

*Pain in Children with
Down Syndrome*

**Identification &
Intervention by Parents**

Principle Investigator

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Background & Significance

- **Down syndrome:**
 - Leading congenital cause of cognitive impairment worldwide
 - Incidence – 1/1000 live births
- **“Ambiguous” pain expression in children with cognitive impairment** (Oberlander & Craig, 2003)
 - Highly subjective assessment & management

Background & Significance cont.

- **Multiple medical problems associated with Down syndrome**
 - Congenital heart defects
 - Hypotonia
 - Respiratory infections
 - GI reflux
 - Hypothyroidism
 - Leukemia

Background & Significance cont.

- **Communication difficulties in children with Down syndrome.**
 - Delays in speech, comprehension, & expression
 - Need for surrogate

Background & Significance cont.

- **Nursing responsibilities for children with cognitive impairments & pain management**
 - Legal & ethical codes
 - Evidence-based practice
 - Role as surrogate

Research - Pain in Typical Child

- Behavioral pain assessment tools
- Pain rating scales
- Pharmacologic interventions
- Non-pharmacologic interventions

Research - Down Syndrome

- Different pain cry (Lind et al., 1970)
- Different EEG response to auditory stimuli (Barnet, Ohlrich, & Shanks, 1971)
- Higher dosages of morphine needed post cardiac surgery (Gakhal, Scott, & MacNab, 1998)

Research in Down syndrome cont.

- Fewer responses to painful stimuli in Down syndrome laboratory mice (Martinez-Cue et al., 1999)
- Completion of physical map of chromosome 21 (Hattori et al., 2000)

Research in Down syndrome cont.

- Longer time to report pain and larger errors in localization (Hennequin, Morin, & Feine, 2000)
- Parents report more difficulty identifying pain (Hennequin, Faulks, & Allison, 2003)

Research – Pain & Children with Cognitive Impairments

- Multiple indicators of pain
- Non-Communicating Children's Pain Checklist (Breau et al.)
 - Irritable
 - Seeking comfort
 - Furrowed brow
 - Less active
 - Gestures to /touches pain site
 - Tears
 - Sharp intake of breath

Surrogate Reporting of Pain in Child with Cognitive Impairment

Caregivers:

- Are able to identify pain behaviors in children with cognitive impairments (Voepel-Lewis, Malviya, & Tait, 2006)
- Use different pain indicators depending on child's severity of impairment (Fanurik et al., 1999)
- Perceive their children with cognitive impairments respond differently to pain

Need for Further Study

- Differences in children with Down syndrome from other children with cognitive impairments
- Limited research on specific pain behaviors in the child with Down syndrome
- Without identified pain behaviors, interventions cannot be studied

Research Aims

- To describe the decision-making processes parents use to identify pain in their child with Down syndrome
- To examine the relationship between pain identification cues and actions taken by parents to relieve pain in the child.

Methodology

- Qualitative
- Ethnographic interview techniques & data analysis
 - Culture
 - Language (symbolic interactionism)

Data Collection – Inclusion Criteria

- Parent informant
 - Primary caretaker of a school-age child (6-14 years) with Down syndrome
 - Primary caretaker for at least one year
 - Able to speak English
 - Willing to participate in a one-two hour interview

Data Collection – Human Subjects Involvement

- Study approved by the IRB, UTHSCSA
- Recruitment through electronic newsletter of local Down syndrome association
- Parent informants determined time and place for interviews
- Written informed consent was obtained

Data Collection - Interviewing

- Open-ended, semi-structured questions
 - What kind of pain has your child experienced?
 - Tell me about typical things that cause pain for your child.
 - How does this pain compare to other pain that your child has had?

Data Collection – Questions cont.

- How can you tell the difference between a little versus a lot of pain?
- How do your child's responses differ from his/her siblings?
- What do you normally do for your child's pain?
- If your child was admitted to the hospital, what would you tell me about his/her pain?

Data Collection – Parent & Child Characteristics

- | | |
|-----------------------------------|-----------------------------------|
| ■ Parents | ■ Child |
| □ Age | □ Age |
| □ Education | □ Health status |
| □ Ethnicity | □ Problems with touch or movement |
| □ Number of children | □ Adaptive characteristics* |
| □ How learned about Down syndrome | |

*Adaptive Characteristics

- **Communication**
- **Self care**
- **Social skills**
- **Leisure**
- **Health & safety behaviors**
- **Self direction (appropriate to age)**
- **Academics**

Spradley's Developmental Research Sequence (1979) for Data Analysis

- **Domain analysis**
- **Taxonomic analysis**
- **Componential analysis**
- **Theme discovery**

Domain Analysis

- **Purpose: To identify categories of thought related to pain**
- **Steps**
 - Identify a semantic relationship (thought)
 - Identify interview comments that reflect the thought
 - Provide a cover term (domain name) for the thought
- **Current focus for study**

Spradley's Developmental Research Sequence (1979) cont.

- **Taxonomic analysis**
 - To identify the terms within domains
- **Componential analysis**
 - To determine the meaning of terms
- **Theme discovery**
 - To discover the relationship among domains

Data Analysis - Rigor

- Field notes
- Consultation with experts
- Member checking

Findings – Parent Characteristics

- Three parents of children, ages 8, 10, & 11 years (one father; two mothers)
- Parents were in 30s when child with Down syndrome was born
- All had college-level education
- All had other younger children
- All were members of local Down syndrome association

Findings – Child Characteristics

- Able to communicate using words & sentences
- Difficulty with touch, sensation, or movement
- Needed help with adaptive skills
 - Communication
 - Social skills
 - Academics

Findings – Pain Experiences

Informant #1	Informant #2	Informant #3
-Fire ant bites	-Severe leg pain	-Ear infections
-Shots	-Fire ant bites	-Constipation
-Falls & scrapes	-Stomach ache	-Falls, scratches
-Thorns	-Constipation	-Headache
-Hits	-Knocks, falls	-Toothache
-UTI (infant)	-Monthly shots	-Surgery (PE tubes)
	-Periodic labs	-Noise (ear pain)
	-Heart surgery (infant)	-Growing pains

Findings - Domains

- Child's use of words
 - "Verbally now she can tell me. Before it was more pointing, now it's more 'my head hurts, my throat hurts, my tummy.'"
 - "He would say, 'It hurts; it hurts down here; it hurts.'"

Findings – Domains cont.

- Child's use of crying
 - "She will cry or yell out now that she's gotten older . . . And she starts crying whereas before when she was hurt she wouldn't cry."
 - "He can literally cry for like two hours straight in the middle of the night with leg pain."

Findings – Domains cont.

- **Decreased intensity of pain response**
 - “I really think there is some decreased sensitivity at least with his extremities. I have seen fire ant bites on his feet that you and I would really have a hard time with. Now if you bring it to his attention, then it’s ‘Don’t touch it. Put some medicine on it.’ But I could let him walk around the house, and I don’t think I’d ever hear about it.”

Findings – Domains cont

- **Decreased length of pain response**
 - “And she calms down or gets over it faster than the other kids seem to.”
 - “I remember they took out her adenoids. . . . She would cry a little bit then they brought in popsicles and it was like for her it was over.”

Findings – Domains cont.

- **Questioning or probing strategies**
 - “He takes my hand and says ‘there, there, there.’ But I say you show me. . .he does much better when . . .you show mommy where it hurts. Take my hand and put it where it hurts.”
 - “And sometimes we have to be careful what we are asking – she used to get confused between the what and the where. We ask her different ways to be sure where the pain was.”

Findings – Domains cont.

- **More diligence/time**
 - “You have to be more diligent with her and it just takes more time. It takes more time and it takes more observation and it takes more communication. Not an easy thing, believe me.”
 - “But yeah it takes her a little longer; whereas my younger child will just blurt exactly what happened and tell me in a matter of a minute or two.”

Findings – Domains cont.

- **More sense of uncertainty**
 - “Usually I can only tell by his mood – lying around or listless – he might have a fever, he might have a headache, he might have a sore throat, he might have a stomachache. It is – that’s pretty much a crapshoot; I just don’t know.”

Findings – Domains cont.

- **Ability of child to interpret pain experience**
 - “We would have to be careful what we asked her. . . It was more of a communication – she didn’t have the capacity to – it was easier to say the very last thing. Are you crying because you’re upset or you got hurt? ‘I got hurt.’ And then we could turn the question around. Are you crying because you got hurt or because you’re upset? ‘Because I’m upset.’”

- “I think he really has [the leg pain] figured out. That’s an easy one for him to identify. He’s had trouble with his stomach before and he hasn’t been able to tell what was wrong until he threw up. ‘Oh, my tummy was hurting.’”

Findings – Domains cont.

■ Actions to relieve pain

- Use of medications
- Use of external things
 - Band-aids
 - Massage
 - Rubbing
 - Covering pain site with a towel

Implications for Practice

- Avoid generalizations about children with cognitive impairments
- Recognize parents as key informants.
- Recognize potential causes of pain.
- Identify individual behaviors associated with pain. Don’t wait for typical pain behaviors.

Implications for Practice cont.

- Determine the child’s ability to communicate.
- Attempt to obtain a self report even if just ‘yes’ or ‘no.’ Avoid pain scales.
- If in doubt, use an analgesia trial.
- Carefully evaluate non-pharmacologic interventions for effectiveness.

Plans for Continued Study

- Continue with ethnography as methodology
- Continue recruitment of parents of school-age children
- Focus on parents of children who do not have serious health problems
- Complete the ethnographic data analysis for theme development.

Summary

“People in your setting . . . the problem is everyone is rushed and you just have to slow down. Really if you are trying to focus in on where they are, it just takes longer. It takes 5 seconds to know where our boys are on a pain level, but it takes 5 minutes to hone in on where [our child with Down syndrome] is at. And I’m sure a lot of people in your profession, it goes against what’s normal – very hectic, very fast paced. They need to slow down.”