Discovering communication: What vocabulary do children with communication challenges need to express feelings of pain?

Ensa Johnson (MAAC)
Supervisors: Prof Juan Bornman (Ph.D)  
Dr. Kerstin Tönsing(Ph.D)

Centre for AAC, University of Pretoria, South Africa

www.caac.up.ac.za
The main aim of this research study is to identify the vocabulary used by children with typical development to describe physical pain and/or pain-related experiences for use by non-literate and pre-literate children who use augmentative and alternative communication.
Problem statement

• Earlier believed: children and/or people with disabilities who cannot speak do not feel pain or may have very high pain thresholds (Bottos & Chambers, 2006).

• “pain is whatever the patient says it is and occurs whenever the patient says it does” (McCafferey, 1968)

• healthcare staff overlooked other signs (behavioural changes etc)
Problem statement

- Communication vulnerable patients (Costello, Patak, & Pritchard, J., 2010). [ICU-settings]

- Children with complex communication needs [children with disabilities such as CP, Down Syndrome, ASD = acute and/or chronic pain conditions]

- ✓ experience pain
- ✓ need appropriate pain-relieving treatment (Bottos, & Chamber, 2006).
- ✓ augmentative and alternative communication (Bottos & Chambers, 2006; Costello, Patak, & Pritchard, J., 2010)
Describing pain

Pain is difficult to describe and measure (Ely, 1992; Jerret & Evans, 1986; Kortesluoma, Punämaa, & Nikkanen, 2008).

Subjective nature

Crying

Verbalisations/words

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

Exh effort

unrecognised

untreated
Expressing pain

• Inability to express pain in conventional manner:

  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; Stähle-Öberg & Fjellman-Wiklund, 2009; Stallard et al., 2001).
Research Design

Sequential exploratory mixed method design
(Creswell, 2014)

Phase 1
Qualitative data:
Collection and analysis of qualitative data

Phase 2
Development of instruments

Phase 3
Quantitative data:
Collection and analysis to develop product

Develop instruments

qual data collection
qual data analysis

QUAN data collection
QUAN data analysis
interpretation
Method and focus

• Studies focusing on children’s pain-vocabulary were reviewed.
• Children’s drew and discussed own physical pain experiences.
• Set of hypothetical physical pain scenarios was developed.
• Physical pain-related vocabulary children use to express their pain or discomfort was identified.
Participants (6-9 yr; n=74;)

- 6 yr: 10 boys, 12 girls
- 7 yr: 8 boys, 9 girls
- 8 yr: 9 boys, 17 girls
- 9 yr: 3 boys, 6 girls
Hypothetical physical pain scenarios

1. Falls out of a tree
2. Falls from bicycle
3. Car accident
4. Hit by ball
5. Operation
6. Thorns
7. Bodily pain
8. Burn wound
9. Bee sting
10. Drip/injection
Literature

Concrete operations stage (Piaget, 2003)

- Include **intensifiers** with descriptor words: “really bad”; “throbbing”; “poking”; “itching”; “stinging”

- **Concept of pain more abstract**
  “Sometimes it is worse and sometimes more like stabbing, but I can stand it because it is always over soon.” (Kortesluoma & Nikkonen, 2006); “Some pain makes you feel like crying, others do not. It depends on how much it aches.” (Savedra, et al., 1982)

- **Distractions** “try to ignore the pain”

- **Escape** “go home”; “can’t work/think/concentrate”

- **Strategies** “put on plaster/bandage”

Abu-Saad, 1984; Esteve, & Marquina-Aponte, 2011; Kortesluoma & Nikkonen, 2006;; Hay et al., 2009; ., 1982; Savedra, et al; Wennström and Bergh, 2008; Wilkie et al., 1990
Results

Vocabulary selection process

• Transcriptions of interviews – been checked by 2nd person with 98% correlation
• Spelling conventions: he’ll = he + will; couldn’t = could + not etc.
• Frequency count of all the words used (Atlas-ti word cruncher).
• All words which appear 10 or more times were identified and the rest (below 10) removed from the list.
• Core vocabulary identified (Marvin, Beukelman & Bilyeu, 1994 and Banayee, Dicarlo, & Stricklin, 2003.)
• Pain, other and scenario-related vocabulary
Vocabulary: 20 pain and other

- **Pain**:
  - sore: 622
  - take: 189
  - hurt: 186
  - painful: 121
  - ow: 118
  - plaster: 117
  - hospital: 107
  - arm: 103
  - ice: 98
  - bee: 97

- **Other**:
  - bandage: 88
  - thorns: 71
  - medicine: 67
  - ouch: 65
  - cold: 60
  - hurts: 59
  - into: 58
  - cream: 55
  - stung: 53
  - burnt: 51

- **Scenario**
Vocabulary: top 21 pain

- Sore: 622
- Hurt: 186
- Painful: 121
- Ouch: 118
- Ow: 65
- Hurts: 59
- Pain: 38
- Swollen: 38
- Sting: 37
- Cry: 34
- Headache: 28
- Broke: 25
- Sick: 24
- Scream: 16
- Crying: 15
- Hurting: 15
- Broken: 13
- Burning: 12
- Ouchie: 12
- Ache: 11
- Eina: 10
Pain categories

(a) vocabulary to describe unpleasant sensations: It hurts very bad; It is painful; very sore

(b) vocabulary to request help or assistance: Mommy, please help me; Take me to the doctor; Clean it; Put a plaster on; Put on ice; muti; cream; medicine

(c) exclaimations to indicate pain: ow! ouch! oh! eina! eish! (cry and scream)
Pain categories

(d) vocabulary to describe pain location/visible signs of injury: *The bones are cracked; it is broken; swollen*

(e) vocabulary to describe the causes of the pain: *I fell down; I burnt my hand*

(f) vocabulary to comfort the distressed child: *It will be better; don’t think about it/ignore it; carry on; wasn’t sore at all*
Pain categories

Pain categories added

(g) vocabulary to describe regret for injury and how it could have been prevented: I should have; I can’t believe I got hurt; I was not focusing; It was an accident

(h) vocabulary of strategies of how to cope with pain (Johnson, Boshoff, Bornman, submitted): sleep/lie in bed/lie down/relax; rub it; don’t move it/keep it still/hold it; kiss it; suck it; wait a bit

(i) vocabulary to describe positive outcomes due to pain: Mommy, bring my teddy bear/presents/sweets; granny will come; a friend to play with
Final remarks on outcomes

- Importance of inclusion of generic words ("stuff"/")things") on a communication board
- Time of data collection (seasonal implications)
- Language switching (eina, muti)
- Use of the word "medicine"
- Older children – coping strategies for pain
Designing a communication board is NOT “one size fits all” = individualized

NB: Pain-related Communication board should include all categories
References


References


Thank you

For more information:
Contact the Centre for Augmentative and Alternative Communication

www.caac.up.ac.za
ensajohnson@up.ac.za