

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 - Quiet and withdrawn (most described)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: Child Factors

- **Learning the concept**
 - Responses received from others
 - Imitating others' behaviors
 - Previously experiencing the pain
 - Needing visual cues

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., bandaids)
 - 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.