**Pain in Children with Down Syndrome: Assessment and Intervention by Parents**

Research
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**Purpose**
The purpose of this study was to investigate pain assessment and intervention by parents of school-age children with Down syndrome.

**Aims**
- To describe how parents assess pain in their child with Down syndrome
- To examine the relationship between pain assessment and decisions by parents to intervene to relieve pain in their child.

**Need for Study**
- Differences in children with Down syndrome from other children
- Limited research on pain behaviors and Down syndrome
- Without identified pain behaviors, interventions cannot be studied

**Qualitative Methodology**
- Ethnographic interview techniques
  - Culture
  - Language (symbolic interactionism)
- Data analysis
  - Spradley’s Developmental Research Sequence (1979)

**Interview Questions**
- How parents identified that their child was experiencing pain
- What alternative causes other than pain were considered
- How decisions to intervene were made
- What interventions were used
- How these interventions were evaluated for effectiveness for pain relief
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-hour interview

Findings: Child Factors

- General responses
  - Lessened responses in most
  - Emotional factors
  - Quick recovery
- Use of language
  - Single words to simple sentences
  - Both location-specific and nonspecific
  - Repeating what has been suggested

Findings: Child Factors

- Pain behaviors
  - Showing or pointing
  - Crying for more severe pain
- Changes in behavior
  - Refusal to do usual things
  - Irritable, whiney, fidgety, agitated
  - Increased dependence
  - Quiet and withdrawn (most described)

Findings: Parent Factors

- Strategies
  - Observing the child’s behaviors
  - Differentiating pain from other emotional responses
  - Recognizing a potential pain event
  - Questioning the child
  - Using others to confirm problems
  - Evaluating the length of the problem

Findings: Parent Factors

- Interventions
  - Comfort and reassurance
  - Use of external things (e.g., band aids)
  - Limited use of medications
Conclusions

- Pain responses in children with Down syndrome may not be the immediate responses seen in other children without Down syndrome.
- Children with Down syndrome appear to learn how to respond to pain.
- Language skills play an important role in pain communication.

Conclusions

- Children with Down syndrome appear to perceive pain but may not be able to cognitively evaluate it and consequently communicate the type or intensity of pain.
- Interventions used for pain relief in the child with Down syndrome may be the same interventions as those used for other children without Down syndrome.