UNDERSTANDING
THE PATIENT'S
PERSPECTIVE

CBTRijnmond
Centrum Bijzondere Tandheelkunde Rijnmond

Assessing dental pain in patients with intellectual disabilities

Can we see their pain?

Yes, we can !

Elinor Bouvy-Berends

ISDH, Kilkenny 19th June 2015

presentation

1. Pain in people with IDs
   growing evidence
2. "Know their Pain"
   results Down study 2010
3. Pain & Cognition in Adults with Down Syndrome
4. The 2015 Dutch Guideline Signalling Pain in People with Intellectual Disabilities (IDs)

ken hun Pijn

The Lancet 1987
dr.Kanwaljeet J. "Sunny" Anand

- doctors in the eighties ...
  newborns and fish have no pain

RANDOMISED TRIAL OF FENTANYL ANAESTHESIA IN PRETERM BABIES UNDERGOING SURGERY: EFFECTS ON THE STRESS RESPONSE

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Pain 1979

- "an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage " IASP 1979

- American Pain Society (APS)

- *Pain, the fifth vital sign (1995) (heart rate or pulse, blood pressure, respiratory rate and body temperature)*

Self report : the golden standard

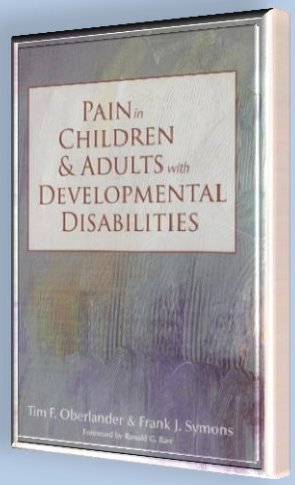
"The inability to communicate does not negate the possibility that an individual is experiencing pain and is in need of appropriate pain-relieving treatment"

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)
In: Oberlander & Symons:
Pain in children and adults with developmental disabilities

Pain in people with IDs

- 25% healthy children :every week one of more painful events
- 60 % of children and 75% of adults with a sensory or intellectual disability has chronic pain (Breau 2003)

Pain in people with IDs

- *Co-morbidity*: dislocation of hips, muscular spasm, reflux or scoliosis >less pain medication in comparison with cognitively intact individuals (Malviya et al.2001).

- *Prevalence health problems*: 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 or 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 *"pain blindness by healthcare professionals"*
  (Versloot et al. 2004)
- Need for treatment in IDs underestimated, *oral pain & discomfort not recognized* by parents, carers, dentists
  (Hennequin et al , 2000)

Much to be learned from clinical anecdotes

Young man with Autism

fracture of the mandibula, unnoticed by caregivers

Dental malocclusion in molar region observed in a periodic oral examination

>> delay in
pain management & treatment

John

- … “a delayed diagnosis of the presence and cause of pain >>
  setback in hospitalization and increased death rates” (Weiner et al, 1999)

Pain sensitivity & pain response

- "people with IDs feel little or no pain"
- increasing interest among scientists and practitioners
- growing evidence to the contrary
- increased life expectancy
- 
  a high clinical relevance of identifying pain in IDs

Oscar Fingal O'Flahertie Wills Wilde (Dublin, 16 October 1854 – Parijs, 30 November 1900)

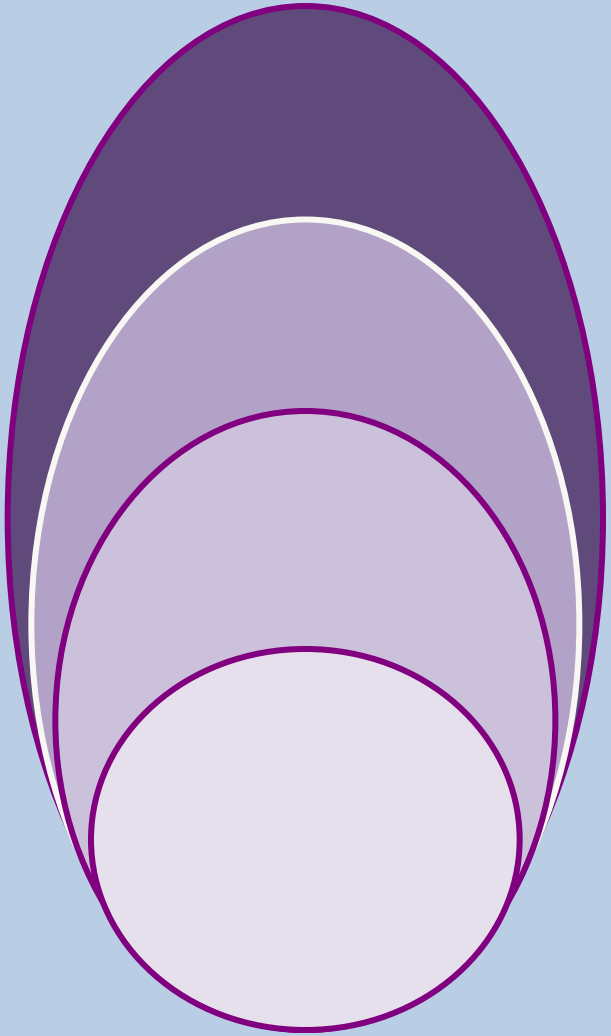
“I don’t mind pain as long as it doesn’t hurt”

(by courtesy of A.Valkenburg)

1882: Napoleon Sarony
Metropolitan Museum of Arts

Pain Model Loeser

John Loesser, neurosurgeon(2000)
The different layers of pain explained



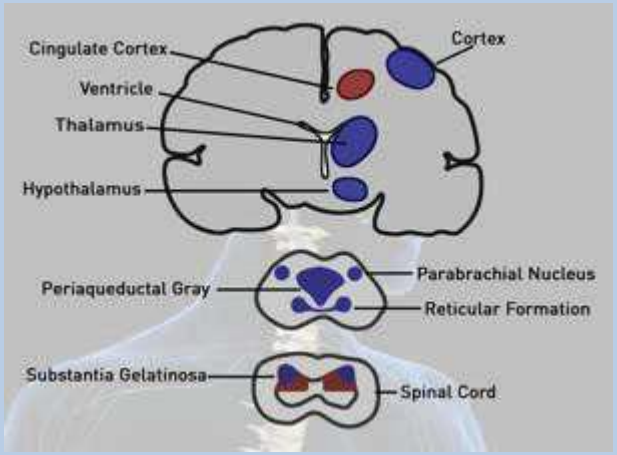
Pain behavior
>>*observation scales*

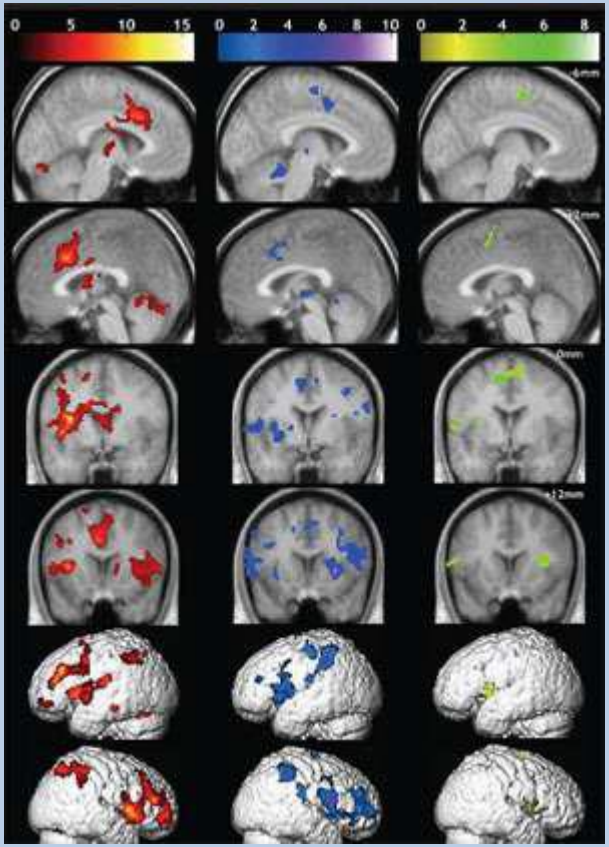
Suffering
>> self report

Pain perception
>> sensory testing

Nociception
>> fMRI

Visualization of the path of pain by fMRI





Observational tools for pain assessment in children with Ids

Association between observable behavior and pain experience

- *30 observational tools* for the "non-verbals" neonates, young children

Lynn Breau , 2000, Canada: *the Non-communicating Children's Pain Checklist NCCPC*

- *only 5 observationals* tools for intellectual disabled children

Terstegen , 2003, ErasmusMC Rotterdam: *Checklist Pain Behaviour CPG*

Behavioral Pain Indicators in People With Intellectual Disabilities *(N.C.de Knegt)*

The Journal of Pain, Vol 14, No 9 (September), 2013: pp 885-896

- Association between observable behavior and pain experience
- Unique individual pain response
- A possible clinical relevant set of indicators

- *Motor activity*
  Facial activity
  Social emotional indicators
  Nonverbal vocal expressions

Facial expression : the most important communication channel.

Facial expressions of fear, anger,pain and sadness

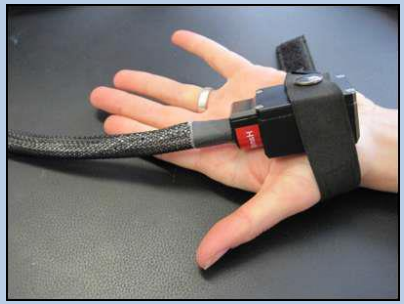
"The facial display of pain"

- Brow Bulge
- Eye squeeze
- Naso-labial furrow
- Open mouth
- Horizontal mouth stretch
- Vertical mouth stretch
- Cup tong
- Tongue protrusion
- Chin quiver
- Lip purse

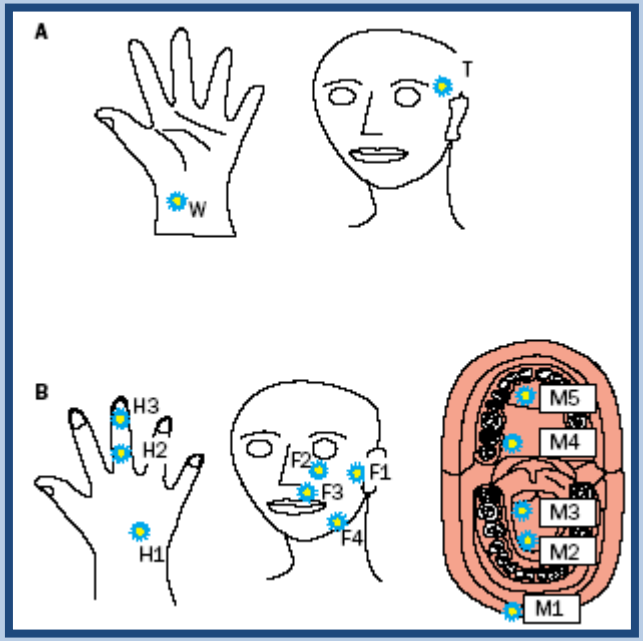
Oberlander et al. 1999, LaChapelle et al. 1999, Nader et al. 2004

next step in pain research in IDs

- from observation of behaviour possibly due to pain
- *to*
- measurement of pain (sensitivity)by sensory testing



Hennequin, M., Morin, C. & Feine, J.S. (2000). Pain expression and stimulus localisation in individuals with Down's syndrome. *Lancet*, 356, 1882-1887



Down syndroom

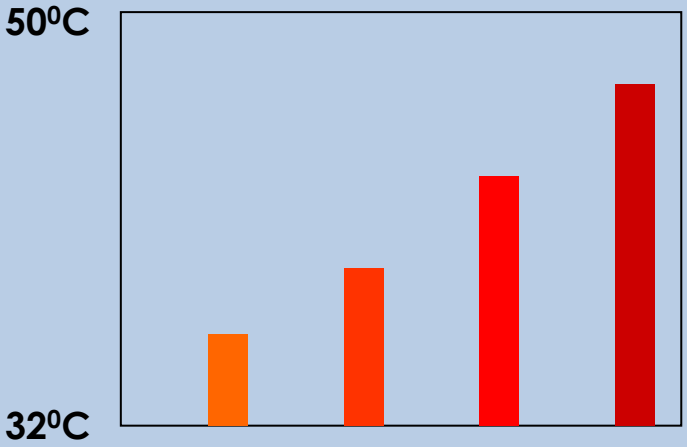
26 subjects, 75 controls

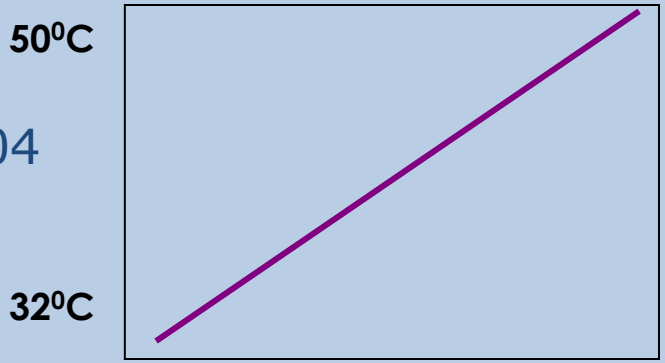
Greater latency times

Higher pain threshold ?

More difficulties in localizing cold stimuli

Pain Sensitivity Down Syndrome





Defrin et al. Pain 2004

Down syndrome
25 ID adults (11 DS)
14 controls

Method of Levels MLE:
reaction time independant

Method of Limits MLI :
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 ,

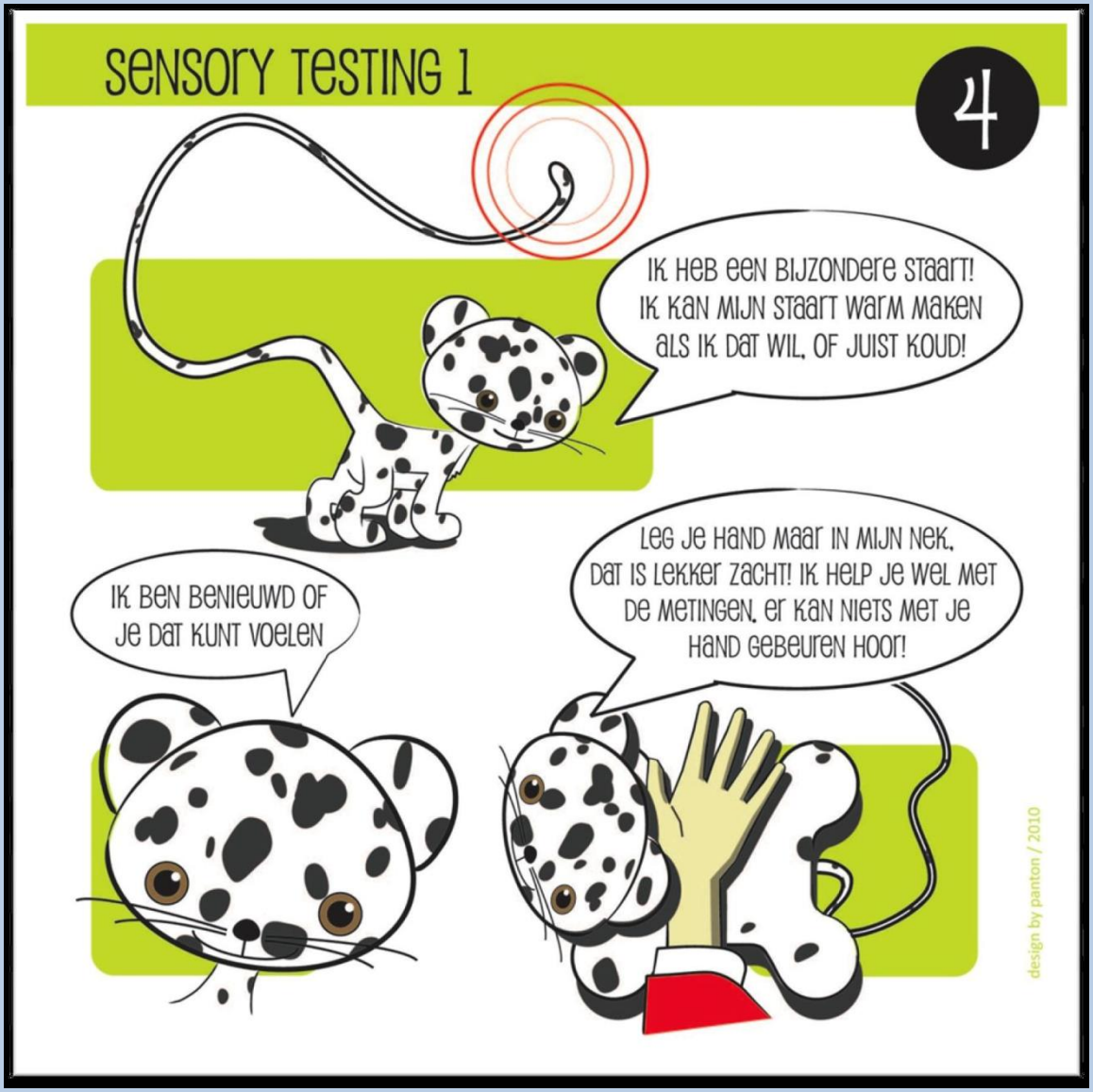
"Common sensation is generally much less acute than in ordinary persons. Pain is born with wonderful callousness. It is not uncommon for children of this class to allow a thecal abscess to be opened with a scalpel without a grimace or *without uttering a word.*"

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*

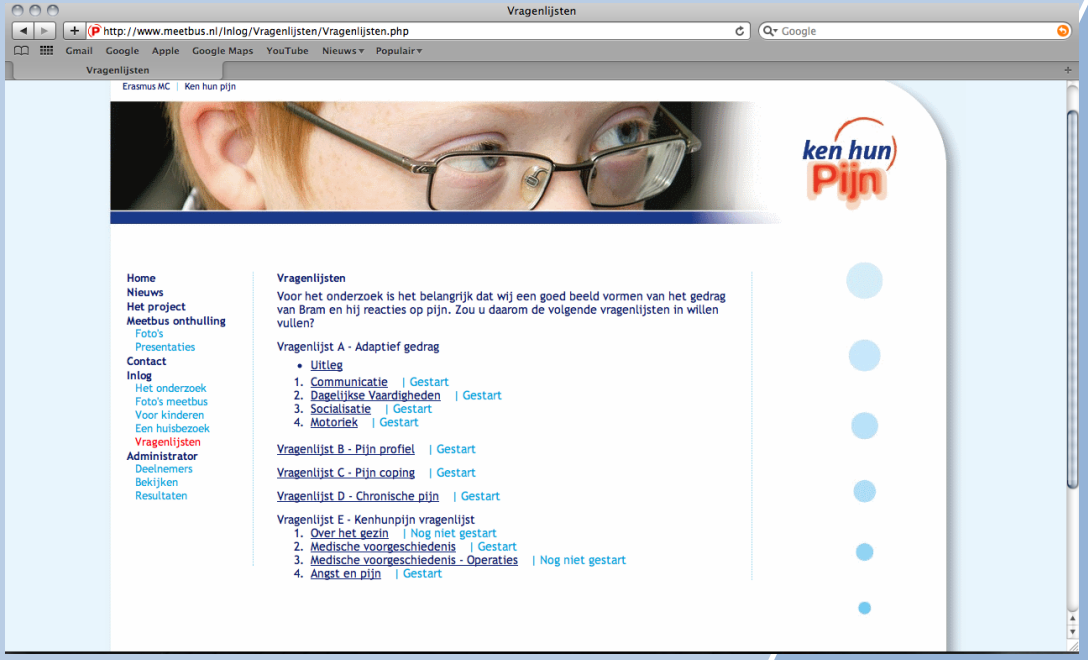


I have a special tail! If I wish I can make my tail hot or cold

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

Quantitive Sensory Testing : A bridge too far ?

42 DS (mean age 12 yrs),
24 siblings (mean age 14 yrs)

Significantly longer reaction time to pain

inadequate self report for pain

85% DS verbalize pain,
20% DS quantify pain,
only 46% localize pain

QST possible ?

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

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 primarily distraction coping styles ; DS children do not make attempts to deal with the pain

conclusion

- 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

FOTO MARC GIJSBERS, THEATER MAATWERK

Pain and Cognition in Adults with Down Syndrome

The PhD project of Nanda C. de Knegt,

Clinical Neuropathology,

VU University Amsterdam, The Netherlands

Pain in adults with intellectual disabilities

Nanda de Knegt, Erik Scherder PAIN 152 (2011) 971–974

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 PAIN 152 (2011) 971–974

- *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, *grumpy*
change in behavior

Old age, dementia or stress?

Pain related neuropathology in IDs

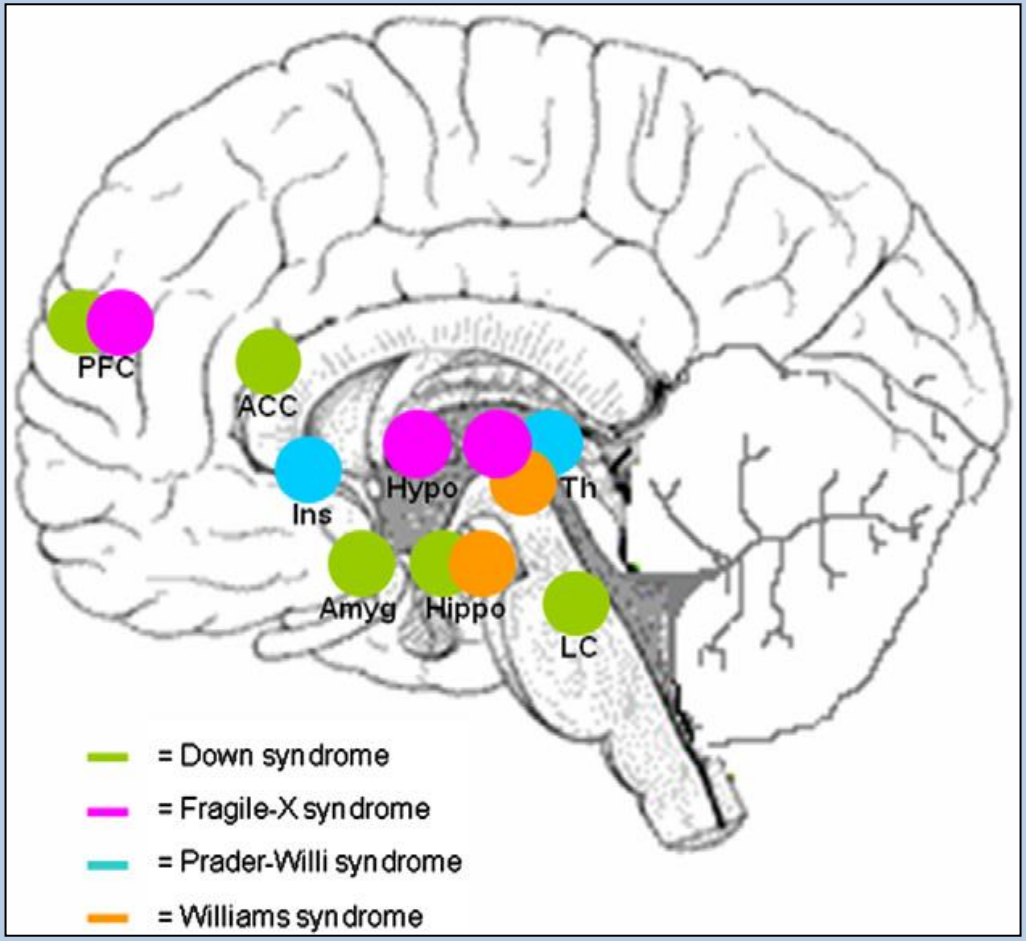


Fig. 1. Pain-related gray matter neuropathology in the most prevalent subtypes of Intellectual Disability (ID)

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 !

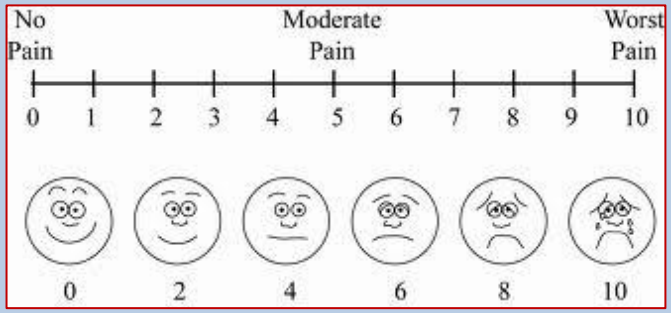
DS stronger visual-spatial than verbal abilities

assessment of comprehension

Paulus de Groot

numeric rating scale NRS &
Facial Affect Scale FAS

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



N.C.de Knegt, H.M.Evenhuis et al. Does format matter for comprehension of a facial affective scale and a numeric scale for pain adults with Down syndrome? Research in Developmental Disabilities 34 (2013) 3442-3448

The DS patient in the Dental Office

Use “open questions” and simple language

Repeat final option in questions with multiple answers

Unreliably self report for pain & localisation of pain

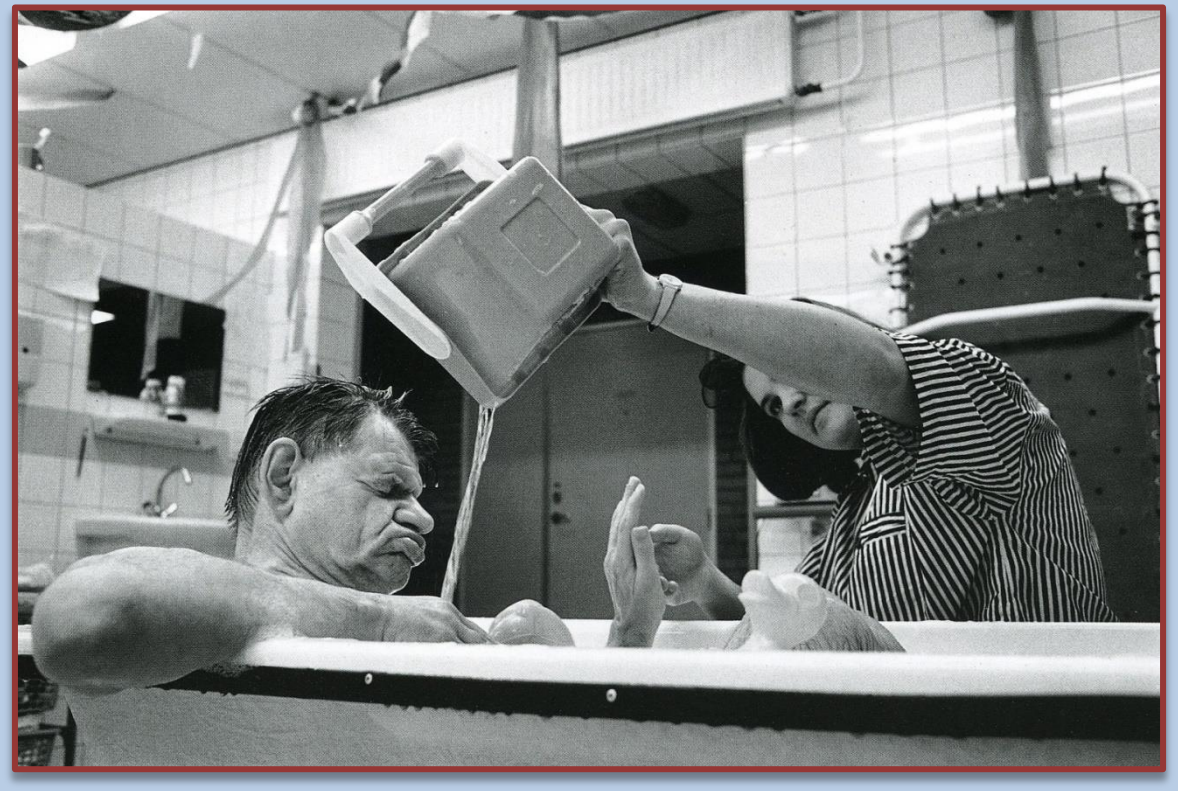
prevent pain experiences

The DS patient in the Dental Office

Longer reaction time
& slower verbal response
use local analgesia &
the rule of 6 (seconds)

Different coping styles:
better understanding of
fear and anxiety
in dental setting

Pain
in Adults with Intellectual Disabilities and Impaired Verbal Expression



The 2015 Dutch Guideline Signaling Pain in People with Intellectual Disabilities (IDs)

- The professional association of healthcare professionals V&VN

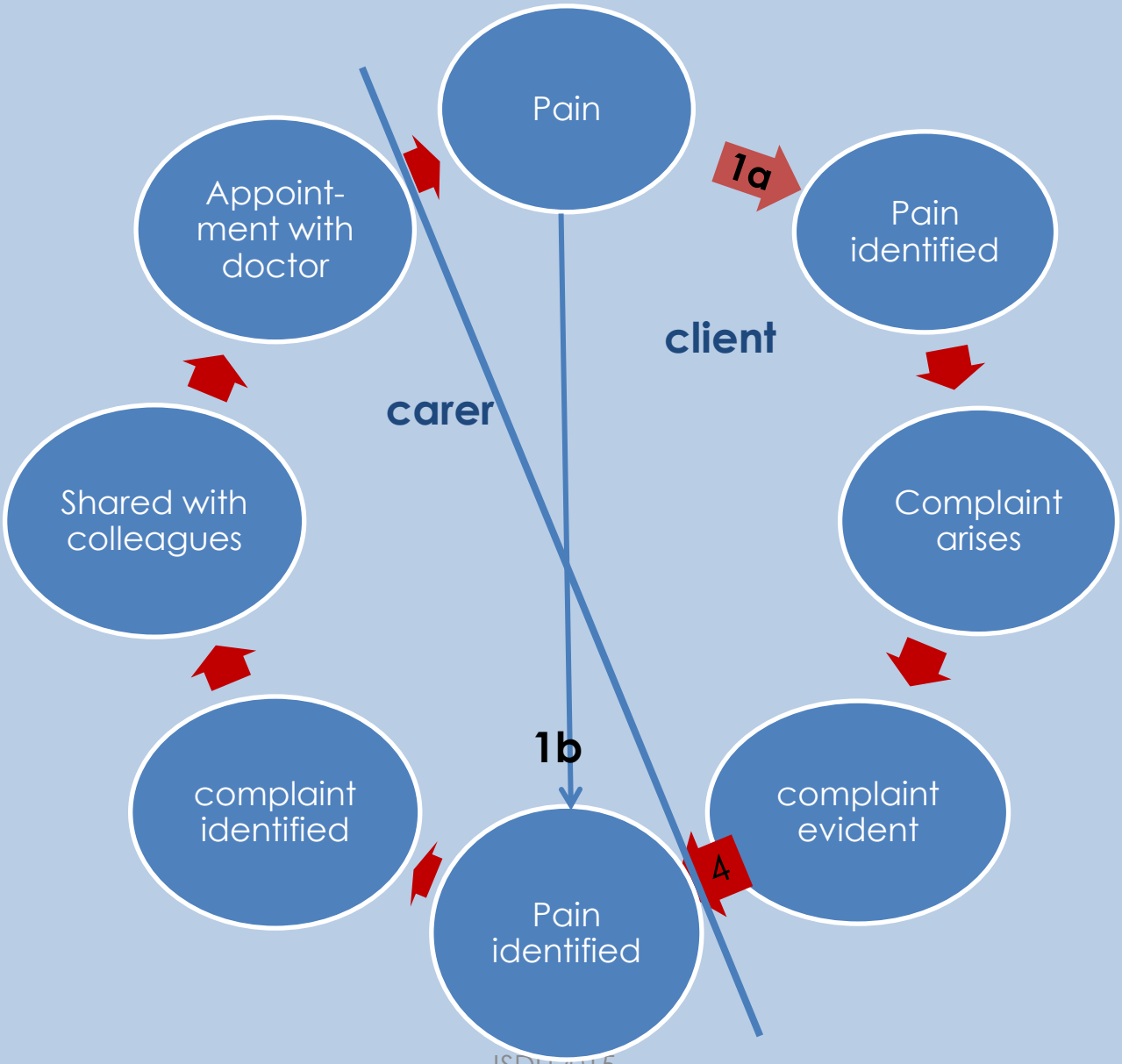
- 18-50 yrs of age with IDs ánd communication difficulties
- for nurses and caregivers *"the people at the bedsite"*

Basic attitude of genuine interest in the other

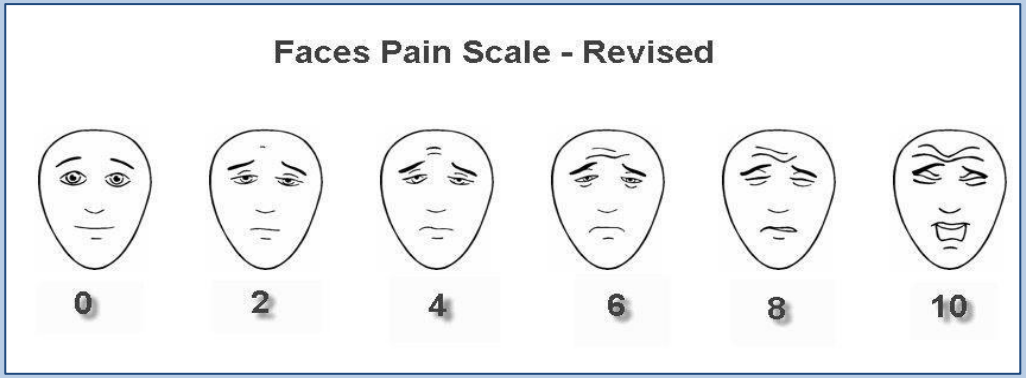
Professional awareness

Exchange of health information

Cycle of exchange of pain information from client to caregiver



Application of pain observational tools

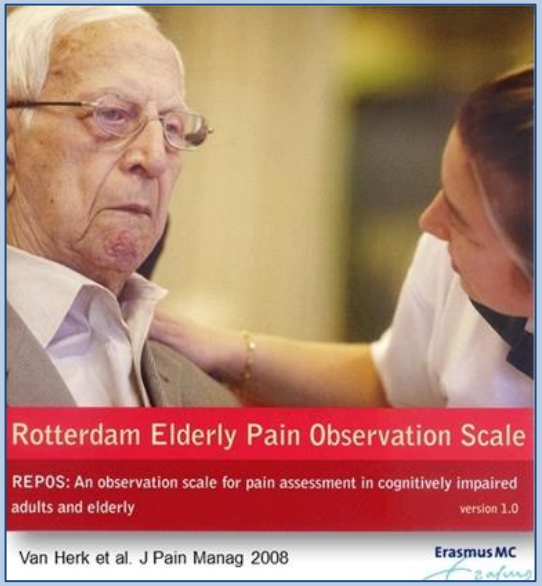


Capable of self-report >

Facies Pain Scale FPS-revised

Not capable of self-report >

Rotterdam Elderly Pain Observation Scale REPOS



Orofacial Pain in Dementia Patients:
A Diagnostic Challenge

Frank Lobbezoo, Roxane Weijenberg, Erik Scherder

J Orofacial Pain 2010; 25: 6-14

no specific orofacial pain indicators in ADD, DS-DAT, Doloplus 2, PACSLAC en PAINAID

Develop a specific observational tool for orofacial/dental pain

for dental patients with IDs ,
acquired brain injury, dementia

To prevent unnecessary suffering & treatments

Guideline signaling pain in people with intellectual disabilities

Special attention for oral health
possible signals of pain in orofacial area

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

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!