DOULEUR ET SANTE MENTALE : DE LA RECHERCHE A LA CLINIQUE DE L'APPROCHE INDIVIDUELLE AU PROJET DE SOCIÉTÉ / **MESURES CHEZ LES** DYSCOMMUNICANTS

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Centre universitaire de santé McGill



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Canada

Hopitaux Shriners Shriners Hospitals



2^{ÈMES} JOURNÉES FRANCO-QUÉBÉCOISES

SANTÉ MENTALE

Centre Universitaire en Santé McGill Hôpital Shriners pour enfants - Canada Hôpital pour enfants de Montréal





Douleur chez l'enfant Problematique

- Aspects varies et types de douleur peuvent être difficiles à décrire, ...ce qui devient un défi lors du choix de thérapie;
- Même si les connaissances et les moyens de soulager la douleur sont connus, la douleur chez l'enfant est trop souvent non-reconnue, sous-traitée, ignorée et même déniée.



Outline

- Challenges of assessing pain in pediatric population;
- Overview of the clinical methodology;
- Introduction of a pilot study.



Pain



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- Like other children, inevitably experience pain in their everyday life
- May be confronted more frequently with painful situations
 - Challenging behaviors
 - Medical issues



The Literature says...

- There is a lack of knowledge about pain reactions in children with autism spectrum disorders (Dubois 2010)
- Few studies:
 - Predominant idea of pain insensitivity (Gillberg 1995; Militerni 2000; Anand 1987; Goubet 2003)
 - Decreased behavioral reactivity during venipuncture (Tordjman 2009)
- DMS-IV: « ignoring pain », « indifference to pain », « high threshold for pain »



Insensitivity to Pain

- Pain threshold
 - smallest amount of stimulus energy necessary to produce pain sensation
 - Can be regarded as an indicator of the organism's sensitivity to pain (Gescheider 1985; Gracely 1999; Harris 1983; Price 1994)
- Biased by a reaction time (Defrin 2004)
 - Slower peripheral conduction velocity
 - Delays in central processing



Paediatric Anaesthesia 2001 11: 453–458

Pain management in children with and without cognitive impairment following spine fusion surgery

SHOBHA MALVIYA MD, TERRI VOEPEL-LEWIS BSN, MSN, ALAN R. TAIT PhD, SANDRA MERKEL BSN, MSN, ANTHONY LAUER BA, HAMISH MUNRO MD AND FRANCES FARLEY MD Departments of Anesthesiology and Surgery, University of Michigan Health Systems, Ann Arbor, MI, USA

- Fewer children with CI were assessed for pain after surgery
- Conclusion: Discrepency in pain management practices in children with and without CI following surgery



SPINE Research Grou

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Spine Deformity

www.spine-deformity.org



Spine Deformity 2 (2014) 399-403

Are We Undermedicating Patients With Neuromuscular Scoliosis After Posterior Spinal Fusion?

M. Wade Shrader, MD*, Mandy N. Falk, PA-C, Richard S. Cotugno, MHSM, John S. Jones, MD, Greg R. White, MD, Lee S. Segal, MD

Division of Pediatric Orthopaedic Surgery, Phoenix Children's Hospital, 1919 East Thomas Road, Phoenix, AZ 85016, USA Received 6 November 2013; revised 3 April 2014; accepted 17 April 2014



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In the clinic...

- Caregivers seem to underestimate their painful experience and complaints
- Assumption that they have lowered sensitivity to pain
- Behaved in a manner that suggests they have high pain thresholds



Consequences of untreated or undertreated pain

- Hyperglycemia
- Increased protein catabolism
- Increased oxygen consumption
- Decreased gut motility
- Increased heart rate and blood pressure
- Decreased transcutaneous oxygenation.



Will a child remember pain?

- May not directly recall painful experiences
- May demonstrate altered behavioral states from painful experiences
- Long term and permanent alterations in brain development
 - Profound and long lasting dendritic sprouting of sensory nerve terminals
 - Hyper-innervation that continues in childhood and adolescents.

(Grunau RV 1994; Grunau RE 2004; Marlow N 2005; Bhutta AT 2002)



Pain in Children

Major public health problem





Optimal pain management:

- accurate and thorough pain assessment.
- a treatment plan is developed, including pharmacological and nonpharmacological interventions.



Pediatric Pain

- Marked age-related changes affecting all aspect of pain management:
 - Physiological
 - Assessment
 - Pharmacological responses
 - Clinical outcomes









Pain is subjective

Measured indirectly by strategies:

The way that children react in response to pain (behavioral measures)

How children's bodies respond to pain (biological measures)

What children report about their experience (self-report measures)



Problematic

language of pain

uncontrollable dying screaming like a pin like an ache punching annoying awful forever crying on and off continuous sudden hot sore sharp burning miserable once in a while dizzy horrible sickening blistering suffocating swollen constant cramping hurting aching bad deadly killing stabbing frightening steady sneaks up pin like biting hurting like a hurt sometimes cutting

Particularly in the Non Verbal Patient



Nonverbal patients

- Populations:
 - Infants
 - Preverbal toddlers
 - Intubated and/or unconscious patients
 - Cognitively impaired
 - Inability to communicate pain and discomfort because of cognitive, developmental or physiologic issues is a major barrier for them being adequately assessed for pain and to achieve adequate pain management interventions.



Clinical Pain Assessment Tools



Methods of assessing infant pain



Assessment tools

Summary of neonatal pain ass	essment tools					
Pain Assessment Tool	Gestational Age/ Post-conceptional Age	Physiologic Components	Behavioral Components	Type of Pain	Adjusts for Prematurity	Scale Metric
PIPP (Premature Infant Pain Profile) ⁵⁸	28–40 wk	Heart rate, oxygen saturation	Alertness, brow bulge, eye squeeze, nasolabial furrow	Procedural and Postoperative	Yes	0 to 21
CRIES (Cries, Requires Oxygen, Increased Vital Signs, Expression, Sleeplessness) ⁵⁹	32–56 wk	Blood pressure, heart rate, oxygen saturation	Cry, expression, sleeplessness	Postoperative	No	0 to 10
NIPS (Neonatal Infant Pain Scale) ⁶⁰	28–38 wk	Breathing pattern	Facial expression, cry, arms, legs, alertness	Procedural	No	0 to 7
COMFORT (and COMFORTneo) ^{35,61}	0–3 y (COMFORTneo: 24–42 wk)	Respiratory response, blood pressure, heart rate	Alertness, agitation, physical movements, muscle tone, facial tension	Postoperative (COMFORTneo: prolonged)	No	8 to 40
NFCS (Neonatal Facial Coding System) ⁶²	25 wk to Term	None	Brow bulge, eye squeeze, nasolabial furrow, open lips, stretch mouth (vertical and horizontal), lip purse, taut tongue, chin quiver	Procedural	No	0 to 10
N-PASS (Neonatal Pain, Agitation, and Sedation Scale) ³³	0–100 d	Heart rate, respiratory rate, blood pressure, oxygen saturation	Crying/irritability, behavior state, facial expression, extremities/tone	Acute and prolonged pain Also assesses sedation	Yes	Pain: 0 to 10 Sedation -10 to 0
EDIN (Échelle de la Douleur Inconfort Noveau-Né – Neonatal Pain and Discomfort Scale) ³²	25–36 wk	None	Facial activity, body movements, quality of sleep, quality of contact with nurses, consolability	Prolonged	No	0 to 15
BPSN (Bernese Pain Scale for Neonates) ⁶³	27–41 wk	Respiratory pattern, heart rate, oxygen saturation	Alertness, duration of cry, time to calm, skin color, brow bulge with eye squeeze, posture	Procedural	No	0 to 27

Facial expressions



Child Facial Coding System

Facial actions	Descriptions
Brow lower"	Eyebrow is lowered and the eyebrows are pulled together
Eye squeeze ^a	Eyelids are tensed and there is bulging in the lower eyelid
Eye squint ^a	Eye opening is narrowed, eyelid appears tense, and there is bagging of the lower eyelid
Blink	Eyes are closed for less than one-half of a second
Nasolabial furrow [®]	The line adjacent to the nostril is deepened and pulled upward
Nose wrinkler ^a	Skin around the nose is drawn upwards and horizontal puckers appear across the nose
Flared nostril	Nostrils flared or dilated
Cheek raiser ^a	Cheek is raised toward the eye and bulging appears under the eye
Open lips	Lips are parted
Upper lip raiser"	Center of the lip is raised slightly, upper teeth are visible
Lip corner puller	Corners of the lips are elongated and pulled back and upward
Horizontal mouth stretche	Lips, lip corners, and surrounding skin are stretched laterally
Vertical mouth stretcha	Lips are parted and jaw is lowered

Contact the Pain Research Laboratory at Dalhousie University to obtain a copy of the manual with more complete descriptions and pictures. ^aCoded for intensity.



Self-reports of Pain Intensity



Estimate of the proportion of children at different ages who are able to provide reliable self-report of pain when given an age-appropriate scale under optimal conditions. (von Bayer 2004)

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Clinical Assessment of Pain - Pediatrics

Self-reporting

Intensity Faces Pain Scale - Revised



5 yrs and up Not as good but ...

Observer's reporting scales

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Clinical Assessment of Pain - Pediatrics

Observer's reporting scales

For very young 7 month - 7 yr age

FLACC SCALE – (Face, Legs, Activity, Cry, Consolability)

	0	1	2
FACE	No particular expression or smile, eye contact and interest in surroundings	Occasional grimace or frown, withdrawn, disinterested, worried look to face, eyebrows lowered, eyes partially closed, cheeks raised, mouth pursed	Frequent to constant frown, clenched jaw, quivering chin, deep furrows on forehead, eyes closed, mouth opened, deep lines around nose/lips
LEGS	Normal position or relaxed	Uneasy, restless, tense, increased tone, rigidity, intermittent flexion/ extension of limbs	Kicking or legs drawn up, hypertonicity, exaggerated flexion/ extension of limbs, tremors
ACTIVITY	Lying quietly, normal position, moves easily and freely	Squirming, shifting back and forth, tense, hesitant to move, guarding, pressure on body part	Arched, rigid, or jerking, fixed position, rocking, side to side head movement, rubbing of body part
CRY	No cry or moan (awake or asleep)	Moans or whimpers, occasional cries, sighs, occasional complaint	Crying steadily, screams, sobs, moans, grunts , frequent complaints
CONSOLABILITY	Calm , content, relaxed, does not require consoling	Reassured by occasional touching, hugging, or talking to, distractible	Difficult to console or comfort

Voepel-Lewis & al. American Journal of Critical Care 19 (1): 55-61. 2010

Clinical Assessment of Pain

- Pediatrics

Observer's reporting scales

Developmentally Disabled NCCPC-R

Non-Communicating Children's Pain Checklist-Revised

7 Fields: Vocal / Social / Facial / Activity / Body-Limbs / Physiological / Eating-Sleeping : 30 points

0 = 1	NOT AT ALL 1 = JUST A LITTLE 2 = FAIRLY OFTEN 3 = VE	RY O	FTEN	NA :	= NOT APPI	LICABLE	
I V	(acal						
1. V		0	1	2	2	214	
1.	Moaning, whimpering (fairly soft)	0	1	2	3	NA	
2.	Crying (moderately loud)	0	1	2	3	NA	
3.	Screaming/yelling (very loud)	0	1	2	3	NA	
4.	A specific sound or word for pain (e.g., a word, cry or type of laugh)	0	1	2	3	NA	
							_
II. S	ocial						
5.	Not cooperating, cranky, irritable, unhappy	0	1	2	3	NA	
6.	Less interaction with others, withdrawn	0	1	2	3	NA	
7.	Seeking comfort or physical closeness	0	1	2	3	NA	
8.	Being difficult to distract, not able to satisfy or pacify	0	1	2	3	NA	
							_
III.	Facial						
9.	A furrowed brow.	0	1	2	3	NA	
10.	A change in eyes, including: squinching of eyes, eyes opened wide, eyes frowning	0	1	2	3	NA	
11.	Turning down of mouth, not smiling	0	1	2	3	NA	
12.	Lips puckering up, tight, pouting, or quivering	0	1	2	3	NA	
13	Clenching or grinding teeth chewing or thrusting tongue out	0	1	2	3	NA	

2 hours Observation

Score: > 7 pain

Score: <= 6 no pain.



Breau, L.M.& al. Anesthesiology, 96 (3), 528-535. 2002

Pain is not unidimensional

Situational Factors:

How it is cognitively construct and dealt with



Factors Influencing Pain



Individual's Psychology



Catastrophizing

Depression



Anxiety



Stress



Credits Jill Greenberg

Psychological Assement

Pain Catastrophizing Scale

- three subscales: rumination, magnification, helplessness
- The child is presented with 13 items and is asked to rate each on a scale from 0-4
- Construct validity of the measure is supported by its relation with functional disability and pain intensity ratings.

1. When I am in pain, I worry all the time about whether the pain will end. NOT AT ALL MILDLY MODERATELY SEVERELY **EXTREMELY** 2. When I am in pain, I feel I can't go on like this much longer. NOT AT ALL MILDLY MODERATELY SEVERELY EXTREMELY 3. When I am in pain, it's terrible and I think it's never going to get better. MODERATELY NOT AT ALL MILDLY SEVERELY EXTREMELY

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Sullivan, Scott, Bishop, Pivik. 1995.

Psychological Assement

- State Trait Anxiety Inventory (STAIc)
 - State versus Trait
 - widely used self-report anxiety assessment instrument.
 - higher scores denote higher levels of anxiety.
 - Respondents are presented with statements of how people describe themselves and are asked to evaluate if they agree.



Spielberger, Gorsuch, & Lushene, 1970.

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Psychological Assement

Brief Behavioral Distress Scale

Table I. Behavioral Definitions of Categories for the Observation Scale of Behavioral Distress

Category	Definition	Examples
Information seeking	Any questions regarding medical procedure	"Is the needle in?"
Cry	Onset of tears and/or low- pitched nonword sounds of more than 1-second duration	
Scream	Loud, nonword, shrill vocal expressions at high pitch intensity	
Physical restraint	Child is physically restrained with noticeable pressure and/or child is exerting bodily force and resistance in response to restraint.	
Verbal resistance	Any intelligible verbal expression of delay, termination, or resistance	"Stop" "I don't want it"
Seeks emotional support	Verbal or nonverbal solicitation of hugs, physical or verbal comfort from parents or staff	"Mama, help me" Pleading to be held
Verbal pain	Any words, phrases, or statements in any tense which refer to pain or discomfort	"Ouch" "My leg hurts" "That hurt"
Flail	Random gross movements of arms, legs, or whole body	Kicking legs; pounding fists
Verbal fear"	Any intelligible verbal expression of fear of apprehension	"I'm scared"
Muscular rigidity"	Noticeable contraction of observable body part	Clinched fists; gritted teeth; facial contortions. Legs bent tightly upward off R _x table
Nervous behavior ^a	Physical manifestations of anxiety or fear. Consist of repeated, small physical actions	Nail biting; lip chewing

An Observation Scale for Measuring Children's Distress During Medical Procedures¹

Charles H. Elliott Department of Psychiatry, University of New Mexico

Susan M. Jay² Department of Pediatrics, University of Southern California, School of Medicine

Patricia Woody Childrens Hospital of Los Angeles

J Ped Psychol, 12:4, 1987



*Eliminated after item analysis.

Factors influencing Pain



Individual's Psychology & Individual's Physiology



Primed Inflammatory System





Sensitized facilitatory system

Excessive brain opioid activity

Inefficient descending Inhibitory system



Psychophysiology of Pain

Quantitative Sensory Testing (QST)

- Non-invasive method based on varying sensory modalities;
- Detect large and small nerve fiber function;
- Can assist in early detection, therapy selection and monitoring the progression and recovery of patients





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Clinical Laboratory Shriners Hospital for Children – Canada



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Pain sensitivity underlying autistic features in children with Christianson Disease

- Characterize the pain and social deficits in CS children
 - Obtain an assessment of the nature of pain deficit/elicit

McGill University

Dr. John Orlowsky & Dr. Reza Sharif-Naeini, Department of Physiology Dr. Catherine Ferland, Department of Pediatric Anesthesia







Pain sensitivity underlying autistic features in children with Christianson Syndrome

- Characterize the pain and social deficits in CS children
 - Obtain an assessment of the nature of pain deficit/elicit

In collaboration with the CSA Questionnaires

Prévalence : <1 / 1 000 000
Hérédité : Dominante liée à l'X
Âge d'apparition : Petite enfance, Néonatal
CIM-10 : Q87.8



CS – Clinical Characteristics

 ...un déficit intellectuel profond, une microcéphalie, un mutisme, une épilepsie précoce de types variables, des **mouvements anormaux**, un retard de développement et une hypotonie. Les autres manifestations incluent une ophtalmoplégie, une ataxie tronculaire ou de la marche, une dystonie avec des mouvements stéréotypés des mains, des sourires fréquents avec des épisodes de rire incontrôlé, une trouble autistique, une bouche ouverte, une incontinence salivaire importante et des difficultés à avaler, un reflux gastro-oesophagien et un habitus gracile.

What we know about pain in CS...

- Unusually high pain threshold (Pesconsolido et al, 2014)
- Exhibit little response to pain while experiencing serious injury

"Constipation – [...] bowel blockage to the point of vomiting own bile. [My child] gave me no indicators [of any pain]." "Second degree burns [...] and exhibited no reaction until it was too late. [...] 2 weeks of whirlpool treatments for [wound debridement] and was completely unaffected.



Objectives

- Enlarge understanding of pain expression and pain assessment in CS
- Descriptive analysis of questionnaires distributed throughout the CSA
 - Describing sensations of painful situations
 - Pediatric Pain Profile
- Presentation of preliminary results





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Methodology Sensations



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Results In Summary

Painful Situations Questionnaire (n=9)

Mechanical Pain

- Constipation
- Cutting nails too short
- Stubbing toes, getting hit in the head
- Thermal Pain
 - Touching burning things
 - Eating too hot or too cold food



Methodology

- Developed to help in assessing and monitoring pain in children with severe neurological impairments (Hunt 2003, www.ppprofile.org.uk)
- Children dependant on their carers for interpretation of their signs of pain:
 - Movement, posture, vocalization, facial expression
- The Pain History
 - Early/past pain experience (as an infant, surgery, illness and injury
- Baseline Assessments
 - Description of the pain behaviour
 - 1) at their best or on a 'on a good day'
 - 2) if your child has any current or recurring pains





Results Case Report





Pediatric Pain Profile

On a Good Day

- Cheerful
- Social
- A little hard to console/comfort
- Not reluctant to eat
- Little disturbed sleep
- No grimacing
- Restful
- Little inward flexing or drawing legs towards chest
- Quite a lot of pulling away or flinching when touched
- A great deal of involuntary or stereotypical movements/jumpy/startles or has seizures





Pediatric Pain Profile

On a Bad Day





- Less Cheerful
- Social
- A little hard to console/comfort
- Reluctant to eat
- Grimacing
- Restlessness
- Little inward flexing or drawing legs towards chest



Pediatric Pain Profile

On a Bad Day





- Less Cheerful
- Social
- A little hard to console/comfort
- Reluctant to eat
- Grimacing
- Restlessness
- Little inward flexing or drawing legs towards chest
- No disturbed sleep
- No pulling away or flinching when touched
- Less involuntary or stereotypical movements/jumpy/startles or has seizures



Future Directions

- Distinguish pain sensations
 - Discriminative
 - Emotional
 - Perception
- Understand burden of pain they experience
- Improve pain assessment
 - Other questionnaires
 - Blood sample





Pain is not unidimensional

How it is cognitively construct and dealt with



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Pediatric Pain - Work in Progress

- Research takes time and efforts
- Collaborative work (Families, Researchers, Association)





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Strategies in Pain INtervention Evaluation



Canada

