

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

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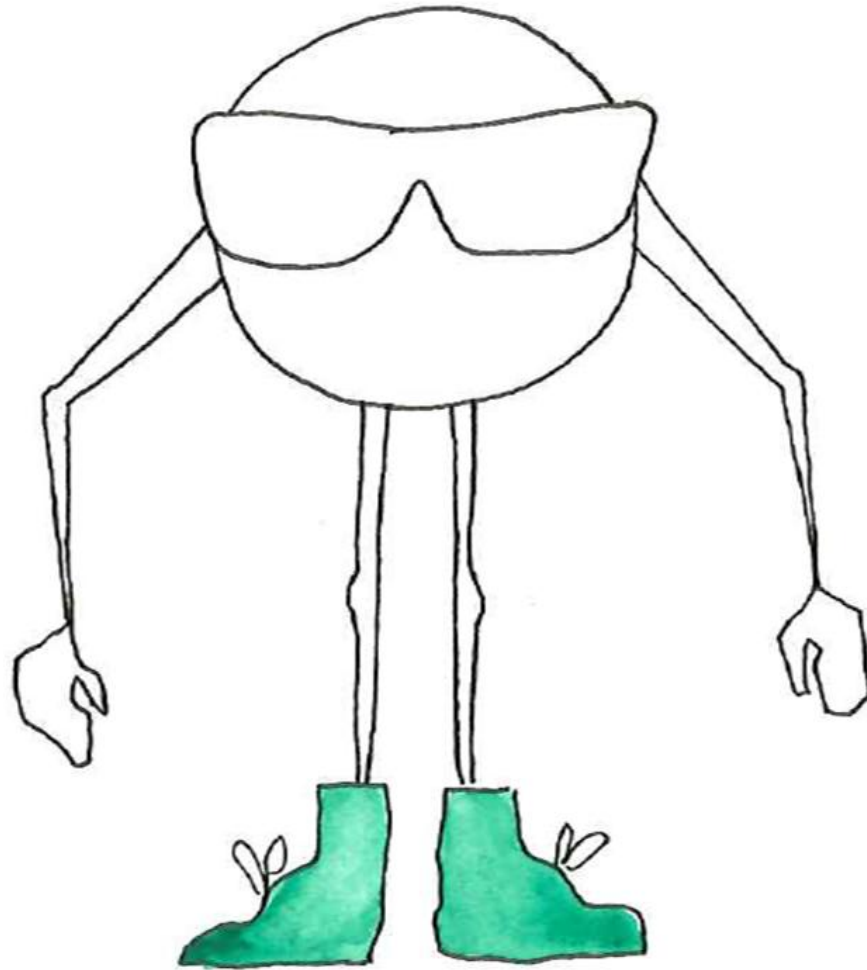
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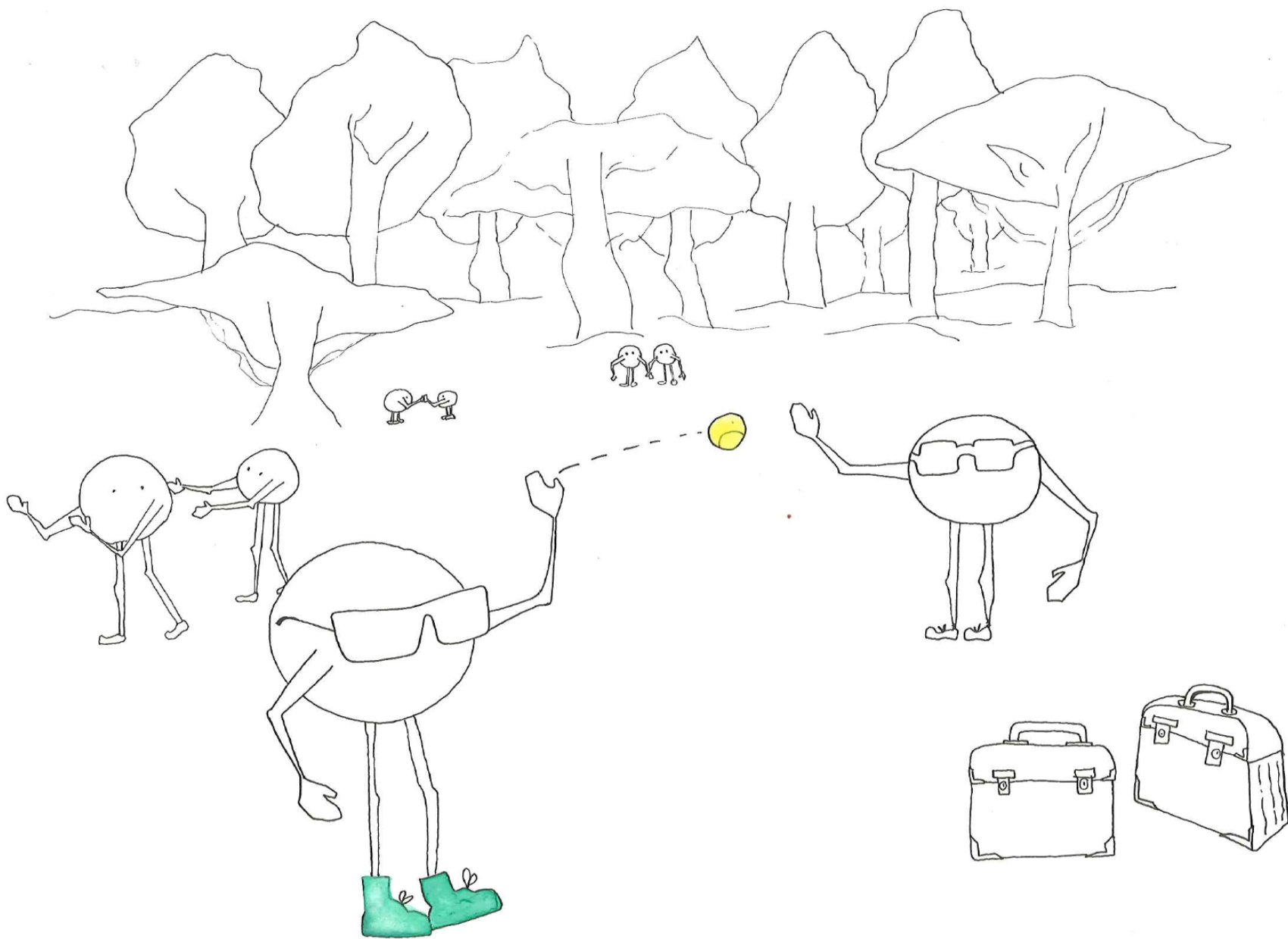
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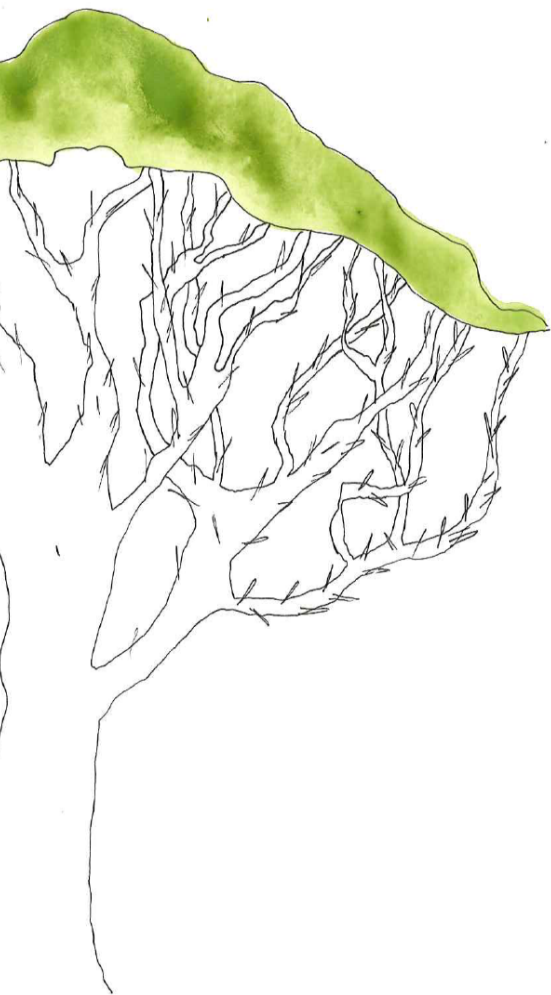
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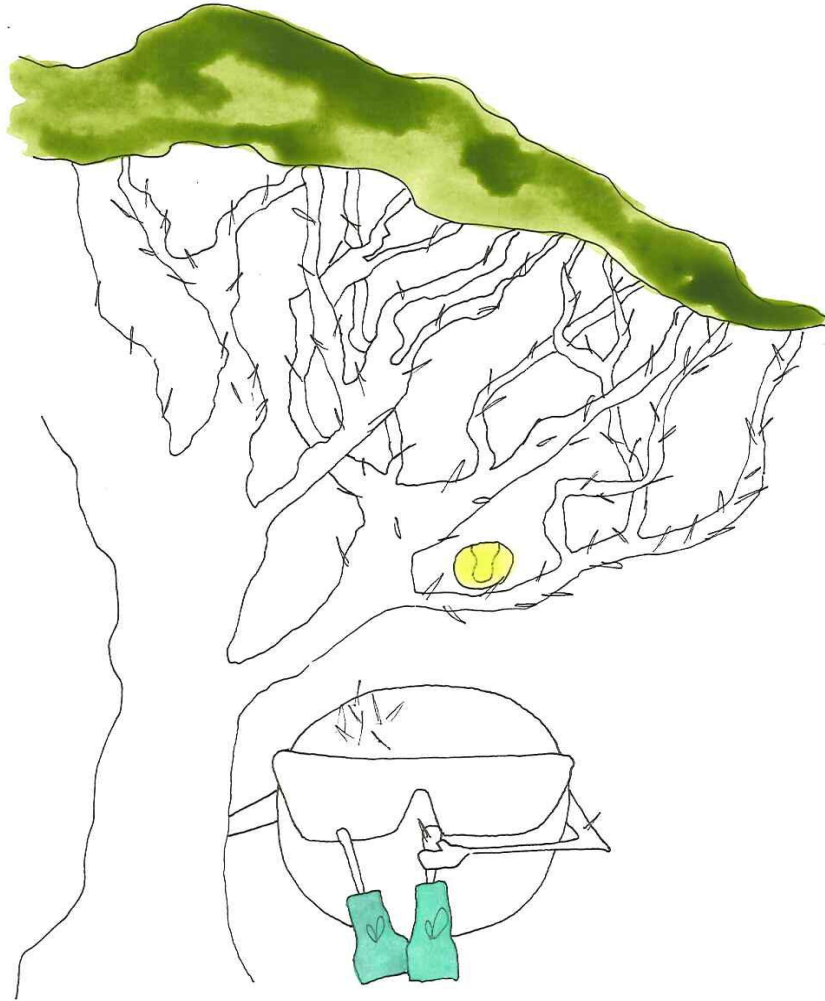
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Aim

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 (Jerret & Evans, 1986; Kortessluoma, Punamäke, 1992;

**Subjective
nature**

Crying

Verbal

CCN

**do not try to draw
attention of others
(Dubois et al. (2010)**

much effort

**unrecognised
untreated**

Self-report

Expressing pain

- **Inability to express pain in conventional manner:**

**Safety
implications**

**Insufficient pain-
relieving treatment**

Fear or anxiety

Distress

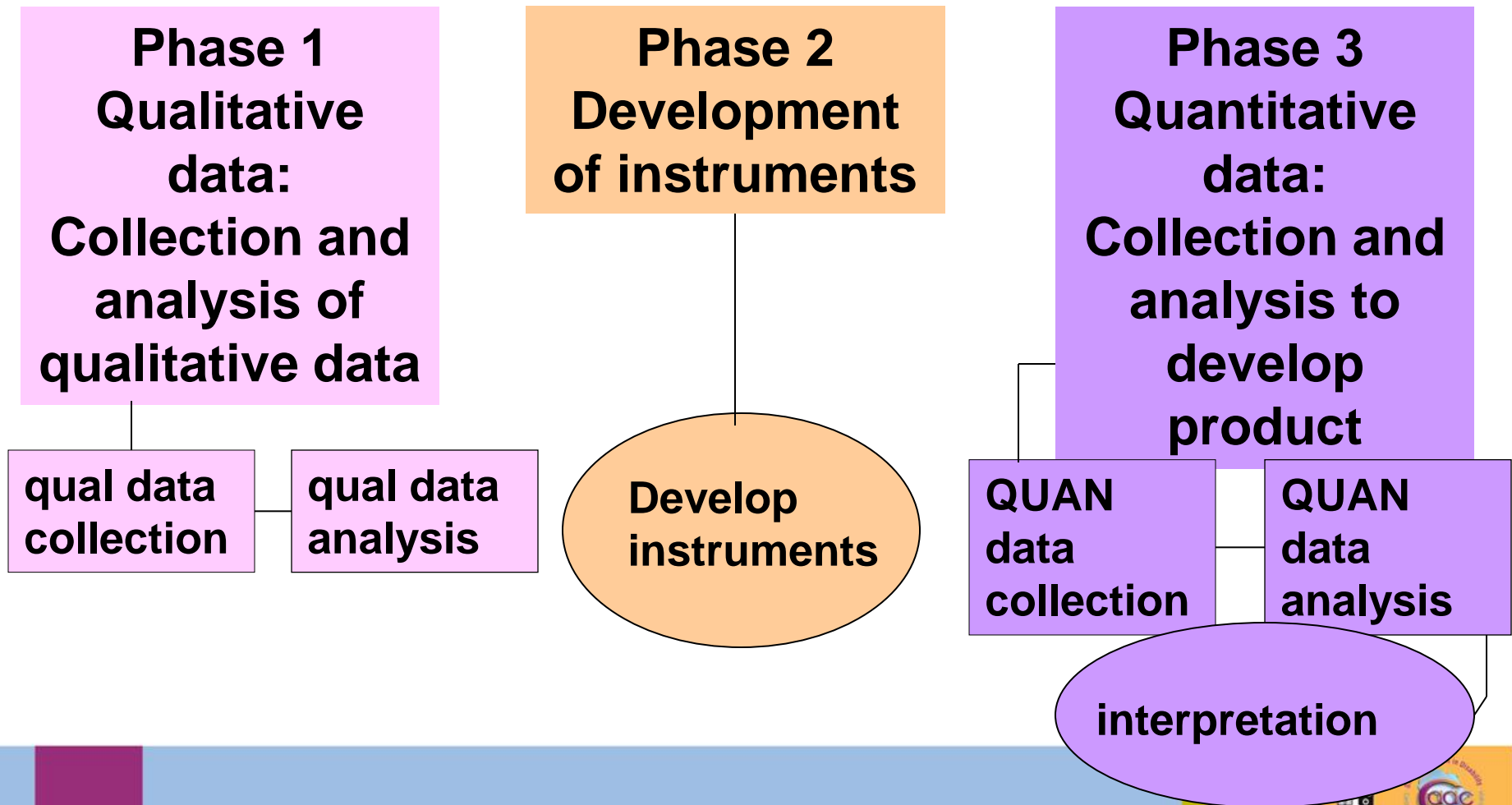
Frustration

Overall deterioration of individual's well-being

Research Design

Sequential exploratory mixed method design

(Creswell, 2014)

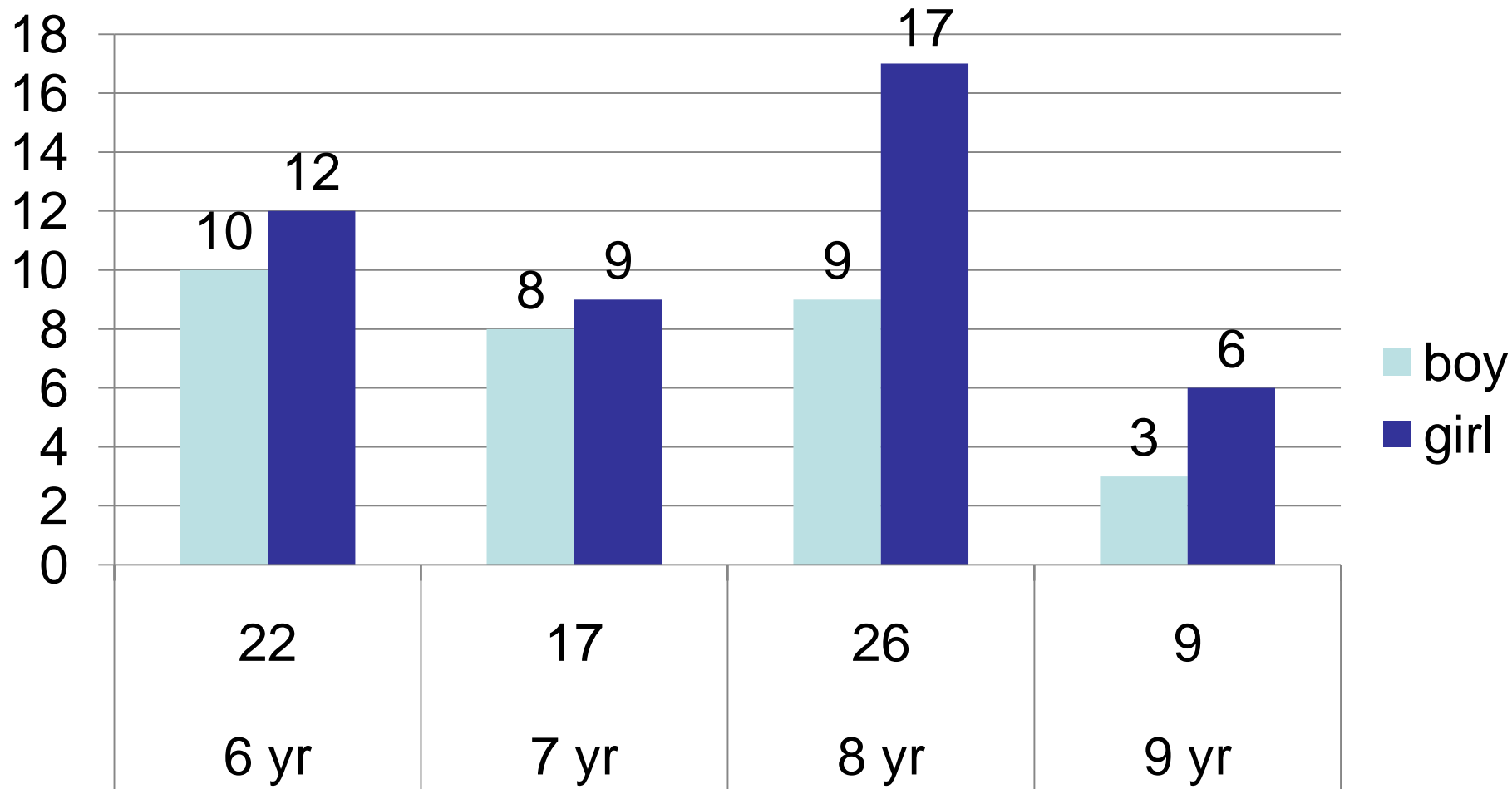


Method and focus

- 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;)



Hypothetical physical pain scenarios

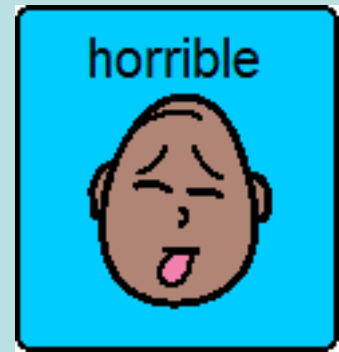
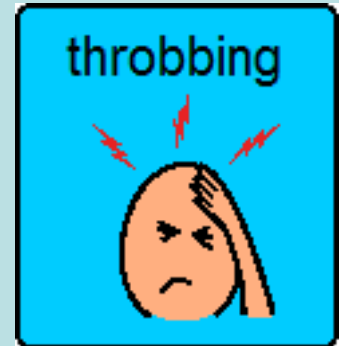
1. Falls out of a tree
2. Falls from bicycle
3. Car accident
4. Hit by ball
5. Operation
6. Thorns
7. Bodily pain
8. Burn wound
9. Bee sting
10. Drip/injection



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*”



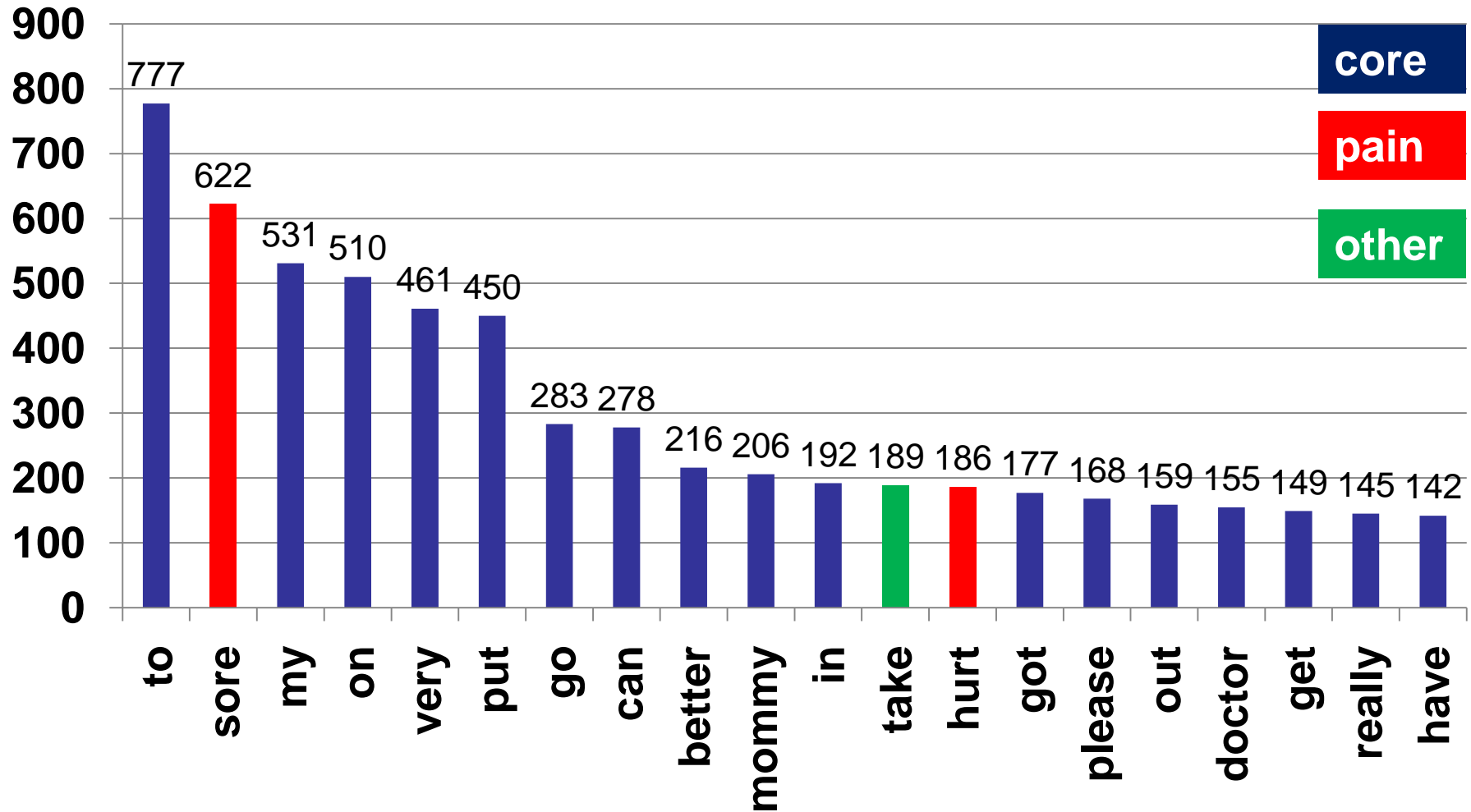
Abu-Saad, 1984; Esteve, & Marquina-Aponte, 2011; Kortesluoma & Nikkonen, 2006;; Hay et al., 2009; ., 1982; Savedra, et al; Wennström and Bergh , 2008; Wilkie et al., 1990

Results

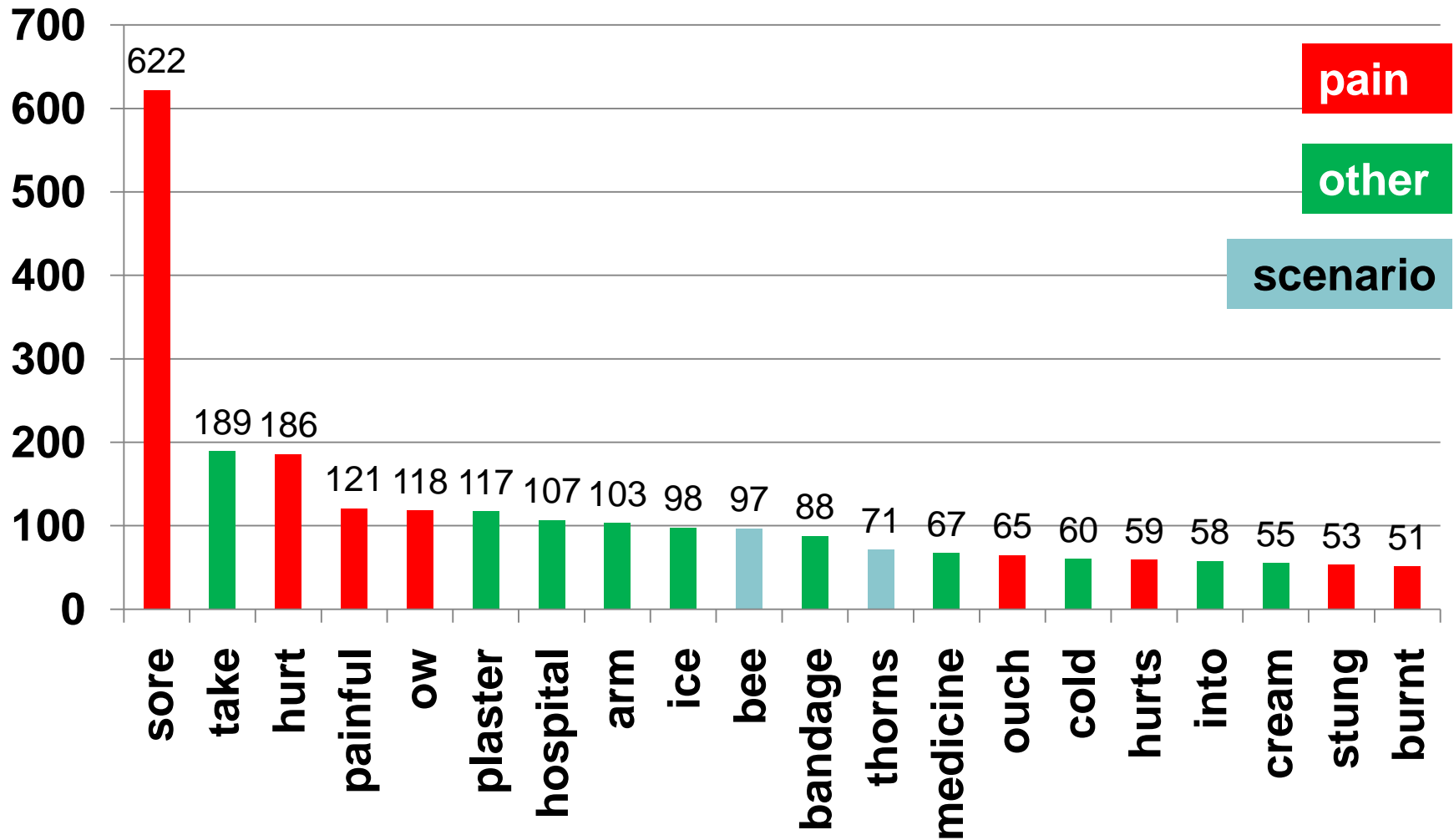
Vocabulary selection process

- **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**

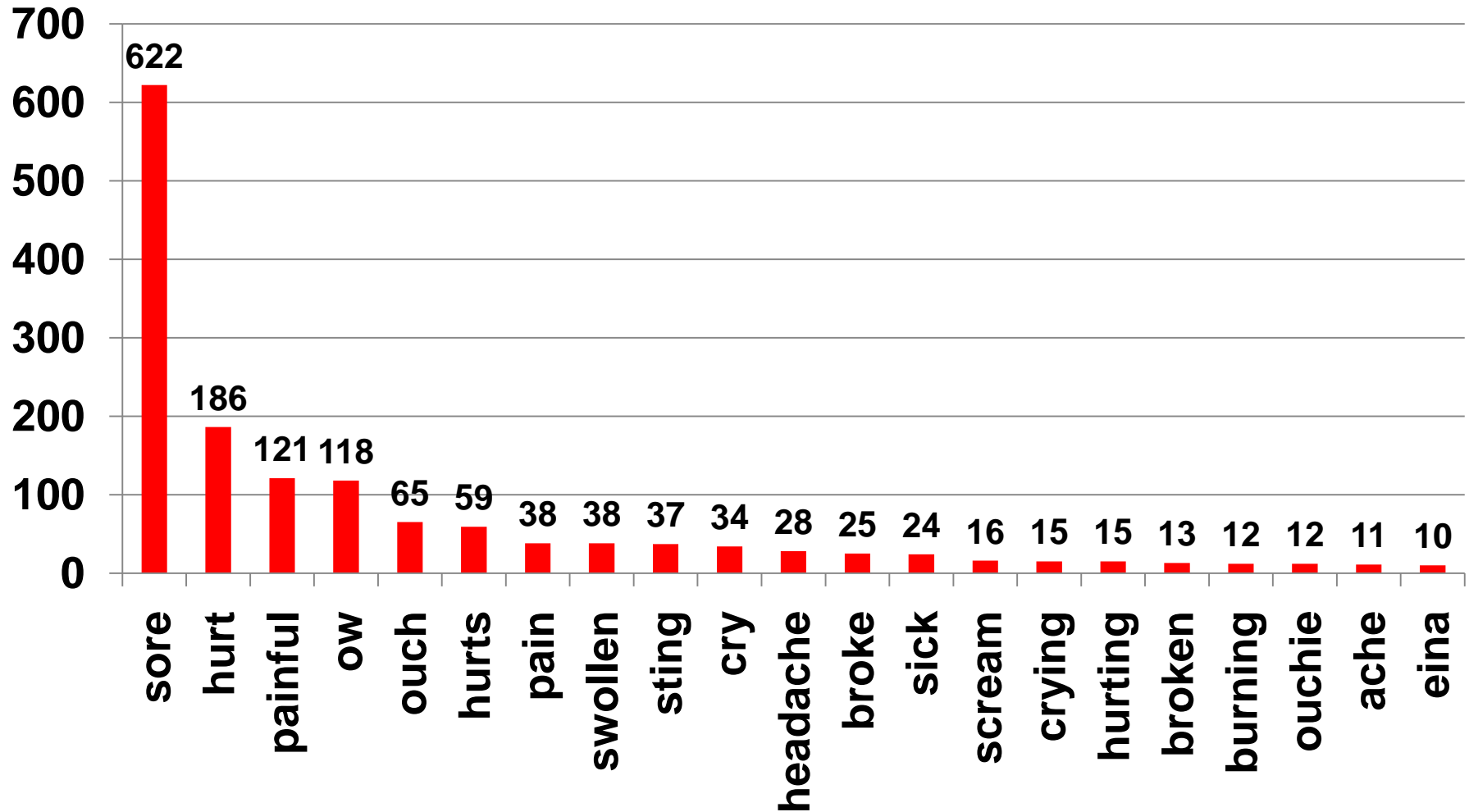
Vocabulary: core + pain + other



Vocabulary: 20 pain and other



Vocabulary: top 21 pain



Pain categories

(Franck, Noble, & Liossi, 2010)

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) exclamations to indicate pain: ow! ouch! oh!
eina! eish! (cry and scream)**



Vocabulary selection

(Franck, Noble, & Liossi, 2010)

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**

Conclusion

- Designing a communication board is NOT “one size fits all” = **individualized**

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



References

- Abu-Saad, H. (1984). Assessing children's responses to pain. *Pain*, 19(2), 163-171.
- Banajee, M., Dicarlo, C., & Stricklin, S. B. (2003). Core vocabulary determination for toddlers. *Augmentative and Alternative Communication*, 19, 67-73.
- Bottos, S., & Chambers, C. T. (2006). The Epidemiology of Pain in Developmental Disabilities. In T. M. Orlander & F. I. Symons (Eds.), *Pain in children and adults with developmental disabilities* (pp. 67-87). Baltimore, Maryland: Paul Brookes Publishing Company.
- Costello, J. M. (2000). AAC intervention in the intensive care unit: The children's hospital Boston Model. *Augmentative and Alternative Communication*, 16(3), 137-153. doi: 0743-4618/00/1603-0137
- Costello, J., Patak, L., & Pritchard, J. (2010). Communication vulnerable patients in the pediatric icu: enhancing care through augmentative and alternative communication. *Journal of pediatric rehabilitation medicine*, 289-301. Doi: 10.3233/prm-2010-0140.
- Creswell, J. C. (2014). Research design: qualitative, quantitative and mixed method approaches. (4 ed.). London: SAGE.
- Ely, J. (1992). The experience of pain for school-age children: Blood, band-aids, and feelings. *Children's Health Care*, 21(4), 168-175.
- Esteve, R., & Marquina-Aponte, V. (2011). Children's pain perspectives. *Child: Care, Health And Development*, 38(4), 441-452.
- Franck, L, Noble, G., & Liossi, C. (2010). From tears to words: The development of language to express pain in young children with everyday minor illnesses and injuries. *Child: Care, Health and Development*. 36 (4), 524-533. doi: 10.1111/j.1365-2214.2010.01084

References

- Hay, I., Oates, J., Giannini, A., Berkowitz, R., & Rotenberg, B. (2009). Pain perception of children undergoing nasendoscopy for investigation of voice and resonance disorders. *Journal of Voice*, 23, 380 – 388. doi: 10.1016/j.voice.2007.10.008 International Association for the Study of Pain (IASP). (2011).
- IASP, (2011). IASP Taxonomy. http://www.iasp-pain.org/AM/Template.cfm?Section=Pain_Defi...isplay.cfm&ContentID=1728#Pain
- Jerrett, M., & Evans, K. (1986). Children's pain vocabulary. *Journal of Advanced Nursing*, 11(4), 403-408.
- Johnson, E., Boshoff, K., & Bornman, J. (submitted). Systematic review of children's pain vocabulary.
- Kortessluoma, R., Punämak, R., & Nikkonen, M. (2008). Hospitalized children drawing their pain: the contents and cognitive and emotional characteristics of pain drawings. *Journal of Child Health Care*, 12(4), 284-300.
- Kortessluoma, R., & Nikkonen, M. (2006). 'The most disgusting ever': Children's pain descriptions and views of the purpose of pain. *Journal of Child Health Care*, 10(3) 213-227. doi: 10.1177/1367493506066482
- Marvin, C. A., Beukelman, D. R., & Bilyeu, D. (1994). Vocabulary-use patterns in preschool children: Effects of context and time sampling. *Augmentative and Alternative Communication*, 10, 224-236.
- McCaffery, M. (1968). *Nursing practice theories related to cognition, bodily pain, and man-environment interactions*. Los Angeles: University of California.
- Patak, L., Gawlinski, A., Fung, I., Doering, L., Berg, J., & Henneman, E.A. (2006). Communication boards in critical care: Patients' views. *Applied Nursing Research*, 19, 182-190. doi: 10.1016/j.apnr.2005.09.006
- Piaget, J. (2003). Part 1. Cognitive development in children: Piaget. Development and learning. *Journal of Research in Science Teaching*, 40(supplement), S8-S18.

References

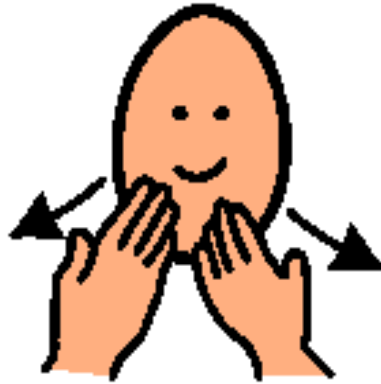
Stähle-Öberg, L., & Fjellman-Wiklund (2009). Parent's experiences of pain in children with cerebral palsy and multiple disabilities – an interview study. *Advances in Physiotherapy*, 11, 137-144. doi: 0.1080/14038190902906318

Stallard, P., Williams, L., Lenton, S., & Velleman, R. (2001). Pain in cognitively impaired, non-communicating children. *Archives of Disease in Childhood*, 85(6), 460-462.

Wennström, B., & Bergh, I. (2008). Bodily and verbal expressions of postoperative symptoms in 3- to 6-year-old boys. *Journal Of Pediatric Nursing*, 23(1), 65-76.

Wilkie, D. J., Holzemer, W. L., Tesler, M. D., Ward, J. A., Paul, S. M., & Savedra, M. C. (1990). Measuring pain quality: validity and reliability of children's and adolescents' pain language. *Pain*, 41(2), 151-159.

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Thank you

**For more information:
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