Assessing dental pain in patients with intellectual disabilities

Can we see their pain?  
Yes, we can!

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presentation

1. Pain in people with IDs a painful gap
2. “Know their Pain” results Down study 2010
3. Pain & Cognition in Adults with Down Syndrome
4. The 2014 Dutch Guideline on Pain in People with Intellectual Disabilities (IDs)

- doctors in the eighties ...
  *newborns and fish have no pain*
Pain, the fifth vital sign (1995)

American Pain Society (APS)
(heart rate or pulse, blood pressure, respiratory rate and body temperature)

“an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage “ IASP 1979
“The inability to communicate does not negate the possibility that an individual is experiencing pain and is in need of appropriate pain-relieving treatment”

Self report : the golden standard

Inability to reliably report pain?
one of the paradoxes of life for people with severe, profound IDs.

their neurodevelopmental disorders place them at a significantly greater risk for pain-related medical conditions.

their level of cognitive impairment precludes the conventional communication of their pain to others.

Bodfish (2006)

Pain in people with disabilities

• 60 % of children and 75% of adults with a sensory or intellectual disability has chronic pain (Breau 2003)

• epilepsy, ear and hearing problems, oral health problems, gastroesophageal reflux disease & obstipation (Van Schojenstein Lantman-de Valk, e.a., 2008)

• Children with Down syndrome: +/- 50% heart of intestinal surgery at a young age
... do we see their pain...?

- Parents underestimate pain of their child >> under-treatment of pain (Chambers et al. 1998)

- Dentists underestimate pain of the child (Versloot et al. 2004) “pain blindness by healthcare professionals”

- Need for treatment in IDs often underestimated, oral pain & discomfort not recognized by parents, carers, dentists (Hennequin et al., 2000)

Down syndrome
26 subjects, 75 controls
Greater latency times
Higher pain threshold?
More difficulties in localizing cold stimuli
Pain Sensitivity Down Syndrome

Defrin et al. Pain 2004

Method of Levels MLE: stepwise changing reaction time independant

Method of Limits MLI: linearly increasing. reaction time dependant

Greater latency time
Heat Pain threshold in IDs and DS lower
More sensitive to heat?

No Consensus about direction of pain sensitivity!
The Down study 2010

Children with Down syndrome do they have another pain sensitivity?

How do children with Down syndrome show that they are in pain? Pain expression.

Is there a genotype-phenotype relationship for the pain sensitivity?
“Know their pain” Down study 2010

a high tech instrument station on the doorstep!

150 DS children
8 -13 yrs of age
‘at home with parents/caregivers’

Monique van Dijk, Bram Valkenburg, Dick Tibboel
Erasmus MC Instrument Van : Citroën HY-1978 ,
“Common sensation is generally much less acute than in ordinary persons. Pain is born with wonderful callousness. It is not uncommon for children of this class to allow a thecal abscess to be opened with a scalpel without a grimace or without uttering a word.”

1887 James Langdon Down

Phd Thesis 2012 (cum laude)
A.J. (Bram) Valkenburg, Erasmus University Rotterdam
In the Instrument Van

- visual-motor reaction time
- pain sensitivity QST
- facial expression
- DNA research pain
I have a special tail! If I wish I can make my tail hot or cold.

I wonder if you feel it.

Put your hand on my neck, which is nice and soft. I'll help you with the measurements nothing can happen to your hand.
questionnaires

Medical history, family

Vineland Adaptive Behavior Scale

Pain Coping Questionnaire

Chronic Pain Questionnaire
Quantitative Sensory Testing: A bridge too far?

- 42 DS (mean age 12 yrs), 24 siblings (mean age 14 yrs)
- Significantly longer reaction time
- 85% DS verbalize pain, 20% DS quantify pain, only 46% localize pain:
  - 88% DS >> cold/warmth/sharp/blunt
  - 33% DS >> detection threshold for warmth
- DS children more sensitive for heat pain and (?) more sensitive to cold pain

Inadequate self report for pain

QST possible?
Parents: minority of children able to self report pain, & parents rate their children as less sensitive to pain

**Verbal and non-verbal pain and pain expressions in DS probably different than expected**

DS children use fewer coping strategies: primarily distraction coping styles; DS children do not make attempts to deal with the pain
DS children remain dependant of pain and stress assessment by proxy, throughout their lives, since self-report is inadequate.

Parents rate their children with Down syndrome as less sensitive to pain, but this is not confirmed by quantitative sensory testing.

Children with DS do not try to deal with pain & distress: they look for distraction.
Pain and Cognition in Adults with Down Syndrome

The PhD project of Nanda C. de Knegt,
Clinical Neuropathology,
VU University Amsterdam, The Netherlands
dementia on the rise!
increase pain studies in dementia.

IDs : increased life expectancy
DS>> musculoskeletal disorders
e.g. arthrosis ( use of analgesics)

dementia in DS : as early as from their fortieth
Pain in adults with intellectual disabilities
Nanda de Knegt, Erik Scherder

• Dementia altered pain experience different pain perception

• Pain perception in adult DS an altered pain experience based on neuropathology?

• Discrimination between pain and mental state of anxiety: paracetamol or haloperidol?
Pain and cognitive functioning

Pain: negative for cognitive functioning:

Poorer memory, distracted, loss of skills, bad mood, change in behavior

Old age, dementia or stress?
Visualization of the path of pain by fMRI
Pain related neuropathology in IDs

Fig. 1. Pain-related gray matter neuropathology in the most prevalent subtypes of Intellectual Disability (ID)
Pain related neuropathology in IDs

- neuropathological changes can affect the pain system in the brains.

- Fragile X syndrome & Prader Willi syndrome: degeneration of white matter >> a lower pain tolerance >> increase in suffering from pain?

- Down Syndrome & Williams syndrome: neuropathology >> suggests both decrease as increase in pain experience?
A self report tool for pain for adult DS?

autonomous functioning!

DS stronger visual-spatial than verbal abilities

assessment of comprehension

numeric rating scale NRS & Facial Affect Scale FAS

>> 70% comprehended at least one of the two scales

in dental practice ...

Limited verbal communication
Use “open questions” and simple language

Unreliably self report for pain & localisation of pain
prevent pain experiences

Longer reaction time & slower verbal response
use local analgesia

Do not overestimate your DS patient!
wait longer for an reaction!
Beware of different coping styles
The 2014 Dutch Guideline on Pain in People with Intellectual Disabilities (IDs)
The 2014 Dutch Guideline on Pain in People with Intellectual Disabilities (IDs)

• The professional association of healthcare professionals  V&VN

• 18-50 yrs of age with IDs and impaired verbal expression
Evidence Based Guideline Development

diversity of the IDs group
individual pain behavioral patterns

for nurses and caregivers ‘the persons around the bed’

> see possible pain behavior
> use adequate observational tools
> take the appropriate actions

a complex, challenging, time consuming process
Basic attitude of genuine interest in the other

Professional awareness

Exchange of health information
Cycle of exchange of pain information from client to caregiver

1a
- Pain identified
- Complaint arises
- Appointment with doctor

1b
- Complaint identified
- Pain identified
- Shared with colleagues

client
carer
Application of pain observational tools

**Faces Pain Scale - Revised**

- Not capable of self-report > Rotterdam Elderly Pain Observation Scale REPOS

- Capable of self-report > Facies Pain Scale FPS-revised
Orofacial Pain in Dementia Patients: A Diagnostic Challenge

Frank Lobbezoo, Roxane Weijenberg, Erik Scherder
J Orofacial Pain 2010; 25: 6-14

“...the patient holds/rub the orofacial area
limits mandibular movements
modified his/her oral (eg.eating) behavior
and/or is uncooperative to oral care ...“

In ADD, DS-DAT, Doloplus 2, PACSLAC en PAINAID lack of orofacial pain indicators!

Develop a specific observational tool for orofacial/dental Pain

for dental patients with IDs acquired brain injury, dementia
Pain expression by DS persons in the dental chair
Stephanie Krijt, Sandra Strampel, Judith Versloot

11 DS patients >> 18yrs
2 Centers for Special care dentistry, 2 years
non-painful stimuli & painful
Videotaped & NRS
dentist & dental assistant

afterwards:
REPOS, NCAPC, FACS, NRS
based on videotapes:

“Tense face, eyebrows move, breath or irregular breathing, change eyes, moaning and moving”

Pain behavior better analyzed after treatment
Pain blindness dentist?
Dental assistant more alert

Most striking feature >>
4 babies in 3 year
Epilogue

Oral diseases
a major impact on physical and mental wellbeing

Timely recognition of orofacial/dental pain in people with intellectual disabilities: a responsibility for oral health professionals & an incentive for further research

Can we see their pain: yes, we can!