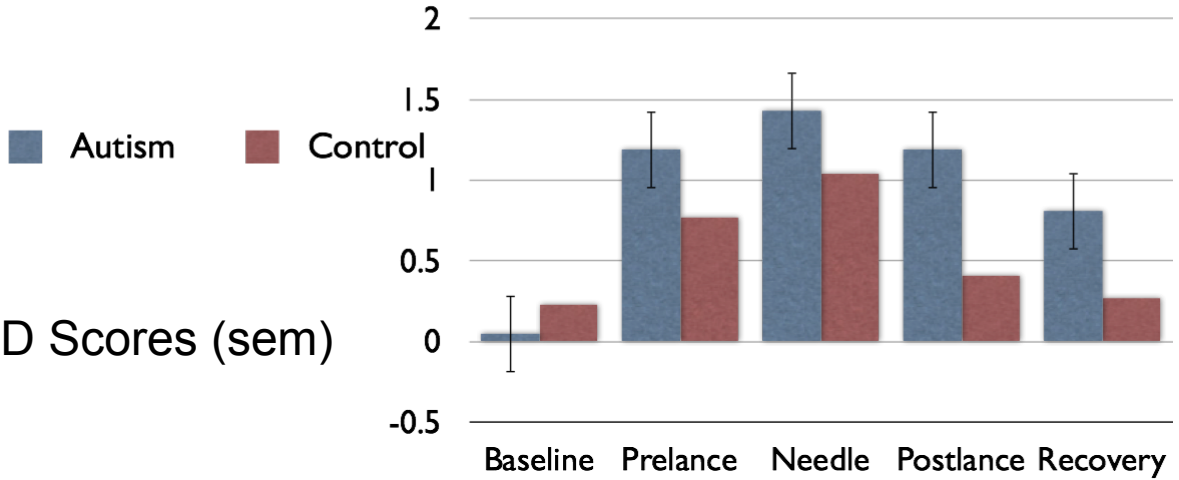

Oberlander TF. Gilbert CA. Chambers C.T. et al *Clinical J. Pain* 1999

# Acute Pain Reactivity in Children with Autism (Nader et al 2003)

CFCS Scores (sem)




OSBD Scores (sem)




Nader R, Oberlander TF Chambers C et al, *Clinical J. Pain* 2003.

ARTICLES

**Pain expression and stimulus localisation in individuals with Down's syndrome**

*M Hennequin, C Morin, J S Feine*

- Latency/delay to detect self administered cold stimuli on wrist and temple
- Significantly longer medium detection latencies
- More difficulties localizing the cold stimulus
- Implications
  - ? Insensitive to pain
  - Higher cold stimuli perceptions or thresholds
  - ? Processing speed delay ?Afferent decoding output?

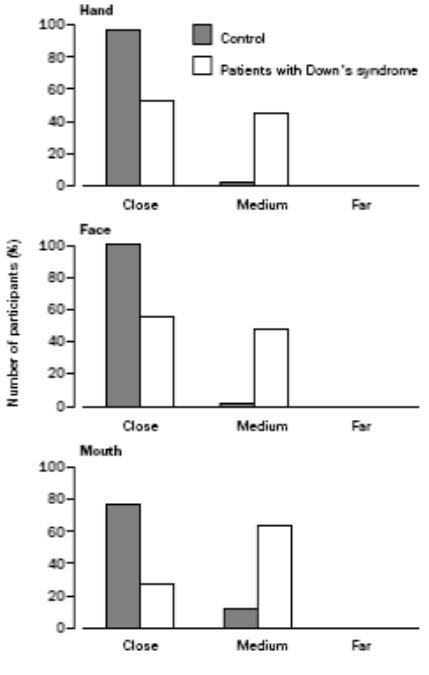



Figure 2: **Percentage of participants in the control and Down's syndrome groups with mean scores for detection of stimuli on the hand, face, and mouth**
CLOSE=perfect localisation; MEDIUM=within 2 cm of the stimulus; and FAR=more than 2 cm away from the stimulus.

Hennequin , Morin JS Feine DDS *The Lancet* - 2 December 2000; 356, 9245, 1882-1887

OPEN ACCESS Freely available online PLoS one

# Pain Reactivity and Plasma β-Endorphin in Children and Adolescents with Autistic Disorder

**Sylvie Tordjman[1,2*], George M. Anderson[3], Michel Botbol[1], Sylvie Brailly-Tabard[4], Fernando Perez-Diaz[5], Rozenn Graignic[1], Michèle Carlier[6], Gérard Schmit[7], Anne-Catherine Rolland[7], Olivier Bonnot[1,8], Séverine Trabado[4], Pierre Roubertoux[9], Guillaume Bronsard[10]**

**1** Laboratoire Psychologie de la Perception, Université Paris Descartes, UMR 8158 CNRS, Paris, France, **2** Service Hospitalo-Universitaire de Psychiatrie de l'Enfant et de l'Adolescent de Rennes, Université de Rennes 1, Rennes, France, **3** Child Study Center, Yale University School of Medicine, New Haven, Connecticut, United States of America, **4** Assistance Publique-Hôpitaux de Paris, CHU Bicêtre, Service de Génétique moléculaire, Pharmacogénétique et Hormonologie, Le Kremlin-Bicêtre, et INSERM U 693, Université Paris-Sud 11, Faculté de Médecine Paris-Sud, Kremlin-Bicêtre, France, **5** Centre Emotion, UFR 3246 CNRS, Groupe Hospitalier Pitié-Salpétrière, Paris, France, **6** Laboratoire de Psychologie Cognitive, UMR 6146 CNRS, Université de Provence, Aix en Provence, France, **7** Centre Hospitalier Universitaire de Reims, Reims, France, **8** Centre référent maladies rares à expression psychotique, Service de Psychiatrie de l'Enfant et de l'Adolescent, Groupe Hospitalier Pitié-Salpétrière, Paris, France,

- 73 children/adolescents with autism &115 typical children
  (matched for age, sex and pubertal stage)
- Behavioral pain reactivity assessed in three observational conditions (parents at home, two caregivers at day-care, a nurse and child psychiatrist during venepuncture)
- Plasma b-endorphin concentrations measured by radioimmunoassay.

Tordjman S, Anderson GM, Botbol M, Brailly-Tabard S, Perez-Diaz F, et al. (2009) Pain Reactivity and Plasma b-Endorphin in Children and Adolescents with Autistic Disorder. PLoS ONE 4(8): e5289.

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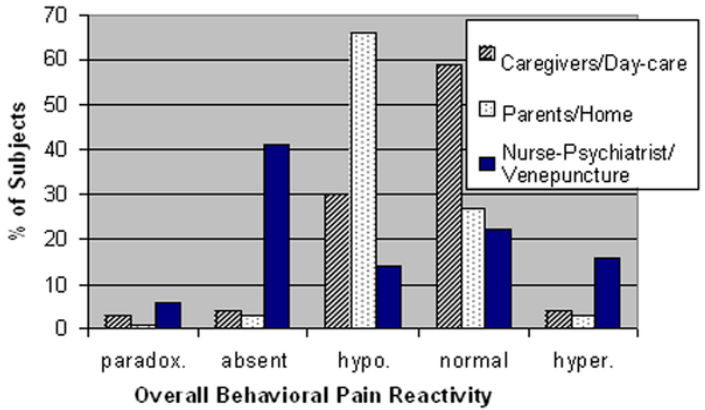
- increased proportion of an absence of behavioral pain reactivity to venepuncture in autism group (41.3%)
- individuals with autism showed tachycardia to the venepuncture
- individuals with autism experienced the noxious stress (venepuncture)
- could their “apparent behavioral analgesia” be related to a different mode of pain response than to endogenous analgesia?

Tordjman S, Anderson GM, Botbol M, Brailly-Tabard S, et al. (2009) Pain Reactivity and Plasma β-Endorphin in Children and Adolescents with Autistic Disorder. PLoS ONE 4(8): e5289.

# Behavioral Pain Reactivity in Autism (Rater/Setting)

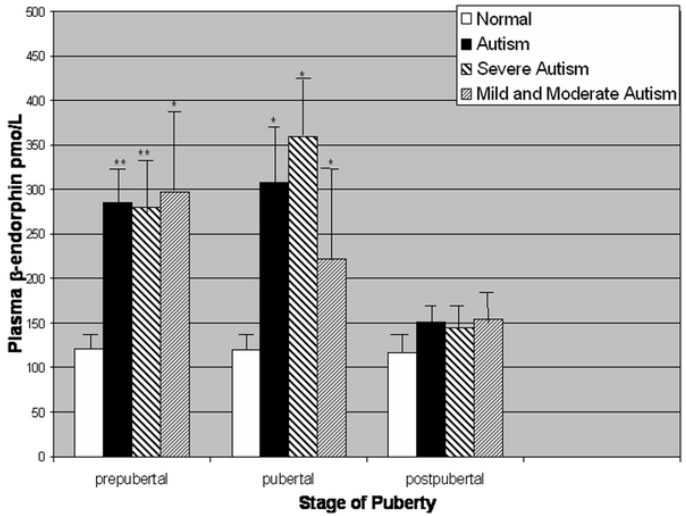



Children with autism:

- displayed ***absent or reduced*** behavioral pain reactivity at home (68.6%), at day-care (34.2%) and during venepuncture (55.6%)
- high rate of absent behavioral pain reactivity during venepuncture (41.3 vs. 8.7%)
- displayed a significantly increased heart rate in response to venepuncture

Tordjman S, Anderson GM, Botbol M, Brailly-Tabard S, et al. (2009) Pain Reactivity and Plasma β-Endorphin in Children and Adolescents with Autistic Disorder. PLoS ONE 4(8): e5289.

## Mean plasma β-endorphin concentrations

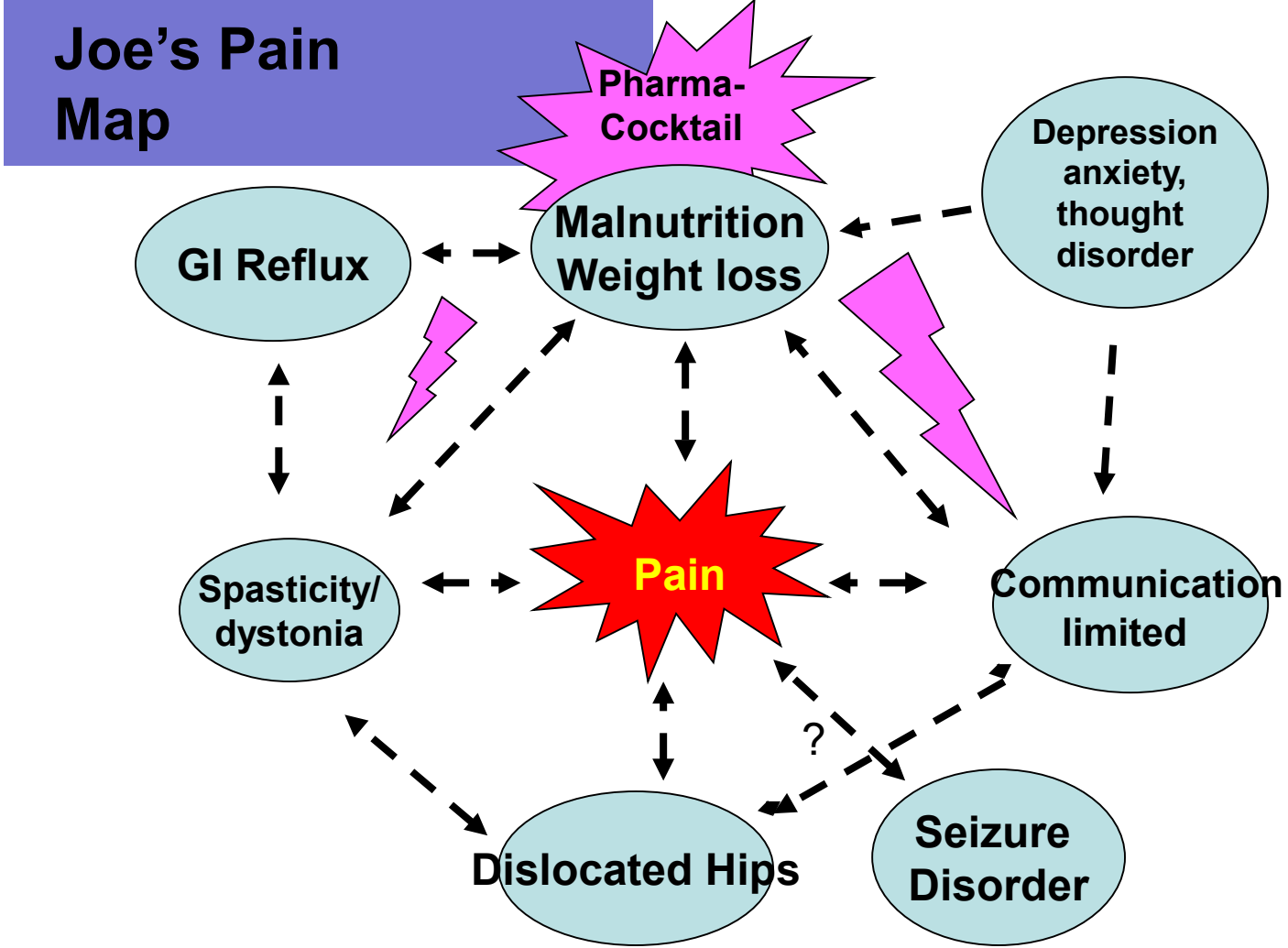



# Plasma b-endorphin levels:

- higher in children with autism and positively associated with autism severity and heart rate before or after venepuncture (P,0.05),
- not associated with behavioral pain reactivity

Tordjman S, Anderson GM, Botbol M, Brailly-Tabard S, et al. (2009) Pain Reactivity and Plasma β-Endorphin in Children and Adolescents with Autistic Disorder. PLoS ONE 4(8): e5289.

# Joe's Pain Map



# 2. Limited Access to Pain Experience

What is the meaning of the non verbal communication?

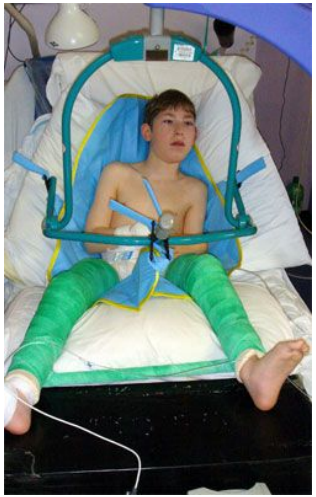
Conflicting pain (or non pain) signals?

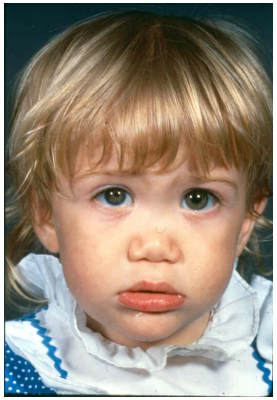
Importance of the assessment…

but is it always possible to distinguish the “pain signal” from other signals?

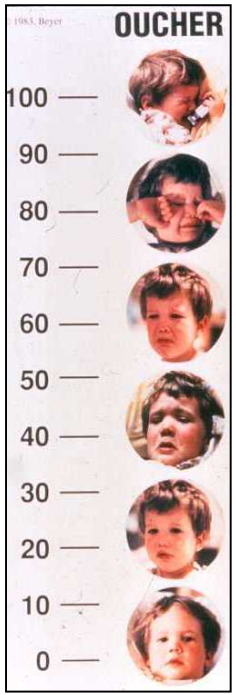
# Assessment

- Self report
- Observer report
- Biomarkers
- Biobehavioral measures

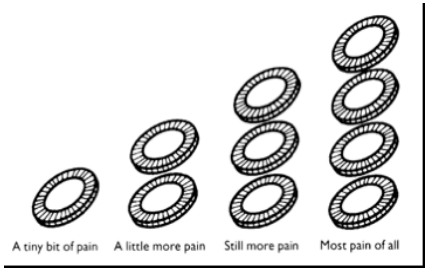




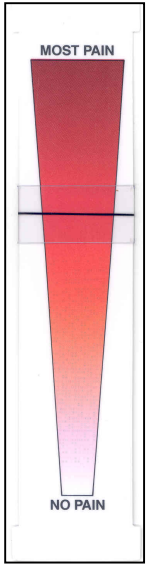
# Self-Report Measures




- Poker Chip Tool




- Numerical Rating Scales
  - 0-5, 0-10, 0-100
- Color Analogue Scales

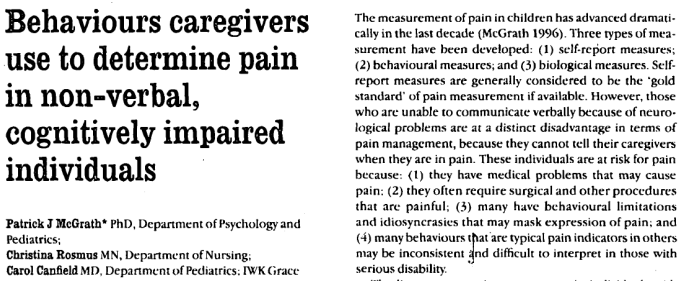


# Is It As Easy As It Looks?

The abilities required to provide a self-report of pain include:

- Classification
- Understanding of “order” (big vs small)
- Attention
- Memory
- Language comprehension and production
- Understanding of emotional states

# Non-communicating Children's Pain Checklist (NCCPC)



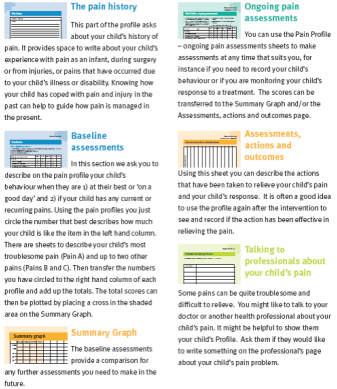
**Behaviours caregivers use to determine pain in non-verbal, cognitively impaired individuals**

**Patrick J McGrath*** PhD, Department of Psychology and Pediatrics;
**Christina Rosmus** MN, Department of Nursing;
**Carol Canfield** MD, Department of Pediatrics; IWK Grace

The measurement of pain in children has advanced dramatically in the last decade (McGrath 1996). Three types of measurement have been developed: (1) self-report measures; (2) behavioural measures; and (3) biological measures. Self-report measures are generally considered to be the 'gold standard' of pain measurement if available. However, those who are unable to communicate verbally because of neurological problems are at a distinct disadvantage in terms of pain management, because they cannot tell their caregivers when they are in pain. These individuals are at risk for pain because: (1) they have medical problems that may cause pain; (2) they often require surgical and other procedures that are painful; (3) many have behavioural limitations and idiosyncrasies that may mask expression of pain; and (4) many behaviours that are typical pain indicators in others may be inconsistent and difficult to interpret in those with serious disability.

- multidimensional instruments demonstrated adequate psychometric features (i.e. reliability and validity) (Breau et al. 2002)
- identifies behaviors common to populations of children

Paediatric Pain Profile



**The pain history**

This part of the profile asks about your child's history of pain. It provides space to write about your child's experience with pain as an infant, during surgery or from injuries, or pains that have occurred due to your child's illness or disability. Knowing how your child has coped with pain and injury in the past can help to guide how pain is managed in the present.

**Baseline assessments**

In this section we ask you to describe on the pain profile your child's behaviour when they are 1) at their best or 'on a good day' and 2) if your child has any current or recurring pains. Using the pain profiles you just circle the number that best describes how much your child is like the item in the left hand column. There are sheets to describe your child's most troublesome pain (Pain A) and up to two other pains (Pains B and C). Then transfer the numbers you have circled to the right hand column of each profile and add up the totals. The total scores can then be plotted by placing a cross in the shaded area on the Summary Graph.

**Summary Graph**

The baseline assessments provide a comparison for any further assessments you need to make in the future.

**Ongoing pain assessments**

You can use the Pain Profile – ongoing pain assessments sheets to make assessments at any time that suits you, for instance if you need to record your child's behaviour or if you are monitoring your child's response to a treatment. The scores can be transferred to the Summary Graph and/or the Assessments, actions and outcomes page.

**Assessments, actions and outcomes**

Using this sheet you can describe the actions that have been taken to relieve your child's pain and your child's response. It is often a good idea to use the profile again after the intervention to see and record if the action has been effective in relieving the pain.

**Talking to professionals about your child's pain**

Some pains can be quite troublesome and difficult to relieve. You might like to talk to your doctor or another health professional about your child's pain. It might be helpful to show them your child's Profile. Ask them if they would like to write something on the professional's page about your child's pain problem.

Pediatric Pain Profile (PPP) (Anne Hunt 2007)

- behavior rating scale for assessing pain in children with severe physical and learning impairments
- semi - individualized measure that gives caregiver/parent derived categories
- base and ceiling for behaviors (0-3)
- highly individual: sensitive, reliable, but may not be generalizable beyond the individual child

Pediatric
Research Paper

OPEN

PAIN REPORTS

# Psychometric properties of the brief pain inventory modified for proxy report of pain interference in children with cerebral palsy with and without cognitive impairment

Chantel C. Barney[a,b,*], Stacy M. Stibb[c], Alyssa M. Merbler[b], Rebekah L.S. Summers[d], Supreet Deshpande[a], Linda E. Krach[e], Frank J. Symons[b]

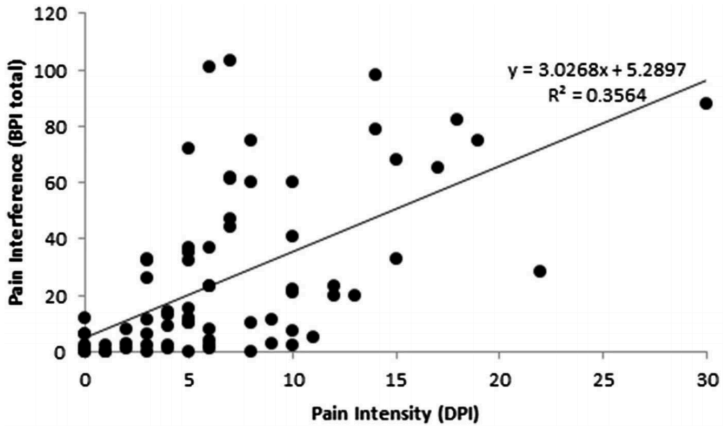



Figure 2. Relationship between the modified brief pain inventory (BPI) pain interference subscale score (scored 0–120) and the Dalhousie Pain Interview (DPI) pain intensity measure (each pain type is scored 0–10 then summed for a total score).

Pain Medicine

Pain Medicine 2015; 16: 249–256
Wiley Periodicals, Inc.

## GENERAL SECTION

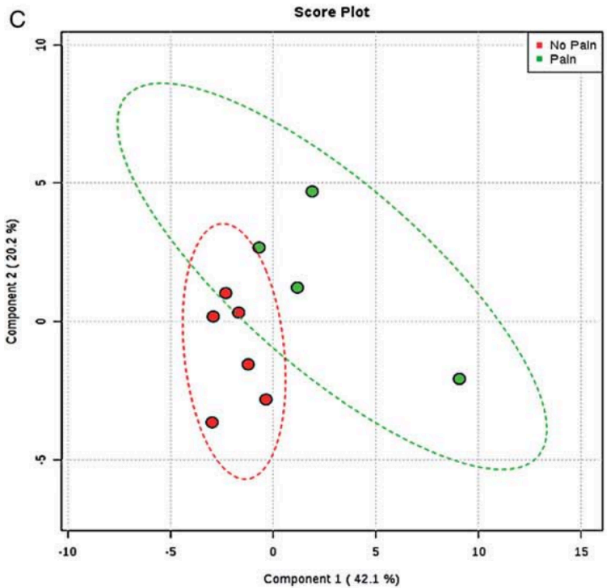
### *Brief Research Report*

# Can Biomarkers Differentiate Pain and No Pain Subgroups of Nonverbal Children with Cerebral Palsy? A Preliminary Investigation Based on Noninvasive Saliva Sampling

Frank J. Symons, PhD,*† Issam ElGhazi, PhD,‡ Brian G. Reilly, BSc,‡ Chantel C. Barney, PhD,*§ Leah Hanson, PhD,¶ Angela Panoskaltsis-Mortari, PhD,** Ian M. Armitage, PhD,‡ and George L. Wilcox, PhD††

**Subjects.** Ten nonverbal pediatric patients with cerebral palsy with and without pain.

**Methods.** Unstimulated (passively collected) saliva was collected using oral swabs followed by perchlo-




Pain Medicine 2015; 16: 249–256

# 3. Is the Diagnosis in Doubt?

- Is the symptom a diagnosis?
- Is a diagnosis even necessary?
- Or even possible to make?
- When to stop the unending search?
- Consider multiple sources
  - resist the search for a unifying DX
  - consider a broad differential diagnosis
  - irritability/suffering ≠ pain
  - occult sources of pain

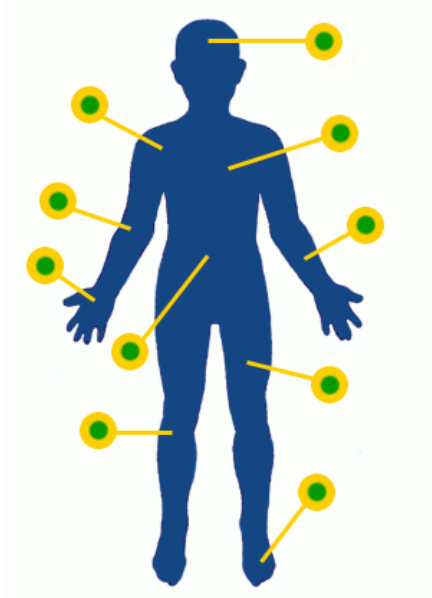
# Irritability/Pain of Unknown Origin (IUO)

**Central & Peripheral Nervous System:**
seizures, migraines, irritable neurons?

**Ear/Nose/throat**: Sinus & ear infections

**Gastrointestinal:**
GERD, PUD, Constipation

**Genitourinary:**
UTI, strangulated testis, menstrual related



**Affective & Psychological:**
mood changes, sleep

**Ophthalmic:** corneal abrasion

**Dental:**
abscess

**Orthopedic:**
fractures (osteopenia, osteoporosis), dislocation

**Skin:**
hair strangulation of digit

# 4. Right Drug, but ….

- Polydrug setting & drug-drug interactions:
  - pharmacodymamics (drug responses)
  - pharmacokinetics (drug disposition, metabolism)
  - pharmaceutics: physical compatibilities
- Pharmacogenetics
- Routes of administration
- Adverse drug reactions?

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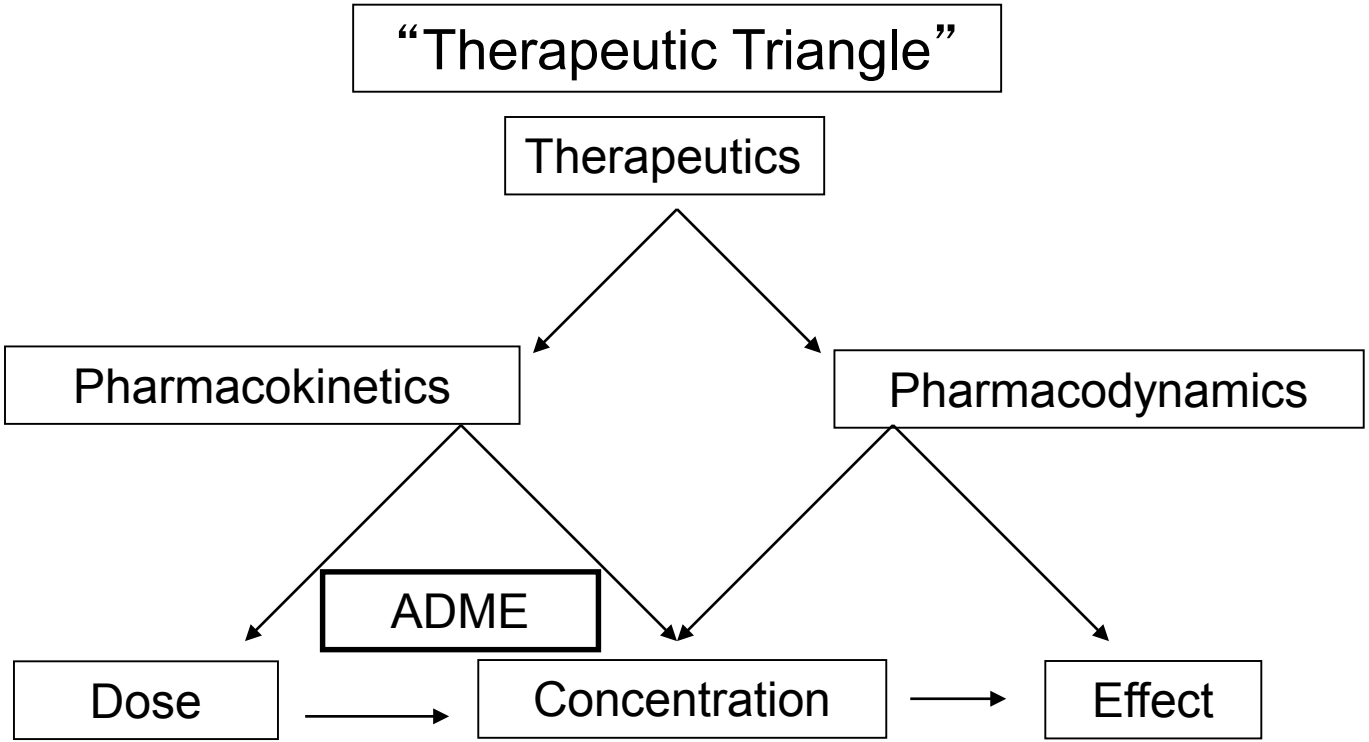
# 4. Selected the Right Drug, but ….



# Pharmacological Factors

## Pharmacodynamics

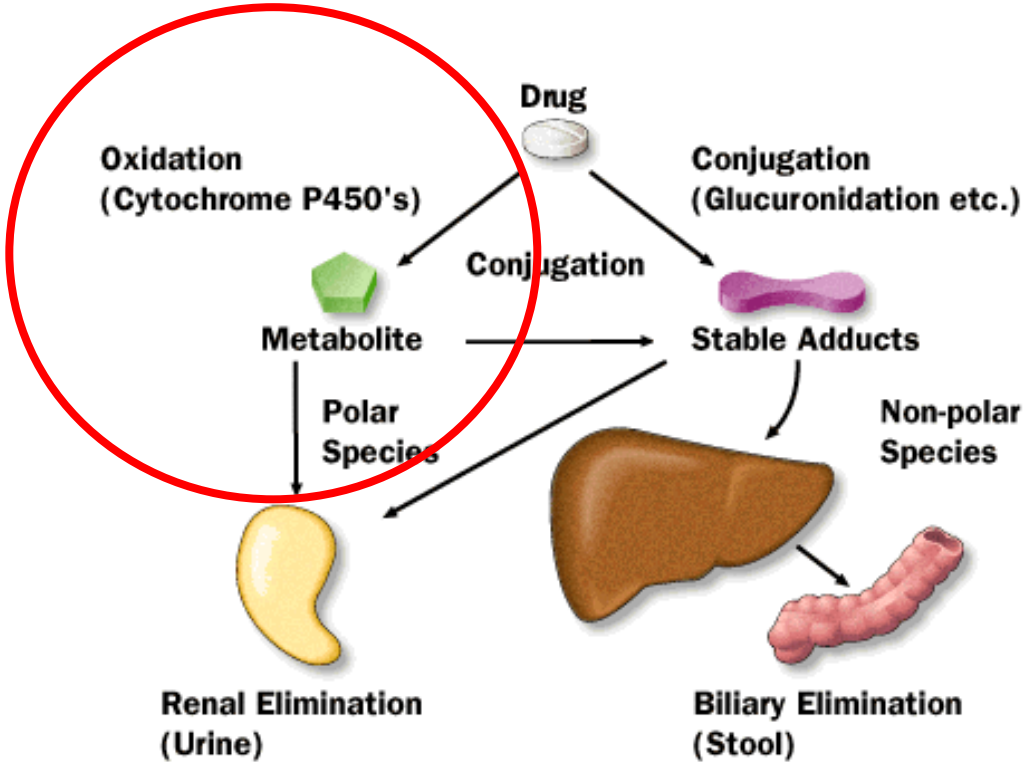
- relationship between drug concentration and pharmacological effect (response)

- receptor number, activity, location, blood brain barrier, illness severity, tolerance

## Pharmacokinetics

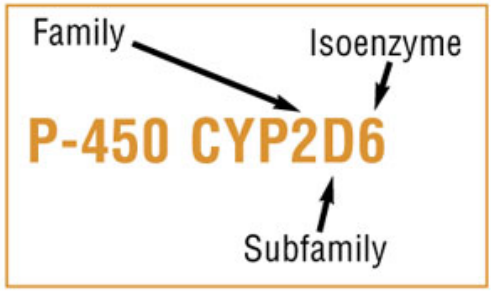
- the quantification of the time course (rate of change in concentration) of a drug and/or its metabolites in the body
- PKs is concerned with the processes involved in:

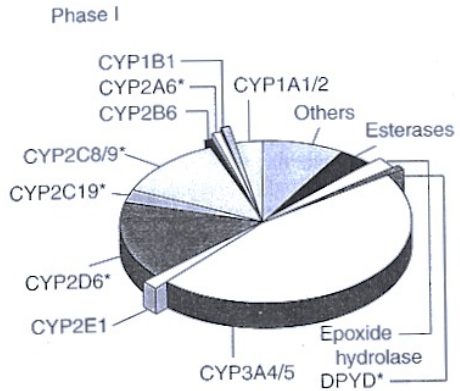
**A**bsorption**, D**istribution**, M**etabolism **& E**xcretion


Drug
Oxidation
(Cytochrome P450's)
Conjugation
(Glucuronidation etc.)
Conjugation
Metabolite
Stable Adducts
Polar
Species
Non-polar
Species
Renal Elimination
(Urine)
Biliary Elimination
(Stool)

# Major CYP450 isoenzymes

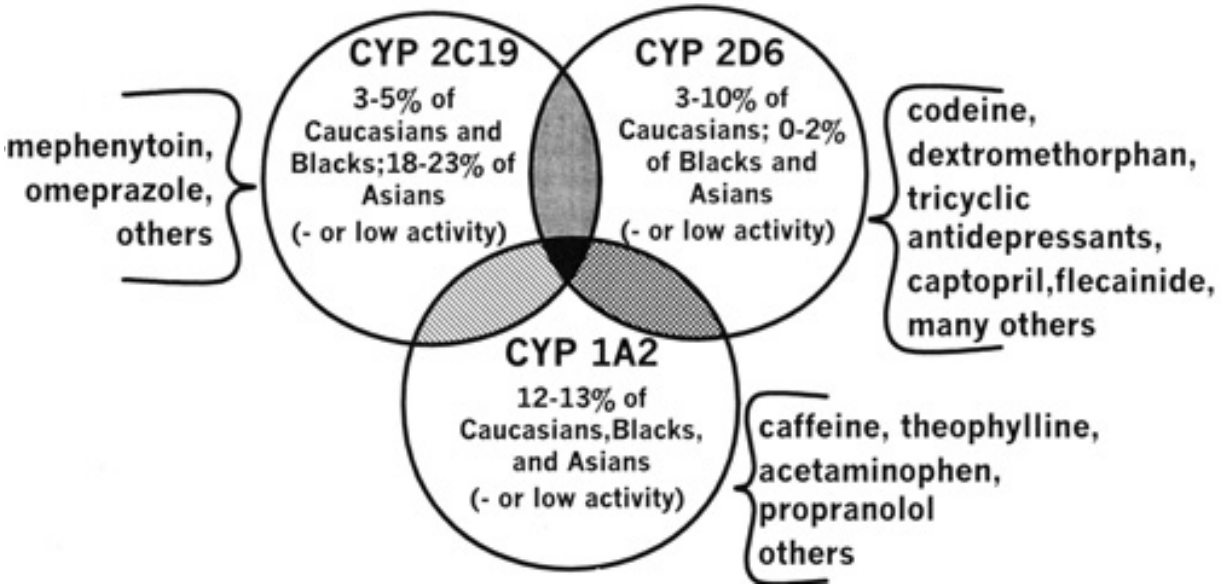
- 20 families of related isozymes
- each enzyme contributes to biotransformation
- ~35-40% of all drugs are metabolized by CYP3A4/5
- increases potential for drug-drug interactions (induction; inhibition)
  - only one drug at a time can serve as a substrate for a given enzyme




* enzymes showing functional allelic variants

# Variability in Analgesic Response



# Properties of the Hepatic CYP450 System

- **Induced**
  - drugs & environmental factors
  - upregulation of gene for a specific CYP450 enzyme
  - increased drug elimination
  - drugs, smoke, barbecued food
  - enzyme induction is reversible

- Not all CYP450s are inducible – major ones include:
  - CYP3A4, CYP2C9 and CYP2C19

# Properties of the Hepatic CYP450 System

- **Inhibition**:
  - decreased activity of cytochrome P450-dependent processes
  - decreases elimination
  - may occur with short and/or long-term exposure
    - e.g. cimetidine, cyclosporine, erythromycin, fluoxetine, nifedipine, pravastatin, grapefruit juice
- Enzyme inhibition reversible upon withdrawal of the agent

## Properties of the Hepatic CYP450 System

- **Saturation**:
  - some P450 enzymes are present in limited amounts
  - if drug concentration exceeds the metabolic capacity available then saturation occurs
    - may result in toxicity due to increased circulating drug levels

# Drug Interactions

| Isoenzyme | Substrate | Inducer | Inhibitor |
|---|---|---|---|
| 3A4 | Fentanyl<br>Midazolam<br>Methadone | Rifampin<br>Phenytoin | Cimetidine<br>Erythromycin<br>Grapefruit Juice |
| 2D6 | Amitriptyline<br>Codeine<br>Meperidine<br>Haloperidol | Antiepileptics | Cimetidine<br>celecoxib<br>Fluoxetine<br>Paroxetine |
| 1A2 | Haloperidol<br>Diazepam | Smoking | Omeprazole<br>Fluvoxamine |
| 2C19 | Omeprazole<br>Diazepam<br>Phenytoin | Antiepileptics<br>Rifampin | Fluoxetine<br>Omeprazole<br>Indomethacin |

# Drug Interactions

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| 1A2 | Haloperidol<br>Diazepam | Smoking<br>Broccoli | Fluvoxamine |
| 2C | Diazepam<br>Phenytoin | Antiepileptics<br>Rifampin | Fluoxetine<br>Omeprazole |

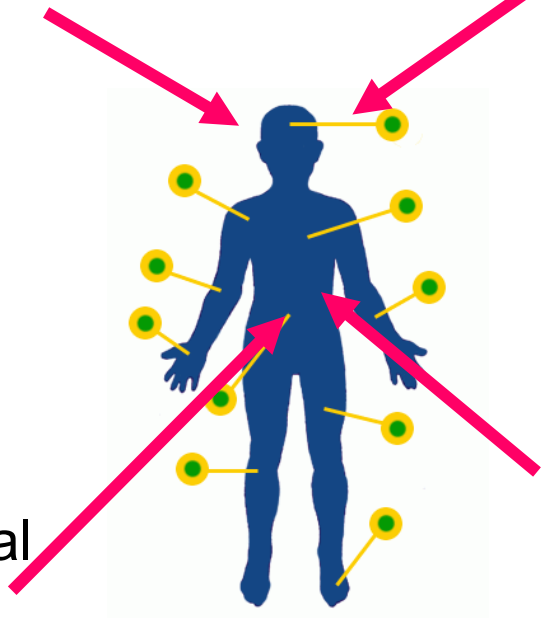
# Drug Interactions

## Mental Health

- meperidine & 5HT inhibition = SS
- SSRIs inhibit 2D6
- haldol & codeine
- 2D6 inhibitors & therapeutic failure

## Seizures

- phenobarb & carbamazepine increase 3A4
- methadone & midazolam = therapeutic failure



## Gastrointestinal Tract

- omprazole inhibits 1A2
- diazepam & phenytoin toxicity

## Infection

- erythromycin inhibits 3A4
- decreased midazolam and fentanyl clearance

# Variability in Analgesic Response

| Single Nucleotide Polymorphisms | Rare Defects |
|---|---|
| Functional mutations | Mutations causing inherited diseases |
| > 1% in different ethnic groups | < 1% of population |
| CYP enzymes with functional genetic polymorphism:<br>CYP2A6<br>CYP2C9<br>CYP2C19<br>CYP2D6<br>CYP3A4 | Rare defect conditions:<br>Huntington's chorea<br>Hemophilia<br>Cystic fibrosis |

# Variability in Analgesic Response

- CYP2D6
  - PM phenotype:
    - 5-10% of Caucasians vs <1-2 % Asian
- Codeine
  - Ineffective with lack of 2D6
  - Lethal with CYP 2D6*2A allele & CYP D6*2x2 gene duplication = ultrarapid metabolizer (Koren G, et al. *Lancet* 2000;368-704)

# Genetic Variations

- Pharmacogenetics
  - differences in drug metabolizing enzyme activity due to genetic variations
- Genetic polymorphisms
  - single nucleotide polymorphisms (SNPs):
    - variations in CYP450 drug metabolism 10-100 fold between poor and extensive metabolizers
  - slow (poor) metabolizer (PM)
    - dysfunctional or inactive enzymes
  - extensive (intermediate) metabolizers (EM)
    - express enzymes having normal activity
  - ultra-rapid metabolizers (UM)
    - increased levels enzyme  results in increased enzyme activity

# Joe & the “Pharmacological Cocktail”

Drug combo = ↓ effectiveness & ↑ health risk

- GI reflux pain: GT omepraxole ≠ crush
- Ibuprofen & airway reactivity = asthma risk
- CYP2D6: ? PM  poor effect with codeine
- Paroxetine & meperidine  combination
  - risk for serotonin syndrome

# Joe & the “Pharmacological Cocktail”

Sorting it out:

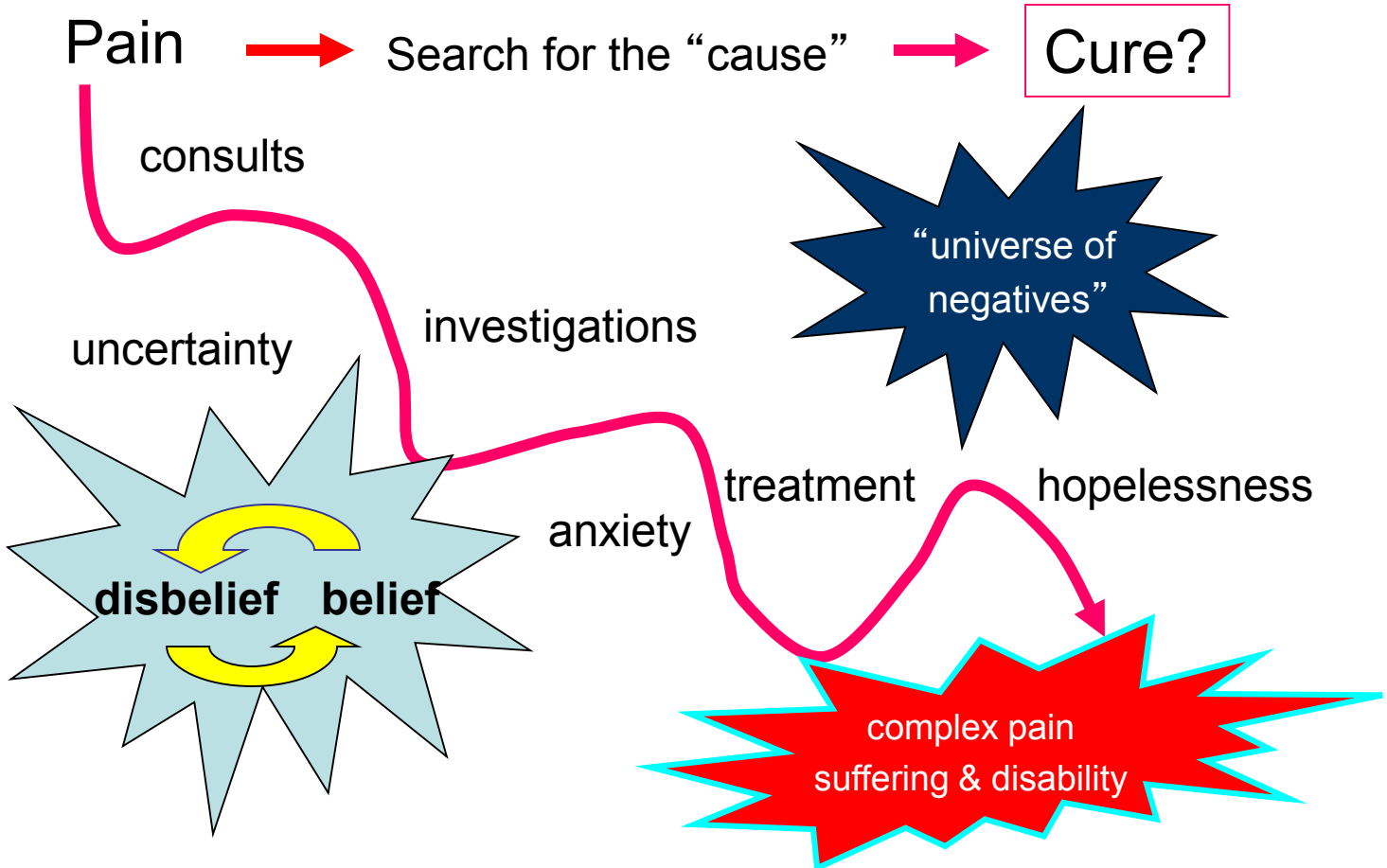
- ranitidine added
- NSAIDs stopped
  - reduced reactive airway disease risk
- methadone replaced codeine
  - avoid a 2D6 substrate
- lamotrigine started
  - avoid phenytoin increased methadone metabolism via 3A4

# 5. Still pain persists - ? Context

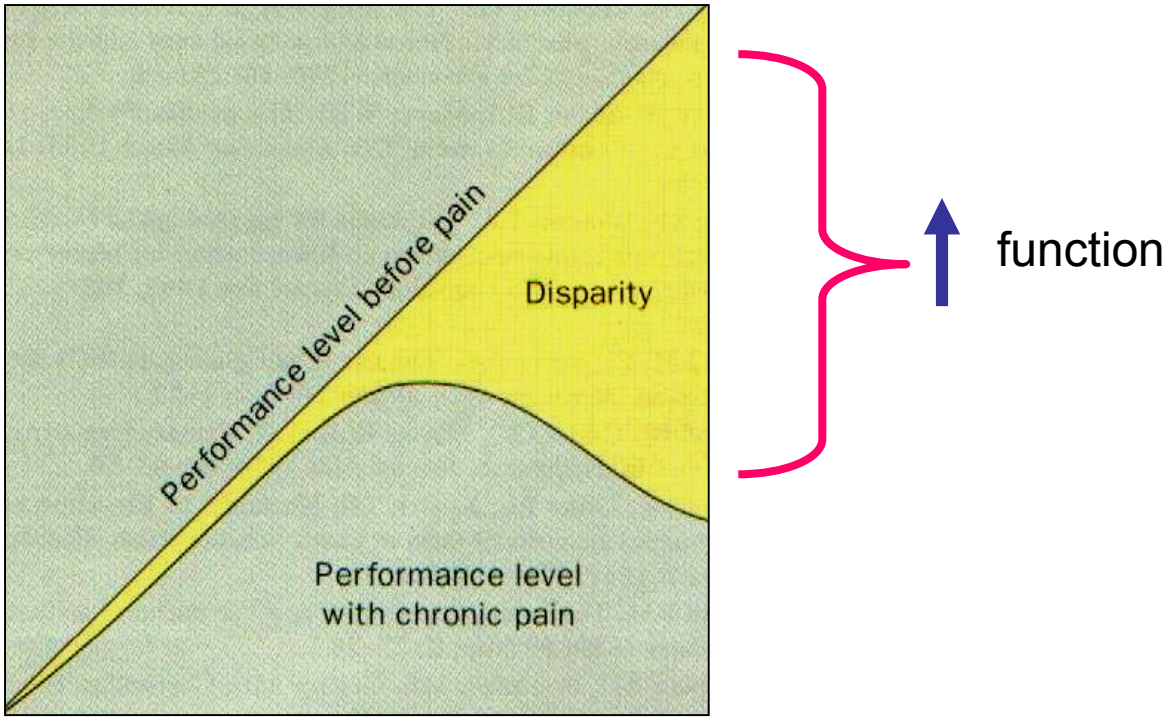
…even with a diagnosis, identification of the source & pain mechanisms, appropriate use of analgesics and consideration of multiple pharmacological confounding factors…

Why does pain management still fail?

# The Causal Quest & Calamity Cascade



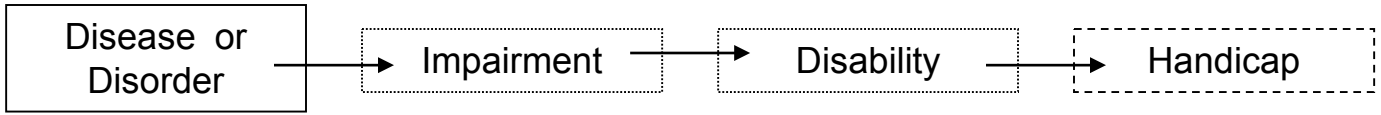
# Goal: Improve Everyday Function




Adapt from Chapman CR, Gavrin J *Lancet* 1999

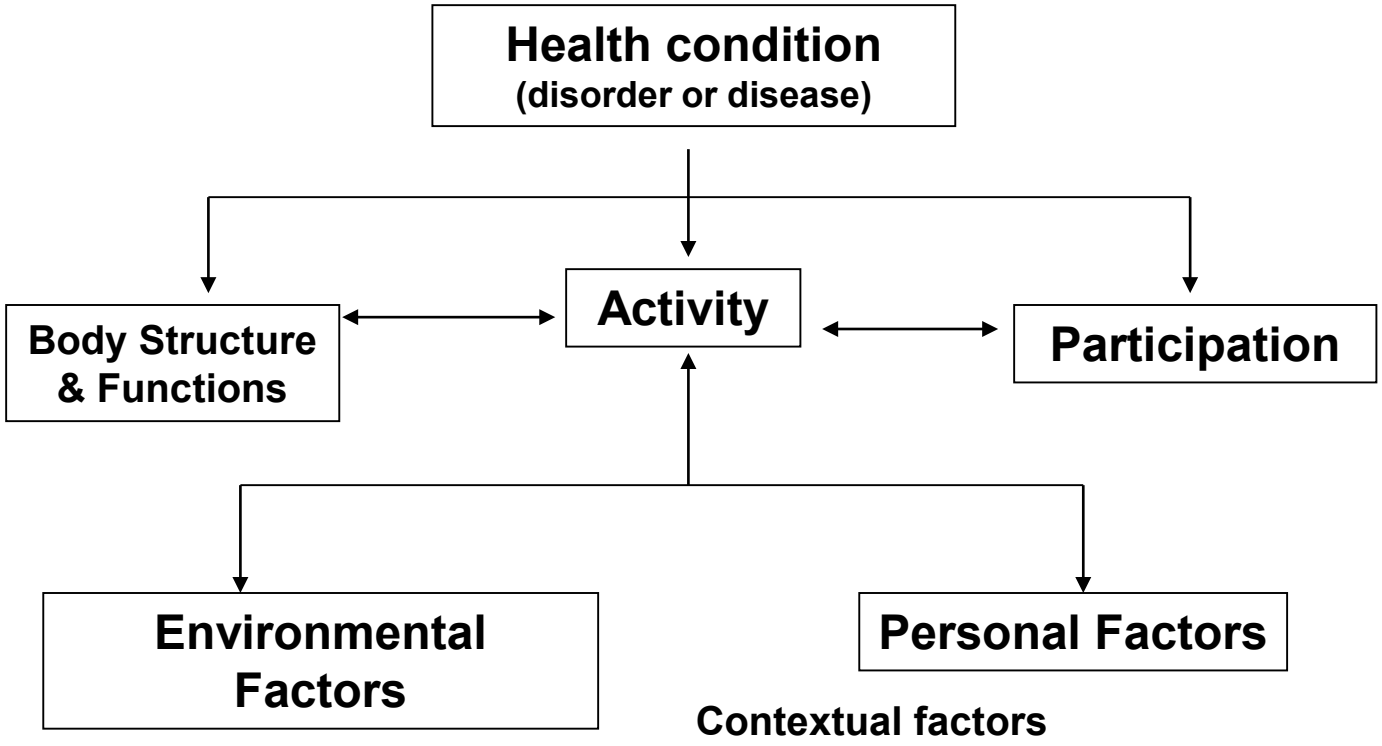
# Classification of Consequences of Disease

(ICIDH, WHO, 1980)




- Attempt to link disability to disease
- Identified three distinct planes of human experience
- Attempt to address need for information about health outcomes (function and disability)

# Move beyond consequences of disease: Assessing Functional Impact (2001,ICF, WHO)




http://www3.who.int/icf/icftemplate.cfm

# Moving Beyond Therapeutic Failure

Consider:

- Knowledge limitations & bias
- Limited access to pain experience
- Diagnostic confusion
- Right drug …. but pharmacological confounding factors (dose, route, interaction, genetic factors etc)
- Function and the broader contextual influences

# Moving Beyond Therapeutic Failure

Cautionary notes:

- Don’t let response to treatment make the diagnosis
- Avoid “consult cascade” & resist “causal quest”
- Improved symptoms ≠ improved function
- Failure to book a follow-up appointment

# Take Home Message

Focus on process that leads to:

- reduced pain where possible
- improved function & coping
- a follow-up appointment
- ongoing message:
  - “there is no end of the road”
  - there is always more to be done

# OPPORTUNITY TO ADVANCE KNOWLEDGE AND CARE:

## OPTIMIZING THE MANAGEMENT OF PAIN AND IRRITABILITY IN CHILDREN WITH SEVERE NEUROLOGICAL IMPAIRMENTS

CIHR Strategy for Patient Outcomes Research (SPOR) CHILD-BRIGHT, PI: Tim Oberlander, Hal Siden

- Children with significant neurological impairment are often non-verbal, experience pain and irritability
- Reasons are often unclear and their behaviors are ambiguous and non specific
- In spite of lengthy investigations, the underlying cause is rarely found
- Leads to further investigations, pain & frustration for the clinician, family and child
- With no obvious correctable source for the pain – this results in

  **inconsistent and ineffective care**



CHILD-BRIGHT Network

# Intervention Outline

**Does an efficient, focused evaluation lead to better identification of *treatable causes* of Pain and Irritability?**

Randomized, control trial 120 subjects, 4 centres: Ottawa, Toronto, Calgary, Vancouver

STEP 1

1. Pain-irritability focused chart review with History & Physical
2. Secondary evaluations and interventions based on findings of H&P

STEP 2

Screening for uncovered sources: urinary, gastric, abdominal-pelvic sources; functional sources (e.g. positioning)

With frequent contact with Study RN and MD



CHILD-BRIGHT Network

# Why We Need Your Help

Study opened in July 2018… 3 children enrolled at the Vancouver site to date

The Pathway is a simple idea; but sometimes the simplest ideas require the most proof because they upset everyone's previous notions

We need this national study to bring the answers back to BC and help children and families here in our community

This work shows BCCH Research at its best:

- Seeking ways to answer questions that come from families
- Collaborating across disciplines, and
- Coordinating research across the country

CHILD-BRIGHT Network

“To cure sometimes, to relieve often, to comfort always”

15th cent. French description of the role of the physician
Cited in Schechter, 1989