Pain and Behaviour in Persons with Dementia

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Pain is…

… an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage.

(IASP 1979)

Pain is…

… whatever the experiencing person says it is, existing whenever the experiencing person say it does.

(McCaffery 1989)

Pain in Older Persons

- Prevalence between 49 % and 83 % (self-report)
- Most common complaints
  - Joint / muscle pain
  - Neuropathic pain
  - Acute pain, eg after falls etc.
  - Tumor pain

- 45 % to 80 % prevalence in long term care (AGS 2002)

Current Study: *Pain and Autonomy in the Nursing Home*

- Funded by Fed. Ministry of Education and Research
- Part of ama-consortium (www.ama-consortium.de)
- Goals
  - Establish prevalence of pain in NH in Germany
  - Characterise use and appropriateness of interventions against pain (pharmacological / non-pharmacological)
  - Describe relationship between pain and autonomy
- Methods
  - Standardized assessment of n = 1000 NH residents
  - Analysis of health insurance data of NH residents
  - **→ Including persons with dementia**

Pain and Dementia

- Prevalence of dementia
  - 65+: between 6 % and 8,7 %
  - 65 – 69: 1,2 % (mean)
  - 90+: 34,6 % (mean)

(Bickel 2000)

- Prevalence in long term care dramatically higher
  - 64,3 % all dementias
  - 28,7 % severe dementia

(Jakob et al. 2002)

- self report of pain possible in mild to moderate dementia
- self report fails in severe dementia

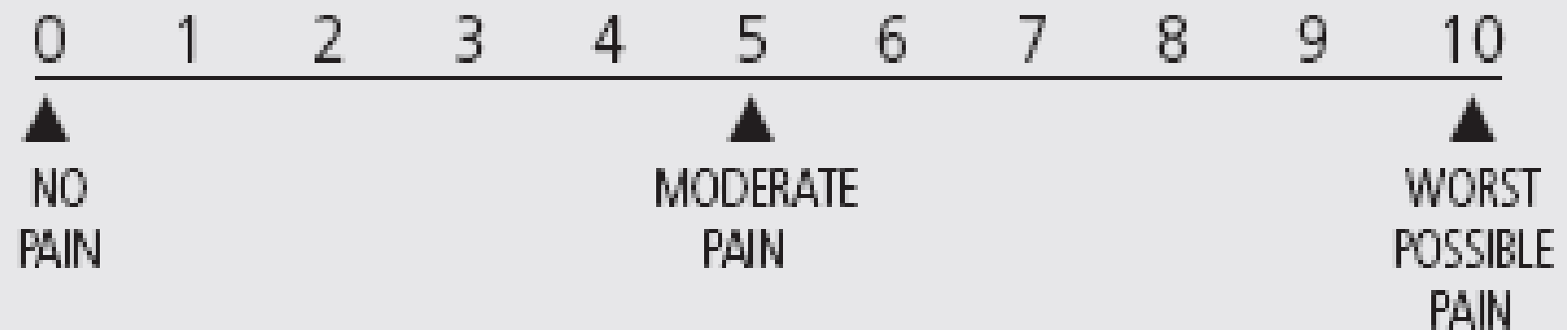## Pain Assessment in Persons with Mild to Moderate Dementia
(Hadjistavropoulos et al. 2007)

- Medical history, physical assessment, self-report usually possible (NRS, VDS, FPS [?])
- Standardized scales often understood
- Patience, continuity of care and adaptation to patients competences necessary
- Involvement of relatives etc.
  - How does the patient usually express pain?
  - What helps?
  - What does the paint not like?
- Comprehensive assessment (incl. psychological and cognitive aspects of pain) is impeded
- Things (pain!) in the past are often forgotten

Numeric Rating Scale (NRS)

APSOC 2005

Numeric Rating Scale (NRS)

Item 2: 10-point Numeric Rating Scale (NRS)

--------- | 0   ◄ NO PAIN   Displayed vertically
--------- | 1
--------- | 2
--------- | 3
--------- | 4
--------- | 5   ◄ MODERATE PAIN
--------- | 6
--------- | 7
--------- | 8
--------- | 9
--------- | 10 ◄ WORST POSSIBLE PAIN
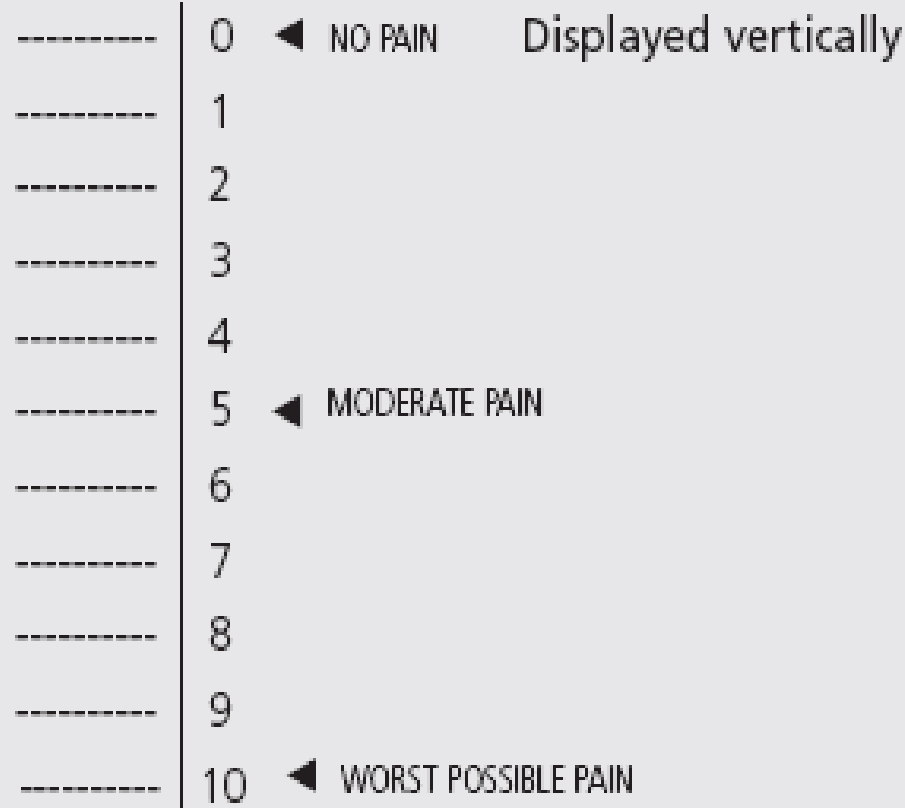
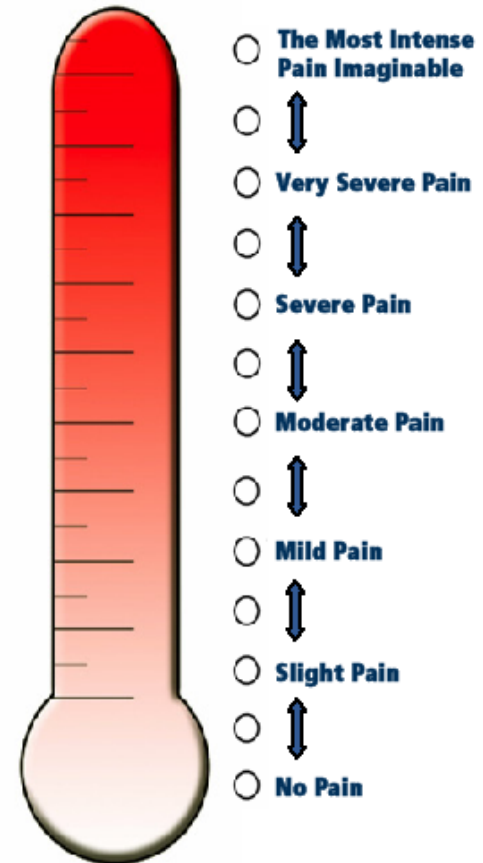APSOC 2005

Iowa Pain Thermometer Scale

Name _____ **Date** _____

Iowa Pain Thermometer Use

This tool is excellent for patients whose cognitive deficits are moderate to severe, or who have difficulty communicating verbally. Have the patient check the circle next to the thermometer to indicate the intensity of current pain.

Iowa Pain Thermometer Scoring

Document the words corresponding to the area of the thermometer the patient marks to identify the level of pain intensity. Evaluate the change in pain descriptors selected by the patient over time to determine the effectiveness of pain treatments. Alternately, the words can be scored from 0 to 12 for recording purposes.

- The Most Intense Pain Imaginable
- Very Severe Pain
- Severe Pain
- Moderate Pain
- Mild Pain
- Slight Pain
- No Pain

Used with permission of Keela Herr, PhD, RN, College of Nursing, University of Iowa.

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Verbal Descriptor Scale (VDS)

APSOC 2005

Pain Assessment in Persons with Severe Dementia
(vgl. Hadjistavropoulos et al. 2007)

- Medical history, physical assessment

- Self-Report mostly impossible

- Proxy rating of pain: pain behaviour?

- Assess pain during an activity that involves movement → same activity if measurement repeated

- Continuity of care

- Involve relatives

- Analgesic trial

- Comprehensive Assessment nearly impossible

Common Pain Behaviours

- Facial expressions
  - Slight frown; sad, frightened face
  - Grimacing, wrinkled forehead, closed or tightened eyes
  - Any distorted expression
  - Rapid blinking
- Verbalizations, vocalizations
- Body movements
- Changes in interpersonal interactions
- Changes in activity patterns or routines
- Mental status change

Need-Driven behaviour and pain

- Pain as cause or mediator for NDB (IPA 2002, Kong 2005, Barton et al. 2005, Halek & Bartholomeyczik 2006)

- Pain linked to verbally-aggressive behaviour (Cohen-Mansfield & Werner 1998, Cohen-Mansfield 2001) and physically aggressive behaviour (Manfredi et al. 2003)

- Pain linked to the number of "agitated" behaviours (Feldt, Warden, Ryden 1998, Geda & Rummans 1999, Cipher & Clifford 2004)

- Reduction NDB after analgesia (Douzjian 1998, Kovach et al. 1999, 2001, 2006, Manfredi et al. 2003)

- No studies on "negative" symptoms like apathy and pain

- "The behaviours that demented patients exhibited appear to be unique to each individual" (Buffum et al. 2001)

The Abbey Pain Scale

Table 9

THE ABBEY PAIN SCALE

For measurement of pain in people with dementia who cannot verbalise

How to use scale: While observing the resident, score questions 1 - 6.

Name of resident: _____

Name and designation of person completing the scale: _____

_____

Date: _____ / _____ / _____   Time: _____

Latest pain relief given was: _____ at: _____ hrs

1. Vocalisation eg whimpering, groaning, crying	Absent **0**	Mild **1**	Moderate **2**	Severe **3**	Q1 ☐
2. Facial expression eg looking tense, frightened, frowning, grimacing	Absent **0**	Mild **1**	Moderate **2**	Severe **3**	Q2 ☐
3. Change in body language eg fidgeting, rocking, guarding body part, withdrawn	Absent **0**	Mild **1**	Moderate **2**	Severe **3**	Q3 ☐
4. Behavioural change eg increased confusion, refusing to eat, alteration in usual patterns	Absent **0**	Mild **1**	Moderate **2**	Severe **3**	Q4 ☐
5. Physiological change eg temperature, pulse or blood pressure outside normal limits, perspiring, flushing or pallor	Absent **0**	Mild **1**	Moderate **2**	Severe **3**	Q5 ☐
6. Physical changes eg skin tears, pressure areas, arthritis, contractures, previous injuries	Absent **0**	Mild **1**	Moderate **2**	Severe **3**	Q6 ☐

Add scores for questions 1 - 6 and record here ▶   ***TOTAL PAIN SCORE*** ☐

Now tick the box that matches the Total Pain Score: **0 - 2** No Pain ☐   **3 - 7** Mild ☐   **8 - 13** Moderate ☐   **14 +** Severe ☐

Finally, tick the box which matches the resident's type of pain   Chronic ☐   Acute ☐   Acute on Chronic ☐

1. Assume that the person is in pain if there is a disease, injury or an intervention present that usually causes pain

2. a.) Establish patient's usual behavior
   b.) assess whether there is pain behaviour present, especially during movement

3. Pain behaviour is *NOT* always present. Pain may show in dementia specific challenging behaviours

4. Analgesic trial if pain is suspected
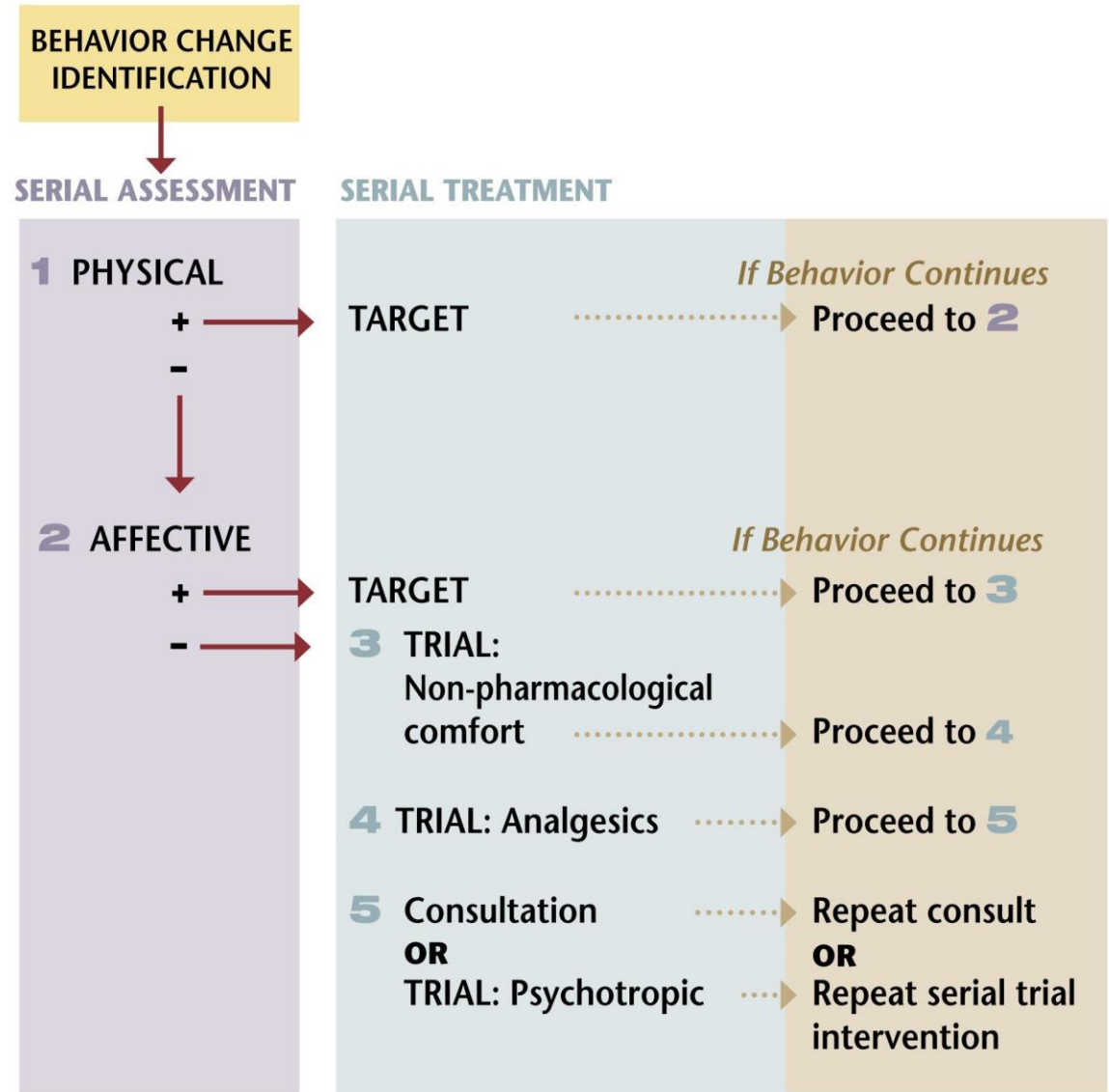
Kovach et al.

Research Question

- Does the application of STI-D in nursing homes reduce need-driven behaviours in residents with dementia to a larger extent than reinforced „usual care"?

- Does STI-D lead to better quality of life?

- Does STI-D lead to reduced rates of psychotropic prescription and increased analgesia prescriptions?

- Does STI-D lead to an increased number of assessments and interventions by nurses?

Design

- RCT
- 3 points of measurement (pre, 1 and 6 months after intervention)
- 19 nursing homes, matched and randomized to two groups
- Training for nurses in both groups (2,5 days)
- Facilitation visits (twice per NH)
- Sample: nursing home residents with diagnosed or probable dementia and MMSE < 24

Outcome Measures

- Primary Outcome: BPSD → NPI-NH
- Secondary Outcomes:
  - QoL: Qualidem
  - Pain: ECPA / BISAD
  - Number of Assessments and Interventions
  - Prescription of Analgesics and Psychotropics
  - Number of Hospital Admissions
- Additional: Management Perspective (Frankfurt School of Finance and Management)
  - Process Analysis of Implementation

Clinical Practice

- Patients should not endure pain of more than 3 on a NRS at any time

- Pain medication to given by the hour, preferably oral route

- Be aware of side-effects – but don't be afraid

- Always offer non-pharmacological treatments *in addition*

- Check out "*Pain in Residential Aged Care Facilities – Management Strategies*" by the Australian Pain Society (www.apsoc.org.au)

Facial Expression and Pain in Dementia

- Facial expression should be included in observational assessment (British Pain Society & British Geriatrics Society 2007)

- „Facial grimacing or wincing" as indicator for inadequately treated pain (McLennon 2007, J Gerontol Nurs 33(7): 5 – 14)

- Facial expression not mentioned specifically, but reference to observational scales and / or AGS Guidelines

  – Australian Pain Society 2005
  – Hadjistavropoulos et al. 2007 (Clin J Pain 23 (1 Suppl): S1 –S43)
  – Herr et al. 2006 (Pain Manag Nurs 7 (2): 44 – 52)
  – Snow & Shuster 2006 (J Clin Psychol 62 (11): 1379 – 1387)

No further differentiation for dementia stage

Pain expression

Ekman 1991

Facial Action Coding System FACS (Ekman & Friesen 1978)

- Assumption: Pain is expressed with the same facial expressions by all humans

- These expressions can be divided into distinct ‚action units' or AU

- Anatomically based, AU can objectively be recorded using FACS

- Based on video recordings

- Interpretation is separated from recording

- FACS can give „objective" information on pain (Prkachin 1997)

- Recommended for use in older persons and those with dementia (Hadjistavropoulos et al. 2002, Hadjistavropoulos 2005, Stolee et al. 2005, Lints-Martindale et al. 2007)

FACS Action Units indicative of pain

- AU 6 Cheek raise
- AU 7 Lid tighten
- Levator Contraction, consisting of
  - AU 9 Nose wrinkle
  - AU 10 Upper lip raise
- AU 20 Lip stretch
- AU 43 Eyes close

"A relatively small subset of actions convey the bulk of information about pain that is available in facial expression. Second, the occurrence of those actions is fairly consistent across different types of pain." (Prkachin 1997:195f)

Pain Expression (FACS) and Dementia

- Experimental: More frequent and intense pain related AU when pain induced in persons with dementia (Hadjistavropoulos et al. 1998, Hadjistavropoulos 2002, LaChapelle 1999)

- Experimental: More and specific facial pain expressions in more severely demented persons (Hadjistavropoulos et al. 2000, Lautenbacher et al., 2007, Porter et al. 1996)

- … which does not necessarily indicate more pain (Lautenbacher et al. 2007)

- No significant correlation between pain self-report and FACS pain ratings (Defrin et al. 2006, Hadjistavropoulos et al. 1998, Hadjistavropoulos 2002, Kunz & Lautenbacher 2004, Labus et al. 2003)

- In contrast: No complex facial expressions in severe dementia (Asplund et al. 1991, Asplund et al. 1995)

ECPA / BISAD

- 8 items

- 4 items to be assessed at rest (facial expression, posture, changes to mobilty and usual behaviour)

- 4 items to be assessed during movement (fear, reactions to movement and touch, verbalisations / vocalisations)

- Scores between 0 and 4 on each item

BISAD Study: Sample

- Convenience sample
- Nursing Homes from Berlin (17), Brandenburg (2) and Hesse (8 NH)
- n = 149 (25 male)
- Mean age: 83.9 years (min 52, max 103)
- Dementia stages (FAST)
  - FAST / GDS 5: n = 1 (0.7%)
  - FAST / GDS 6: n = 80 (53.7 %)
  - FAST / GDS 7: n = 68 (45.6 %)

BISAD results

	BISAD rest	BISAD movement	(log 10) BISAD rest	BISAD movement
N	143	147	143	147
Mean	3,08	5,51	0,46	0,69
95 % CI	2,52 – 3,64	4,78 – 6,24	0,40 – 0,52	0,63 – 0,75
Median	2	5	0,48	0,78
Sd	3,38	4,48	0,37	0,36
Min	0	0		
Max	16	20		

BISAD Scores (log) differ at rest and in a movement situation (T = -8,121, p = 0,000)

BISAD Score / pain causing disease

|	Pain-causing disease	No pain-causing disease	Mann – Whitney – U - Test
BISAD rest (n = 143)	**3,64** (sd = 3,615, KI 2,80 – 4,49)	**2,49** (sd = 3,035, KI 1,76 – 3,21)	Z = -2,032; p = 0,042
BISAD movement (n = 147)	**6,47** (sd = 4,664, KI 5,38 – 7,55)	**4,57** (sd = 4,098, KI 3,62 – 5,52)	Z = -2,779, p = 0,005

BISAD scores differ significantly between residents with and without a pain-causing disease

BISAD / Self-Report

	Pain (according to sel-report)	No pain (according to self-report)	Mann – Whitney – U - Test
BISAD rest (n = 23)	**6,75** (sd = 3,594, KI 1,03 – 12,47)	**2,11** (sd = 2,105, KI 1,09 – 3,12)	Z = -2,520; p = 0,012
BISAD movement (n = 24)	**7,60** (sd = 4,669, KI 1,80 – 13,40)	**3,47** (sd = 3,323, KI 1,87 – 5,08)	Z = -2,015, p = 0,044

BISAD scores differ significantly between those residents who do and those who don't report pain

BISAD Score / verbally agressive behaviour
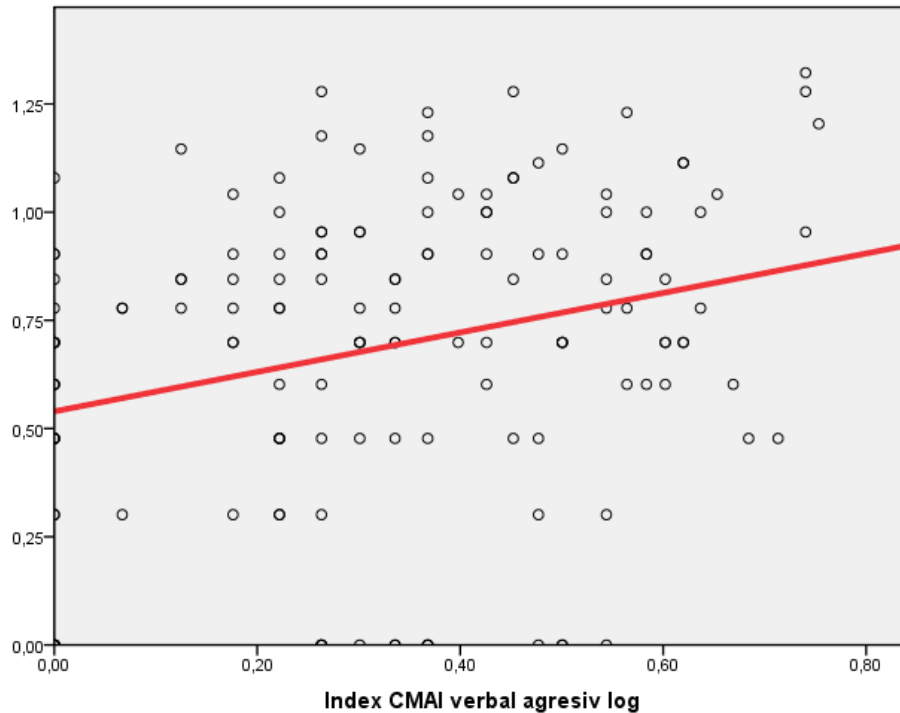
CMAI Behaviours
- Screaming
- Strange noises
- Cursing, verbal aggression
- Complaining
- Negativism
- Constant unwarranted requests

Mean   = 2.367
Median = 2.083
Min   = 1
Max   = 5.67

CMAI – D index score for verbally agressive behaviour ist correlated to the BISAD score at movement (r = 0,271, p = 0,001)

BISAD Study: FACS Results I

No significant association / correlation between FACS scores and

- type of dementia (if available)
- age.

BISAD Study: FACS Results II

Number of different pain related action units per patient (max. 6 possible)

	Rest n = 140	**Movement** n = 135
Mean (SD)	1.0222 (1.23667)	0.8643 (1.21271)
Median	1	0
Min / Max	0 / 6	0 / 5

No significant difference (Z = -0.995, p = 0.32)

BISAD Study: FACS Results III

Maximum intensity of pain related action units per patient (possible range 1 - 5)

	Rest n = 75	**Movement** n = 65
Mean (SD)	2.9369 (1.05733)	2.6969 (0.81379)
Median	3	2.5833
Min / Max	1 / 5	1 / 5

No significant difference (Z = -0.195, p = 0.845)

BISAD Study: FACS Results IV

- Significant association between the number of Action Units at movement and prevalence of a painful diesease (Z = -2.329, p = 0,020)

- Significant correlation between BISAD score (log) at movement and
  - Number of Action Units (r = 0.152, p = 0.024)
  - Intensity of Action Units (r = 0.227, p = 0.016)

- Significant association between the number of Action Units at movement and dementia stage (H = 7.685, df = 2, p = 0.021) (Confounding?)

Reports of diminished facial activity

- *„The results of this study indicate that the clarity and amount of facial cues are reduced in severely demented patients"* (Asplund et al 1995: 532)

- Several studies stopped, that attempted to analyse facial expressions of patients with severe dementia

- Less facial expression in persons with severe cognitive disabilities (Defrin et al. 2006)

- „Freezing" as a reaction to painful stimuli (Defrin et al. 2006)

Possible reasons for diminished facial expression

- No painful stimuli
- No facial expression despite pain (Pasero & McCaffery 2005, Herr et al. 2006, Kunz et al. 2004)
- Facial expression as a "late signalling system" (Prkachin & Craig 1995)
- Differences in individual threshold for pain expression; lack of correlation with self-report (Kunz & Lautenbacher 2004)
- Facial expression linked to affective pain component
- Changes in pain perception (Scherder et al. 2003, 2005, Pautex et al. 2007)
- Neurological damages (e.g. Anterior Cingulate Cortex)
- Apathy (Seidl et al. 2007)
- Hospitalism

Further Investigation

- Develop research designs that include persons in very advanced stages of dementia

- Explore further the neurological basis to understand the association between dementia related changes, pain perception and pain communication

- Link neuroscience, behaviour based studies and clinical knowledge

- Investigate the role of place of residence, dementia related interventions and concepts of care.

- Clarify what kind of facial expression we should really look for to detect pain.

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Factor structure and internal consistency BISAD

	Rest				Movement		
	1	2	3		1	2	3
Item 1	,396	,220	,328		,274	,190	,341
Item 2	,075	,833	-,144		,103	,861	,077
Item 3	-,025	,777	,260		,088	,832	,086
Item 4	,005	,033	,886		-,073	,042	,902
Item 5	,763	,014	,404		,726	,154	,162
Item 6	,823	,058	,192		,738	,069	,285
Item 7	,766	-,087	-,075		,698	,262	-,229
Item 8	,657	,098	-,275		,729	-,061	-,077

Variance explained: 63,4 %
α total: 0,647
α factor 1:   0,748

Variance explained: 60,1 %
α total: 0,658
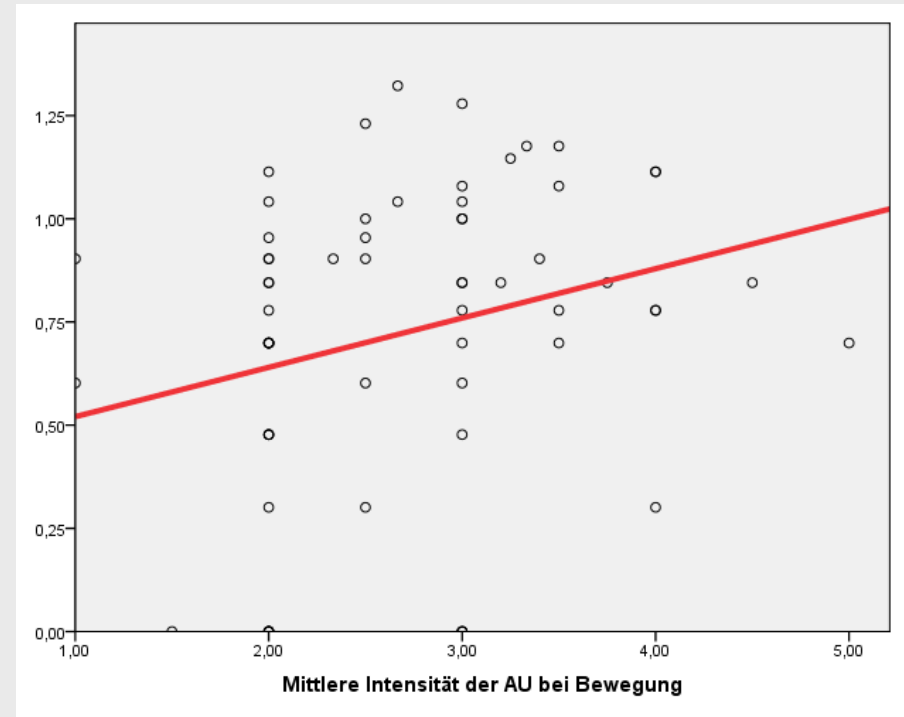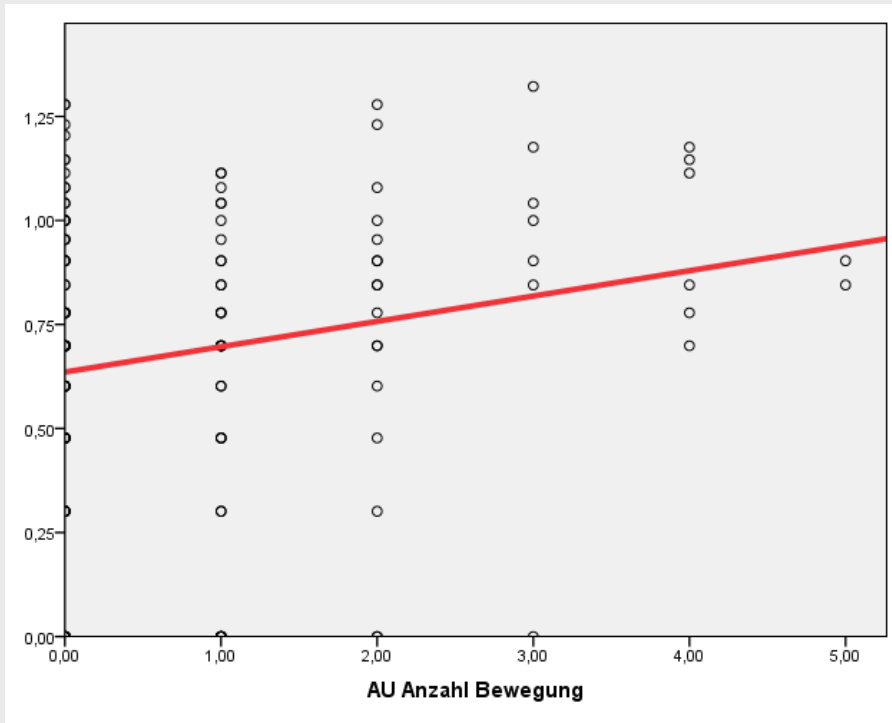α factor 1:   0,766

PAINAD – G (Schuler et al., JAMDA 8: 388-395)

	r_{it}	α	β
Breathing	0.57	0.84	0.71
Vocalization	0.79	0.78	0.89
Facial Expression	0.73	0.80	0.85
Body Language	0.80	0.77	0.89
Consolabilty	0.41	0.87	0.55
Total		0.85	

n = 80

One factor model
Variance explained: 62.36 %

BISAD / Facial Expression

BISAD scores (log) at movement are correlated to the number and intensity of pain specific facial action units
- Number of pain specific facial action unist (r = 0.152, p = 0.024)
- Mean intentsity of pain specific action units (r = 0.227, p = 0.016)

Dicussion

- Indication for construct validity
- Properties comparable to those of other scales
- Further investigation and refinment – concentrate of second part?
- Difficult study setting in Nursing Homes
- First time very severely affected persons have been included in a study like this
- BISAD can help with the assessment of pain in persons with severe dementia