Vocabulary used by young children to express pain: An exploration

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Aim

• Literature review of research studies focusing on children’s pain-vocabulary.
• Focus on physical pain.
• To develop suitable instruments to find common pain-vocabulary children use to express their discomfort.
Problem statement

• All children experience pain almost on a daily basis (Fearon, McGrath, & Achat, 1996; Von Baeyer, Baskerville, & McGrath, 1998).

• Children with disabilities
  - same as typically developing peers?
  - procedures, etc.? (Dubois, Capdevila, Bringuier, & Pry, 2010; Huguet, Stinson, & McGrath, 2010; Stallard, Williams, Lenton, & Velleman, 2001)
Candidates

Who can use a pain-related communication board?

Children and adults who need it for:

• A temporary period:
  – ICU
  – Patients who are intubated
  – Children and adults with burn injuries and post-surgery

/...
Candidates

Who can use a pain-related communication board?

Children and adults who need it for:

• More permanent period:
  – Children and adults who use AAC – medical procedures
Describing pain

Pain is difficult to describe and measure (Ely, 1992; Jerret & Evans, 1986; Kortesluoma, Punämaki, & Nikkonen, 2008)

Subjective nature
- Crying
- Verbalisations/words

Different experiences
- Children CCN
  - do not try to draw attention of others
  (Dubois et al. (2010))

Too much effort
- unrecognised
- untreated

(Stanford, Chambers, Craig, McGrath, & Cassidy, 2005).
(Davies, 2010; Gilbert-MacLeod, Craig, Rocha, & Mathias, 2000; Stallard et al., 2001).
Expressing pain

- Inability to express pain in traditional manner (Ely, 1992; Jerret & Evans, 1986; Kortesluoma, Punämaki, & Nikkonen, 2008)

Safety implications

Insufficient pain-relieving treatment

Fear or anxiety

Distress

Frustration

Overall deterioration of individual’s well-being

(Costello, 2000; IASP, 2011; Patak, Gawlinski, Fung, Doering, Berg, & Henneman, 2006; Price, 2002; Stähle-Öberg & Fjellman-Wiklund, 2009; Stallard et al., 2001).
Definition of pain

• “An unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage (Association for the Study of Pain – IASP, 1979, p.250).

subjective individual

• This definition takes both the sensory and affective dimensions of pain into account (Nilsson, 2010). Pain may cause physical and emotional distress and anxiety in children experiencing medical or surgical procedures.

(IASP, 2011; Nilsson, 2010).
Definition of pain

“One of the most common adverse stimuli experienced by children, occurring as a result of injury, illness and necessary medical procedures.” (American Academy of Pediatrics – AAP, 2002)

(Azize, Humphreys, Cattani, 2011).
• United Nations Convention on the Rights (UNCRC) of a Child recognizes “the right of the child to the enjoyment of the highest attainable standard of health and to facilities for treatment of illness” (UN, 1989).

• Support through AAC to children who experience communication breakdowns due to their illness (or with LNFS) (Sherlock, 2008).

  ICU Other medical settings i.e. clinics
  Natural settings i.e. home, school, play

  (Blackstone, 2007; Costello, 2008; Mesko, Eliades, Libertin & Shelestak, 2011; Sherlock, 2008; UN, 1989;).
Literature review

- Self-report?

- Healthcare staff and parents estimate children’s pain – (bodily signs e.g. FLACC – Face, Legs, Activity, Cry and Consolability) (Kortesluoma & Nikkonen, 2004; Nilsson, 2010; Stähle-Öberg & Fjellman-Wiklund, 2009).


Children give clear self-report – ASK them!
Literature review

- Hypothetical pain scenarios (Belter et al., 1988)
- *Charleston Pediatric Pain Pictures* (CPPP)

![Prepared pain pictures](image)

- Head-bump, burn stove, fall from stairs, needle, thermometer

- Possible other scenarios?

(Adesman & Walco, 1992; Belter et al., 1988; Von Baeyer et al., 2009)
Literature review

• Hypothetical pain scenarios

Burn open fire
Injury in sport – cricket ball
Fall from a tree
Literature review

Four landmark articles

Focus: Children’s pain(-related) vocabulary

1986 – current:

Jerret & Evans, 1986; Ely, 1992; Stanford, Chambers & Craig, 2005; Franck, Noble, & Liossi, 2010
Children’s pain vocabulary

Mary Jerrett RN MS and Kathleen Evans RN BNSC Queen’s University, School of Nursing, 90 Barrie Street, Kingston, Ontario K7L 3N6, Canada

Accepted for publication 26 August 1985

Children’s pain vocabulary
**TABLE 2 Pain descriptors used by children aged 5 years to 6 years 11 months, not found on the McGill Pain Questionnaire word list**

<table>
<thead>
<tr>
<th>Sensory</th>
<th>Affective</th>
<th>Evaluative</th>
</tr>
</thead>
<tbody>
<tr>
<td>Painful</td>
<td>Sad</td>
<td>Bad</td>
</tr>
<tr>
<td>Fall off</td>
<td>Scared</td>
<td>Awful</td>
</tr>
<tr>
<td>Snow</td>
<td>Drive nuts</td>
<td>Ugly</td>
</tr>
<tr>
<td>Ouch</td>
<td>Unhappy</td>
<td>Terrible</td>
</tr>
<tr>
<td>Cymbals clapping</td>
<td>Upset</td>
<td>Not nice</td>
</tr>
<tr>
<td>Warm</td>
<td>No strength</td>
<td>Yucky</td>
</tr>
<tr>
<td>Bullet</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tickled</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Buzzing</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sounds funny</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mosquitoes buzzing</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Note: above categorization was done subjectively by these researchers.
The Experience of Pain for School-Age Children: Blood, Band-Aids, and Feelings

Elizabeth A. Ely

A qualitative descriptive study was conducted to examine words and their meaning when used by children describing their experiences with pain. Eight children (6–8 years) participated. A semistructured interview was conducted in

Next, the research question and design will be discussed. Entree and sampling issues will be presented followed by a description of methods used to collect data. The final section will be an
<table>
<thead>
<tr>
<th>PAIN FEELS LIKE</th>
<th>INSIDE HURT</th>
<th>OUTSIDE PAIN</th>
<th>MAKE IT BETTER</th>
</tr>
</thead>
<tbody>
<tr>
<td>Blood</td>
<td>Talk weird</td>
<td>Blood</td>
<td>Love</td>
</tr>
<tr>
<td>Strange</td>
<td>Friends</td>
<td>Crying</td>
<td>Go home</td>
</tr>
<tr>
<td>Weird</td>
<td>Make fun</td>
<td>Maddening</td>
<td>Forget</td>
</tr>
<tr>
<td>Feeling</td>
<td>Crying</td>
<td>Not fun</td>
<td>Avoid</td>
</tr>
<tr>
<td>Words</td>
<td>Feeling</td>
<td></td>
<td>Friends</td>
</tr>
<tr>
<td>Maddening</td>
<td>Other pain</td>
<td></td>
<td>Cope</td>
</tr>
<tr>
<td>Not fun</td>
<td>Confuse</td>
<td></td>
<td>Distract</td>
</tr>
<tr>
<td>Tease</td>
<td>Sad</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Embarrass</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

* THEMES, Categories, and codes
A normative analysis of the development of pain-related vocabulary in children

Elizabeth A. Stanford\textsuperscript{a,b,*}, Christine T. Chambers\textsuperscript{b,c}, Kenneth D. Craig\textsuperscript{a}

\textsuperscript{a}Department of Psychology, University of British Columbia, 2136 West Mall, Vancouver, BC, Canada V6T 1Z4
\textsuperscript{b}Centre for Community Child Health Research, BC Research Institute for Children’s and Women’s Health, Vancouver, BC, Canada
\textsuperscript{c}Department of Pediatrics, University of British Columbia, Vancouver, BC, Canada

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Fig. 1. Study 1: Frequency of children’s use of pain word-stems and age of emergence. Numbers above the bar indicate the specific frequency (i.e. raw number of children who had used each word in the database transcripts) represented by the bar. Numbers in parentheses below indicate the earliest age of emergence (in months) for each pain word-stem.
Fig. 2. Study 2: Frequency of parent reported children’s use of pain word-stems and age of emergence. Values on the y-axis refer to the number of parents who reported that their children had ever used word-stems. Numbers above the bar indicate the specific frequency (and percentage) represented by the bar. Numbers in parentheses beside the word-stem indicate the earliest age of emergence (in months) for each pain word-stem.
From tears to words: the development of language to express pain in young children with everyday minor illnesses and injuries

L. Franck,* G. Noble* and C. Liossi†

*UCL Institute of Child Health, London, and
†University of Southampton, Southampton, UK

Accepted for publication 19 January 2010

Abstract

Background  Little is known about the development of language to express pain in the young or how children and parents verbally communicate when young children have everyday minor illnesses and injuries.
Literature review

Figure 1. Most common pain words by age of use.
<table>
<thead>
<tr>
<th>Unpleasant sensations†</th>
<th>Assistance/treatment requests‡</th>
<th>Exclamations§*</th>
<th>Pain location/visible sign of injury§</th>
<th>Actions/causes of pain§</th>
<th>Reassurance§</th>
</tr>
</thead>
<tbody>
<tr>
<td>I feel bad</td>
<td>Vocatives (calls for parent by name)</td>
<td>Awww</td>
<td>External</td>
<td>I've banged myself</td>
<td>All better</td>
</tr>
<tr>
<td>I've got a hurt</td>
<td>Mummy I hurt myself</td>
<td>Iya iya iya</td>
<td>I've got a baddie</td>
<td>Bite you</td>
<td>I'm alright</td>
</tr>
<tr>
<td>I have hurt my boo boo</td>
<td>Daddy my (body part) hurts</td>
<td>Oooh</td>
<td>It's bleeding</td>
<td>Bumped it</td>
<td>I'm brave</td>
</tr>
<tr>
<td>I'm not right</td>
<td>Calls for assistance</td>
<td>Ah oh</td>
<td>It's cracked</td>
<td>Had bump</td>
<td>I'm fine</td>
</tr>
<tr>
<td>I feel ill</td>
<td>Fix it</td>
<td>Eh oh</td>
<td>I've got a scab</td>
<td>I cut my (body part)</td>
<td>It's ok</td>
</tr>
<tr>
<td>I have been running...</td>
<td>Help Help</td>
<td>Oh dear</td>
<td></td>
<td>Fall down</td>
<td>Sorry</td>
</tr>
<tr>
<td>Not feeling too good</td>
<td>I want my mummy</td>
<td>Oh no</td>
<td>I feel funny in my head</td>
<td>I fell over</td>
<td></td>
</tr>
<tr>
<td>It's not nice</td>
<td>I need something</td>
<td>Oh oh</td>
<td>I've got nose ache</td>
<td>Injured myself</td>
<td></td>
</tr>
<tr>
<td>Got needles and pins</td>
<td>Make it feel better</td>
<td>Uh uh</td>
<td>Throat is all croaky</td>
<td>I tripped over</td>
<td></td>
</tr>
<tr>
<td>It pains</td>
<td>Need to see a doctor</td>
<td>Ow ow ow</td>
<td>Mummy I have butterflies in my tummy</td>
<td>(Person) hit me</td>
<td></td>
</tr>
<tr>
<td>I got a pain</td>
<td>Protest</td>
<td>I got an ow</td>
<td></td>
<td>Stubbed</td>
<td></td>
</tr>
<tr>
<td>Poor baby</td>
<td>Don't touch it</td>
<td>Oooh</td>
<td></td>
<td>Scratching me</td>
<td></td>
</tr>
<tr>
<td>I feel poorly</td>
<td>Naughty + object</td>
<td>Youch</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>It's poorly</td>
<td>Stop it</td>
<td>Oops</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Feel a bit sick</td>
<td>Specific item requests</td>
<td>Whoopsie daisy</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Got sick</td>
<td></td>
<td>Shoo shoo</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I've got a sick in my tummy</td>
<td>Cream on</td>
<td>Waaaaaa/wahh</td>
<td></td>
<td></td>
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<tr>
<td>Sick sore head</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mummy it's sore</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Don't feel well</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I'm not very well</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yucky</td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physical comfort</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Kiss better</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Need a kiss</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pub (body part)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Need a cuddle</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Want huggles</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Full lexicon of children’s pain words by communicative intent theme available on request.
†Classified as sensory words of APPT (Svedra et al. 1992) or MPQ (Melzack 1975).
‡Classified as directives and responses of the INCA-A (Nirio et al. 1994).
§Classified as markings and responses of the INCA (Nirio et al. 1994) with subcategories: *exclaim in distress, †mark occurrence of event and ‡commiserate, express sympathy for heater’s distress.
APPT, Adolescent Pediatric Pain Tool; INCA-A; Inventory of Communicative Acts-Abridged; MPQ, McGill Pain Questionnaire.
## Literature review

### Summary findings

<table>
<thead>
<tr>
<th>Author, year</th>
<th>Aim</th>
<th>Methodology</th>
<th>Results</th>
<th>Implications</th>
</tr>
</thead>
</table>
| Jerret & Evans (1986) | How children view their pain - children drew pictures that show pain. | **Methodology** (Single group design) | Words were categorised into 3 classes of pain: sensory, affective and evaluative | • Methodology (Single group design)  
• Categorise pain-related words for communication board |
| Ely (1992) | Examine pain-words and their meaning - children drew pictures that show pain; semi-structured interview | **Methodology** (Qualitative descriptive design) – questions for structured interview; videotape and transcribe | 4 Categories: Pain feels like; Inside hurt; Outside hurt; Make it better | • Categories |
## Literature review

### Summary findings

<table>
<thead>
<tr>
<th>Author, year</th>
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<th>Results</th>
<th>Implications</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stanford, Chambers, &amp; Craig (2005)</td>
<td>Document pain-words and age of onset</td>
<td>Pain-word stems <em>hurt, ow, ouch</em> and <em>sore</em> were most frequently used. Pain-word stems gradually increased in frequency from 3 to 6 years.</td>
<td>• Methodology – (parent-survey)</td>
<td></td>
</tr>
<tr>
<td>Franck, Noble, &amp; Liossi (2010)</td>
<td>Pain words during minor injury or illnesses</td>
<td>6 Categories: (a) describe unpleasant sensations; (b) request for help or treatment; (c) exclamations; (d) pain locations/visible sign of injury; (e) words used to describe causes of pain and (f) words to comfort the</td>
<td>• Methodology – (questionnaire structure); • Categories</td>
<td></td>
</tr>
</tbody>
</table>
Children’s way of communicating about pain is affected by the development of:

<table>
<thead>
<tr>
<th>Cognitive skills</th>
<th>Piaget - developmental stages</th>
</tr>
</thead>
<tbody>
<tr>
<td>Language skills</td>
<td>Previous experiences</td>
</tr>
<tr>
<td></td>
<td>Family i.e siblings, parents</td>
</tr>
<tr>
<td></td>
<td>Culture</td>
</tr>
<tr>
<td>Social skills</td>
<td>Previous experiences</td>
</tr>
<tr>
<td></td>
<td>Gender</td>
</tr>
<tr>
<td></td>
<td>Family</td>
</tr>
<tr>
<td></td>
<td>Culture</td>
</tr>
</tbody>
</table>

(Craig et al., 2006; Dubois, Bringuier, Capdevila, & Pry, 2008; Kortesluoma & Nikkonen, 2004).
Children’s cognitive abilities affect how they perceive, understand, remember and report pain.

- **Cries**, start to use verbalizations such as “ow”, or words e.g., “ouch”.
- **Develops expressive pain-related language** e.g., – “Mommy, it is sore.”
- **Describes pain abstractly and in sentences** e.g., “My throat is croaky.”

- **Sensori-motor (0-24 months)**
- **Pre-operational (2 - 7 years)**
- **Concrete operational (7 - 11 years)**

(Versloot, Veerkamp, Hoogstraten, 2006)
<table>
<thead>
<tr>
<th>Age Range</th>
<th>Language Development</th>
</tr>
</thead>
<tbody>
<tr>
<td>12 – 17 months old</td>
<td>One word or involved repetitive sounds (e.g. “ow ow”)</td>
</tr>
<tr>
<td>18 – 24 months old</td>
<td>Use more difficult and pain-related words (e.g. “bruise” and “graze”); start to join words (e.g. “fall down”); begin to describe the location of the pain (e.g. “bump head”) and request support or treatment e.g., “kiss it, mommy” or “I want plaster”.</td>
</tr>
</tbody>
</table>

(Franck, et al., 2010; Stanford, et al., 2005)
### Language development

<table>
<thead>
<tr>
<th>Older than 36 months</th>
<th><img src="image_url" alt="Image" /></th>
</tr>
</thead>
<tbody>
<tr>
<td>Begin to <strong>describe different types of painful experiences</strong> with words such as “<em>pain</em>”, “<em>hurt</em>” and “<em>sick</em>”.</td>
<td></td>
</tr>
<tr>
<td>Start <strong>distinguish</strong> between the experience of “<em>hurt/ouch</em>” to describe a hurtful event</td>
<td></td>
</tr>
<tr>
<td><strong>Use self comforting words</strong></td>
<td><img src="image_url" alt="Image" /></td>
</tr>
</tbody>
</table>

(Franck, et al., 2010; Stanford, et al., 2005)
Factors that influence language development are:

Interpersonal interaction   Experiences over time

- Gender;
- Families: culture, parents, siblings
- Previous exposure (pain is experience together with a painful incident);
- Previous hospitalisations;
- Age.

(Franck, et al., 2010; Harman, Lindsay, Adewami & Smith, 2005; Von Bayer et al., 2004; Jerret & Evans, 1986; Merskey & Bogduk, 1994)
Social development

"Stop crying or Mom will think we're not having fun!"
**Conclusion**

Self-report: aim – child “talk” about pain to be able to report and move on (disclose)

NOT catastrophe

NB: Pain-related Communication board should include all categories
Vocabulary selection

Pain categories

(a) vocabulary to describe unpleasant sensations;
(b) vocabulary to request help or assistance;
(c) exclamations to indicate pain;
(d) words to describe the causes of the pain;
(e) vocabulary to comfort the distressed child.

(Costello, 2000; Dubois et al., 2010; Ely, 1992; Franck et al., 2010; Jerret & Evans, 1986; Stähle-Öberg & Fjellman-Wiklund, 2009; Stallard et al., 2001)
“Not being able to communicate does not mean that I have nothing to communicate.”

Felix Visagie (AAC user)


References


References


References


Thank you

For more information:
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