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The Rotterdam Elderly Pain Observation Scale (REPOS): A New Behavioral Pain Scale for Non-Communicative Adults and Cognitively Impaired Elderly Persons

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Abstract

Several observation scales have been developed to measure pain in elderly persons with cognitive impairments. Most scales, however, do not provide cut-off scores for pain, and previous studies do not include data on non-verbal patients with diagnoses other than dementia. Objective: The development of an easy-to-use, reliable and valid pain observation scale, the Rotterdam Elderly Pain Observation Scale (REPOS), for use in nursing home residents incapable of reporting pain themselves. Methods: In this multicenter case-control study 174 residents of various cognitive levels were videotaped at rest and during a potentially painful activity. Prevalences and co- occurrences of behaviors were examined, and interrelationships were identified. To reduce number of items, multiple linear regression analysis was used. Interrater-, and intrarater agreements and internal consistency were investigated. To estimate validity, REPOS was related to Numeric Rating Scale (NRS) and Pain Assessment in Advanced Dementia-Scale (PAINAD), and activity and rest situations were compared. Results: A one-dimensional model with a good fit was found. After redundancy analysis, ten items remained. Interrater- and intrarater agreements of two observers were good. Internal consistency was moderate. Correlations between REPOS and NRS were small to medium, and between REPOS and PAINAD large. REPOS-scores for the two situations differed significantly. A total score of 3 and higher indicates pain. Conclusions: REPOS appears to be promising for identifying pain in residents of various cognitive levels. To improve pain management, a cut-off score for pain was determined, together with a treatment protocol. Its conciseness suggests good usefulness in daily practice.

Keywords: pain assessment, observation, older adults, cognitive impairment.

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Introduction

Pain assessment and management in older adults is challenged by misconceptions, communication problems, difficulty of chronic pain treatment, polypharmacy and comorbidities (1,2). Especially, cognitively impaired and non-verbal older adults are at high risk for undertreatment of pain (3,4). When self-report is impossible, behavioral assessment is advocated. Up to a dozen behavioral observation instruments have been published by now. Recent reviews, however, point out that most of these instruments show moderate psychometric qualities for older adults and need further psychometric testing (5,6). Therefore, none of them as yet qualifies for broad adoption in daily clinical practice. Some instruments revealed differences in pain behavior between patients with and without cognitive impairments (7,8). In addition, while pain experiences seem to differ for various types of dementia, the instruments mostly focus on dementia in general, or on a specific type of dementia (9). Furthermore, most of these instruments have been tested in mildly cognitively impaired patients only. Previous studies generally lack data on chronic pain behavior in non-verbal patients with diagnoses other than dementia, such as stroke and traumatic brain injury. We felt, therefore, a need for a pain observation instrument for various non-verbal populations other than only patients with dementia. In an earlier, explorative study we constructed a set of fourteen pain behaviors typically seen in nursing home residents. The objective of the present study was to develop an easy-to-use, reliable and valid observation instrument to measure pain in nursing home residents for whom self-report is impossible.

Methods

Design

This is a multicenter case-control study. The Erasmus MC Medical Ethical Review Board approved the study, and so did directors and client boards of the nursing homes involved.

Participants

Residents from somatic, rehabilitation and psychogeriatric wards of six nursing homes in the Netherlands were screened for eligiblity. The inclusion criterion was a nurse's rating of 4 and higher on a numerical rating scale (NRS) from 0 to 10 – indicating moderate to severe pain – of the resident's pain in the preceding weeks (10). Either residents themselves or legal representatives signed written informed consent.

Participants were post-stratified into a case group or a control group on the basis of cognitive status as assessed by the MMSE. The case group comprised moderately to severely cognitively impaired residents (MMSE<18) as well as residents who were verbally unable to communicate at all (impossible to administer MMSE). The control group included cognitively intact to mildly impaired residents (MMSE≥18), who could report their pain themselves.

Measures

Demographics

Demographic and medical data were extracted from medical charts. Classification of most painful diagnoses was in conformity with the WHO International Classification of Diseases (ICD-10, 1994). Cognitive status was assessed by Mini Mental State Examination (MMSE), a valid instrument for older adults. The 11 MMSE-items yield a total score ranging between 0 and 30. Scores 0 to 9 indicate severe cognitive impairment, 10 to 17 moderate cognitive impairment, 18 to 23 mild cognitive impairment, and 24 to 30 no cognitive impairment (11).

Performance status was assessed by the Karnofsky index. Scores range from 0, representing deceased, to 100, representing normal situation without complaints (12).

Pain measures

In a previous explorative study a panel of experts identified fourteen behaviors out of a pool of 138. This was the result of a stepwise item reduction procedure based on videotaped observation of residents in rest and in a potentially painful situation.

Scores on these fourteen behaviors were found to be significantly higher in the potentially painful situation. The preliminary Rotterdam Elderly Pain Observation Scale (REPOS) included 1) tense face; 2) grimace; 3) eyes (almost) squeezed; 4) raising upper lip; 5) frightened/fearful look; 6) aggression/anger; 7) panicky, panics attack; 8) not cooperating; 9) seeking comfort; 10) moving body part; 11) crying softly; 12) moaning/groaning; 13) sounds of restlessness/verbal expressions; and 14) holding breath/faltering respiration. Scoring was on a four-point scale: 0='not present', 1='sometimes present', 2='often present', to 3='always present'; theoretically, the total score ranges from 0 to 42.

The Numeric Rating Scale (NRS) rates pain intensity from 0 ('no pain') to 10 ('worst possible pain'), and was found a reliable and valid pain assessment in older adults with varying cognitive levels (13). In the current study, the ratings of the nurses (NRS-nurse) and those of the residents themselves if feasible (NRS-resident) served to establish convergent validity.

PAINAD was used to establish congruent validity. This five-item observation instrument was developed to measure pain in patients with (severe) dementia (14). Items are scored 0, 1 or 2, resulting in a total score from 0 ('no pain') to 10 ('maximal pain'). For our research purposes PAINAD was translated into Dutch, according to the backward-forward principle. Both versions proved reliable and valid (15).

Procedure

The first researcher (RvH) learned to observe pain behavior and interrater agreement between her and a trained pain specialist was 0.84. A research-assistant learned to observe pain behavior on the guidance of the definitions of the REPOS items and made ten observations in older adults to establish good agreement with the first researcher.

The caregiving nurses identified those residents who had experienced moderate to severe pain in the preceding weeks (NRS≥4). Either the researcher or research-assistant made video recordings of a potentially painful activity such as being washed or dressed, and a rest situation. Directly after a recording both the resident's nurse and the resident, if possible, rated the experienced pain intensity. Within a month, a two-minutes episode of each recording was observed and scored with the 14 item-REPOS and PAINAD. To estimate the interrater agreement, both researchers independently scored the behavior of 31 randomly selected residents. The remaining residents were scored by one of the researchers.

Intrarater agreements of both researchers were estimated over fourteen randomly selected recordings, at a month's interval between the two scoring moments. During scoring of the videotapes researchers were naïve for resident's medical condition and analgesics use. On the day of recording, the resident's cognitive status was assessed by MMSE. Details of resident's medical condition and analgesics use were later extracted from the medical and nursing records.

Statistical Analyses

The categorical data are expressed as percentage, as a measure of central tendency. For the continuous data, either mean and standard deviations (sd) are presented for normally distributed variables, or median and inter quartile ranges (IQR) for not normally distributed variables. Chi-square test and Fisher's Exact test were applied for categorical data, and Mann-Whitney U test and Independent Samples T-Test for continuous data to estimate associations between case and control groups. The level of significance was set at 0.05 (two-tailed). Data were analyzed with SPSS 14.0.

Behaviors

First, co-occurrences and prevalences of the 14 behaviors were calculated in percentages. Behaviors with a prevalence not exceeding 5% during an activity were eliminated.

Activity scores were analyzed by multiple logistic regression analysis, adjusted for gender and age, to identify differences on individual items with case and control group as criterion variable. The odds-ratio (OR) and 95% confidence intervals (CI's) served as measure of individual performance.

The interrelationships of the REPOS items in terms of a clinical-empirical structure were identified with the computer algorithm PROXSCAL (short for Proximity Scaling). To determine the best-fitted model without substantial loss of information, both a one- and two-dimensional solution were carried out. The quantifications (in terms of z-score) of the individual variables indicate the degree of individual performance. As a measure of model performance the Normalized Raw Stress was chosen. Ideally, this coefficient should be <0.05. Additionally, the Tucker's f coefficient of congruence was the measure of correspondence between the Euclidean distances of the data and the distances derived from the model identified. This coefficient should be >0.95.

Redundancy

In view of possible item reduction, we explored qualities in predicting the total score by means of multiple linear regression analysis with total score as outcome variable and individual items as predictor variables. This strategy aims to establish the minimum number of items required to predict the outcome, without substantial loss of information. The explained variance needed to be 90%; redundant items were eliminated. The findings from these analyses will result in the final REPOS scale.

Reliability and Validity Estimates

We determined reliability and validity estimates of the remaining items.

Interrater- and intrarater agreements were measured by means of intra-class correlation (ICC) using the two-way mixed model (16).

Scale reliability was estimated using the Kuder Richardson coefficient (KR20), as the scored items were recoded from four to two response categories (17).

Convergent validity was estimated by correlating REPOS with NRS-resident and NRS-nurse using the Spearman Rank correlation coefficient with 95% CI. Congruent validity was estimated by correlating REPOS with PAINAD using Spearman Rank correlation test (rs) with 95% CI, for case and control group separately as well as for activity and rest situation separately. Cohen's criterion to judge the value of correlation coefficients is: 0.10 to 0.29 (small r); 0.30 to 0.49 (medium r); and ≥ 0.50 (large r) (18). A two-way ANOVA with repeated measurements on the total REPOS score was performed to test any differences between case and control group (differential validity) and activity or rest (sensitivity to change). For significance testing the F-statistic was used.

Any differences in activity scores between two subtypes of dementia, namely Alzheimer and vascular dementia, were investigated with the Chi-square test on item level (differential validity).

To optimally differentiate between activity and rest, the cut-off score at which the combination of sensitivity and specificity was highest for both case and control group was calculated (19).

Results

Residents

In total, 223 residents or their legal representatives were invited to participate. Participation was refused in 29 cases and eight residents died before start of the study. For 12 of the remaining 186 residents, NRS-nurse was < 4.0 and they were, consequently, excluded. The final sample of 174 participants (110 female/64 male) had median age of 82 years (IQR 73 to 87), and median nursing home stay of 16.5 months (IQR 5 to 38).

The case group included 124 residents, for 69 of whom MMSE was not completed (56%): sixty-seven were unable to verbally communicate at all, and two scores of residents were missing. Self-report was not possible or not reliable for these 122 residents due to severe dementia (n=73), cognitive limitations (n=10), severe aphasia (n=26), sedation (n=5), sub-comatose condition (n=4). The control group included 50 residents (see figure 1). In both groups, musculoskeletal and circulatory symptoms most frequently induced painful conditions. Demographics, most painful diagnoses and prescribed analgesics are presented in Table 1.

Table 1. Demographic and medical variables

	Case group n = 124	Control group n = 50	*P* [a]
Gender n females (%)	84 (68)	26 (52)	0.08
Median age (IQR)	83 (74 to 89)	78 (70 to 84)	0.02
Mean MMSE (sd)	9.6 (5.1)	23.7 (4.0)	0.00
n (%)	55 (44)	50 (100)	
Median Karnofsky (IQR)	50 (40 to 50)	60 (50 to 60)	0.00
Median length of stay in months (IQR)	24 (6 to 45)	9 (2 to 18)	0.00
Pain diagnoses n (%)			
musculoskeletal system	52 (42)	23 (46)	0.53
circulatory system	30 (24)	15 (30)	
skin and subcutaneous tissue	19 (15)	3 (6)	
nervous system	6 (5)	5 (10)	
injury, poisoning etc	7 (6)	2 (4)	
neoplasms	3 (2)	-	
digestive system	1 (1)	1 (2)	
genitals	2 (2)	-	
external causes	3 (2)	1 (2)	
Unknown	1 (1)	-	
Highest prescribed analgesics n (%)			
None	30 (24)	5 (10)	0.32
Step 1 routine	54 (44)	24 (48)	
Step 2 routine	11 (9)	6 (12)	
Step 3 routine	11 (9)	6 (12)	
As needed [b]	18 (14)	9 (18)	

[a] two-tailed; [b] residents receiving only as needed pain medication in one of the WHO steps.
Abbreviations: IQR = Inter Quartile Range; MMSE = Mini Mental State Examination; sd = standard deviation.

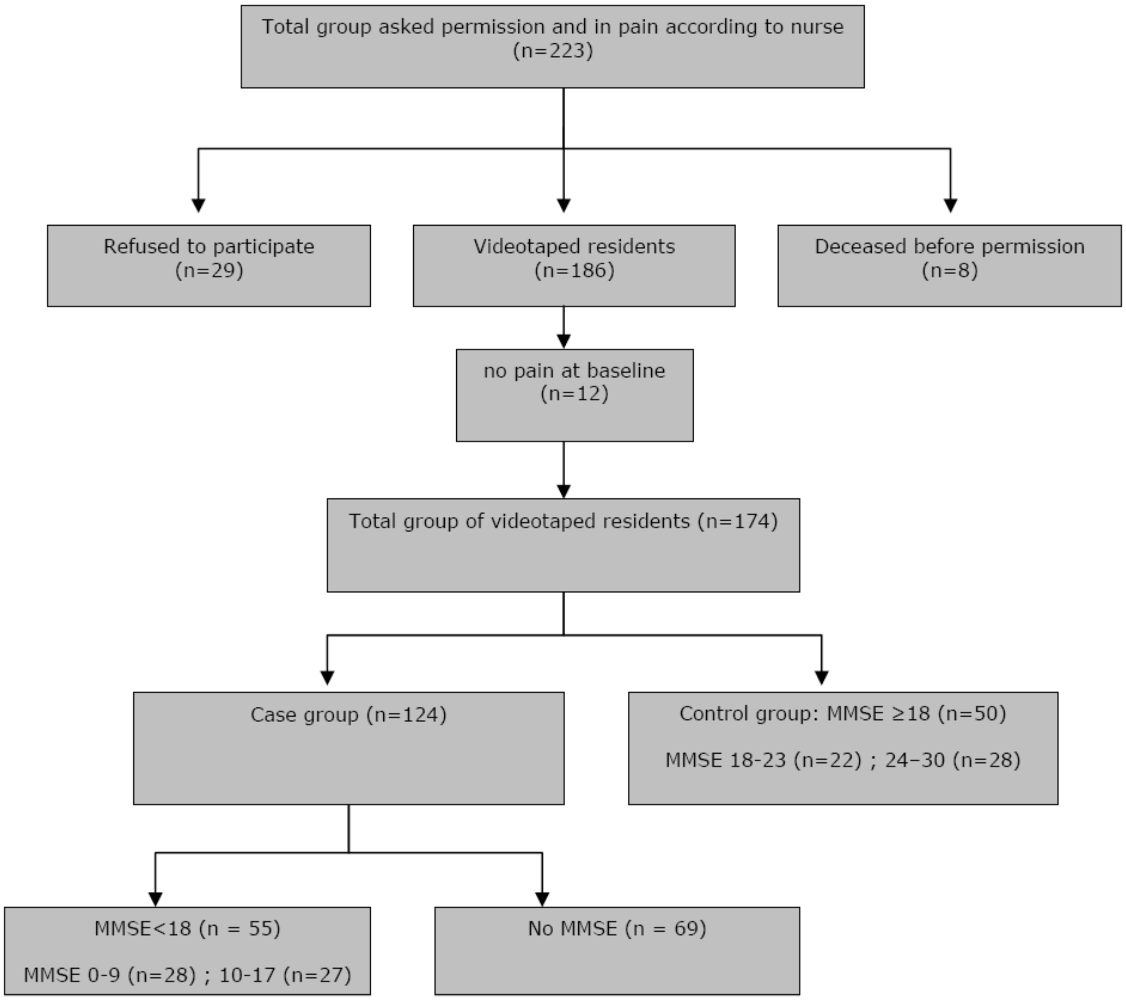
Behaviors

All 174 residents were observed during an activity, and 172 at rest. Prevalences of almost all behaviors were either 0 (never present) or 1 (sometimes present). For all other items, except tense face, the answer category ‘sometimes’ was much more frequent than ‘often’ and ‘always’ together. For this reason, the 0 to 3 range was dichotomized by recoding ‘never present’ into 0 and other categories into 1. The correlation between the total scores of the 0 to 3 scale and the total scores of the dichotomized version was large (r_s=0.88).

The matrices of prevalences and co-occurrences (see table 2) demonstrate that tense face was always present. The prevalence of crying was less than 5%, and this behavior, consequently, was eliminated. Ninety-four percent of the residents showed at least two pain behaviors, and 88% at least three.

Multiple logistic regression analysis on the activity scores revealed significant higher scores for the case group on three items: panicky, panics attack (OR=3.67, p=0.01), aggression/anger (OR=11.73, p=0.02), and moaning/groaning (OR=3.13, p=0.01) (see table 3).

PROXSCAL multidimensional scaling revealed no substantial differences in the empirical structure and the model fit between case and control group.



MMSE = Mini Mental State Examination

Figure 1. Flow chart of participants.

Table 2. Prevalences and co-occurrences of 14 pain behaviors in all patients and according to case and control group

	TF	G	FL	CE	RL	MB	P	NC	SC	A	C	M	S	HB
Matrix of co-occurrences of pain behaviors in all residents (n=174), %														
Tense face (TF)	**100**													
Grimace (G)	**40**	**40**												
Fearful look (FL)	**30**	**11**	**30**											
Closing eyes (CE)	**79**	**40**	**20**	**79**										
Raising upper lip (RL)	**58**	**33**	**15**	**53**	**58**									
Moving body part (MB)	**28**	**14**	**8**	**25**	**16**	**28**								
Panicky (P)	**24**	**9**	**10**	**19**	**12**	**13**	**24**							
Not cooperating (NC)	**11**	**8**	**5**	**9**	**8**	**5**	**5**	**11**						
Seeking comfort (SC)	**19**	**6**	**9**	**16**	**9**	**7**	**6**	**2**	**19**					
Aggression (A)	**13**	**8**	**5**	**11**	**7**	**10**	**8**	**5**	**2**	**13**				
Crying (C)	**1**	**1**	**0**	**1**	**1**	**0**	**0**	**0**	**0**	**0**	**1**			
Moaning/groaning (M)	**37**	**15**	**12**	**32**	**22**	**13**	**14**	**6**	**7**	**6**	**1**	**37**		
Sounds/verbal (S)	**20**	**8**	**5**	**17**	**13**	**9**	**10**	**3**	**5**	**6**	**1**	**8**	**20**	
Holding breath (HB)	**31**	**16**	**9**	**28**	**18**	**10**	**10**	**5**	**6**	**5**	**1**	**16**	**8**	**31**

	TF	G	FL	CE	RL	MB	P	NC	SC	A	C	M	S	HB
Matrix of co-occurrences of pain behaviors in case group (n=124), %														
Tense face (TF)	**100**													
Grimace (G)	40	**40**												
Fearful look (FL)	33	12	**33**											
Closing eyes (CE)	80	40	23	**80**										
Raising upper lip (RL)	57	31	16	52	**57**									
Moving body part (MB)	30	16	10	27	18	**30**								
Panicky (P)	29	12	12	23	15	16	**29**							
Not cooperating (NC)	14	9	7	11	9	7	7	**14**						
Seeking comfort (SC)	20	6	11	16	9	7	8	3	**20**					
Aggression (A)	17	11	7	15	10	13	11	7	2	**17**				
Crying (C)	2	1	0	2	2	0	0	0	0	0	**2**			
Moaning/groaning (M)	44	17	16	36	26	15	19	8	8	9	2	**44**		
Sounds/verbal (S)	23	10	6	21	15	11	12	4	7	8	1	11	**23**	
Holding breath (HB)	32	18	11	27	20	11	12	7	7	7	1	19	8	**32**
Matrix of co-occurrences of pain behaviors in control group (n=50), %														
Tense face (TF)	**100**													
Grimace (G)	40	**40**												
Fearful look (FL)	22	8	**22**											
Closing eyes (CE)	78	40	14	**78**										
Raising upper lip (RL)	60	38	12	56	**60**									
Moving body part (MB)	22	10	4	20	12	**22**								
Panicky (P)	10	2	4	8	4	6	**10**							
Not cooperating (NC)	4	4	0	4	4	0	2	**4**						
Seeking comfort (SC)	16	6	6	14	8	6	2	0	**16**					
Aggression (A)	2	0	0	2	0	2	0	0	2	**2**				
Crying (C)	0	0	0	0	0	0	0	0	0	0	**0**			
Moaning/groaning (M)	20	10	2	20	12	8	2	2	4	0	0	**20**		
Sounds/verbal (S)	10	2	4	8	8	4	4	0	0	0	0	0	**10**	
Holding breath (HB)	30	12	4	28	14	10	4	0	4	0	0	8	6	**30**

The main diagonals with the bold figures present the prevalence of the pertinent items.

Table 3. Logistic regression analysis on scores of painful activities with case/control group as criterion variable and pain behaviors as independent variables

	OR[a]	*P*	95% CI
			low - up
Tense face[b]	-	-	-
Grimace	1.05	0.88	0.53 to 2.08
Frightened/fearful look	1.71	0.17	0.79 to 3.72
Eyes (almost) squeezed	1.21	0.65	0.53 to 2.73
Raising upper lip	0.94	0.87	0.48 to .186
Moving body part	1.56	0.27	0.71 to 3.41
Panicky, panics attack	3.67	0.01	1.34 to 10.08
Not cooperating	3.76	0.09	0.83 to 17.05
Seeking comfort	1.25	0.63	0.51 to 3.04
Aggression/anger	11.73	0.02	1.51 to 91.06
Moaning/groaning	3.13	0.01	1.42 to 6.87
Sounds of restlessness/verbal expressions	2.53	0.08	0.91 to 7.07
Holding breath/faltering respiration	1.11	0.77	0.54 to 2.31

[a] Figures in bold signify significant odds ratios (0.05; two-tailed); [b] item is continuously present, and could therefore not be executed in this analysis. Abbreviations: OR=odds ratios; CI = Confidence Interval.

Normalized Raw Stress values were 0.03 and 0.01, respectively for case and control group, and the Tucker's coefficient was 0.99 for both groups. This justified combining these groups in the next analyses. Furthermore, both the one- and two-dimensional solution showed a good fit, with a Normalized Raw Stress value of 0.02 and 0.01, respectively, and a Tucker's coefficient of 0.99. Because of the principle of parsimonious modeling, the one-dimensional solution was the preferred choice (see table 4).

Table 4. Dimensional loadings of the REPOS items

	Quantification (z-score)
Tense face	**1.44**
Eyes (almost) squeezed	**1.14**
Raising upper lip	**0.84**
Grimace	**0.23**
Moaning/groaning	**-0.08**
Holding breath/faltering respiration	**-0.18**
Moving body part	**-0.35**
Sounds of restlessness/verbal expressions	**-0.39**
Not cooperating	**-0.45**
Panicky, panics attack	**-0.46**
Aggression/anger	**-0.46**
Seeking comfort	**-0.59**
Frightened/fearful look	**-0.69**

Redundancy

Multiple regression analysis with the 13 items sum score as outcome revealed that ten of the thirteen items jointly explained 92% of the variance. Consequently, the other three items i.e. not cooperating, aggression, and seeking comfort, were eliminated. The final scale thus comprises 10 items and is further referred to as the Rotterdam Elderly Pain Observation Scale (REPOS) (see appendix 1-3).

Reliability and Validity Estimates

All reliability and validity outcomes are estimated for the dichotomized final 10-item version.

Both interrater agreement (ICC=0.92) and intrarater agreements of the two researchers (ICC=0.96 and 0.90) were good. The Kuder Richardson coefficient was 0.49, which indicates moderate internal consistency.

For 159 residents (91%) nurses' pain ratings were available, for both an activity and a rest situation. In the control group (n=50), pain self-report was available for 49 residents (98%) during painful activity and for 48 residents (96%) at rest. REPOS and NRS-resident had a correlation of r_s=0.01; (95% CI:-0.27 to 0.29) for the activities and a correlation of 0.40 (95% CI:0.13 to 0.61) for the rest situations. Correlations between REPOS and NRS-nurse were small to medium (r_s = -0.12 to 0.36); correlations between REPOS and PAINAD were large (r_s =0.61 to 0.75) (Table 5).

Median REPOS activity score was 5 (IQR 3 to 6) and 4 (IQR 3 to 5) for respectively case group and control group. Median REPOS rest score was 1 for both groups. The two-way ANOVA showed that REPOS score for the case group was significantly higher than for the control group (F=10.1; df 1,169; p=0.002). In terms of sensitivity to change, significant differences were found between activity scores and rest scores (F=280.1; df 1,170; p=0.00). No interaction effect between groups (case and control) and condition (activity and rest) (F=0.01; df 1,170; p=0.95) was found. Overall, scores for residents with vascular dementia were higher than those for residents with Alzheimer, but did not differ significantly. Only for one item, eyes (almost) squeezed, a trend in terms of a difference was found (p=0.10). This behavior was seen in all but one of the 23 residents with vascular dementia (96%) during an activity. It was seen in 18 of the 24 residents with Alzheimer's disease (75%).

Cut-Off Scores

For the whole sample REPOS score 3 had the highest differential qualities with a good sensitivity (0.85) and specificity (0.83). Sensitivity was 0.86 and 0.82, and specificity 0.78 and 0.96 for case and control group, respectively. This would seem to indicate that the same cut-off score is applicable for each group.

Table 5. Spearman Rank correlations between REPOS and other pain scales

	Case group r_s (95% CI)	Control group r_s (95% CI)
REPOS ***during painful activity***		
NRS-resident	-	0.01 (-0.27 to 0.29)
NRS-nurse	0.19 (0.01 to 0.35)	0.36 (0.09 to 0.58)
PAINAD	0.75 (0.66 to 0.82)	0.61 (0.40 to 0.76)
REPOS ***at rest***		
NRS-resident rest	-	0.40 (0.14 to 0.61)
NRS-nurse	-0.12 (-0.29 to 0.06)	0.20 (-0.08 to 0.45)
PAINAD	0.64 (0.52 to 0.73)	0.66 (0.46 to 0.80)

Abbreviations: CI = Confidence Interval; REPOS = Rotterdam Elderly Pain Observation Scale; NRS = Numeric Rating Scale; PAINAD = Pain Assessment in Advanced Dementia.

Discussion

In the present study we explored pain behavior in nursing home residents of various cognitive levels, from cognitively intact to severely cognitively impaired. The 10-item REPOS showed good concurrent validity with PAINAD. The correlations with resident's self-report and nurse's NRS were disappointingly low.

We restricted the population to residents with chronic pain, defined as pain intensity of four or higher in the preceding weeks as judged by caregiving nurses. The clinical diagnoses indeed provide further evidence of chronic pain.

Since the gold standard of pain assessment, self-report, cannot be achieved in non-communicating older adults, observing pain behavior during activities may be the only alternative. Chronic pain implies that residents may have pain with the slightest movement, and for that reason, we observed residents when being washed or being dressed.

Proximity scaling did not yield a substantial difference between case and control group, which justified inclusion of all residents in our model. The resulting one-dimensional model showed a good fit. This model allows summing up items into a total score. Furthermore, we found it was justified to dichotomize the REPOS response categories. An additional benefit is meeting the desirability of pain scales being as user-friendly as possible.

Our findings show low internal consistency of the 10 items, which might partly be explained by the overall low prevalences and co-occurrences of the behaviors. The relatively low prevalences of behaviors found during activities are in line with other studies concluding that older adults show fewer and weaker responses to pain (20,21). So do older adults with cognitive impairment in particular, as they have limited ability to express themselves; personal and sociocultural factors might then be of relevance. Nevertheless, a significant difference was found for REPOS scores between case and control group, but on item-level only two of the ten items were significantly more frequent in the case group, namely panicky, panics attack and moaning/groaning. A comparable study found higher scores for facial expressions and guarded behavior in cognitively impaired patients compared with cognitively intact patients (8).

Correlations between REPOS and NRS-resident and NRS-nurse were low, yet comparable to those of previous studies (8,20,22,23). A possible explanation why the elderly would underreport pain is reluctance to complain, a tendency to resist (too much) medication, or simply being convinced that pain is normal in later life (1). In addition, sufferers of chronic pain may tend to avoid painful procedures and are accustomed to pain always being present. This could explain why they typically underestimate pain when being asked. Nurses or nursing assistants are known to underestimate pain in many different settings (24). This may be even more so in nursing home settings, because there is considerable understaffing. It is difficult to even fulfill basic care and this may result in an unwanted neglect of pain and pain treatment. Furthermore, nursing assistants usually are hardly educated on pain management. Future studies need to evaluate REPOS, self-report and nurse's report in different settings, e.g. postoperatively in hospital or during physiotherapy, in the same type of study group. This would show whether the low correlations are consistent in other settings and/or situations as well.

We did find large correlations between REPOS and PAINAD. Overall, our validity estimates, varying from small to large, were not unequivocal. Being aware that nurses tend to underreport pain intensity, we feel confident that the congruent validity of REPOS is adequate.

We compared pain behavior between 24 residents with Alzheimer's disease and 23 residents with vascular dementia, but scores on none of the behaviors differed significantly between these groups.

Our samples of the two types of dementia are small, which could be explained by the fact that the diagnosis of dementia is often unknown. Nursing homes residents do not routinely undergo CT-scans to diagnose the type of dementia. Therefore, dementia may remain unrevealed, or residents may have combined types of dementia, as often was seen in our study.

In a review study, Scherder et al. (25) reported different functioning of pain-related brain areas among various dementia groups, suggesting possible differences in pain experiences. For example, Alzheimer patients report less pain intensity and pain affect than non-demented people, and patients with vascular dementia tend to demonstrate more intense pain behavior than controls do. We would need larger sample sizes to further explore these differences and their effects on daily pain treatment.

We found REPOS scores of three and higher to be indicative of (chronic) pain. The cut-off of three seems somewhat low, but also subtle facial activities and a limited number of behaviors could suffice to indicate pain.

Additionally, scores of three or higher could also result from other emotional states, like anger or sadness, without pain. We, therefore, provide a decision tree that asks caregivers to reflect on the significance of the score obtained, and act in accordance with what they conclude. Our results suggest that the cut-off score of three might be useful for nursing home residents with any level of cognitive function. Nevertheless, further research is needed in larger populations in order to substantiate this supposition.

Strengths and Weaknesses of the Study

We did not include assessments before and after administration of analgesics and we did not document time since last administered analgesic. We chose a similar activity (being washed or dressed) for all residents because we believe this type of activity exacerbates the chronic pain always lurking in the background. We realize, however, that this choice is based on experience only and not scientifically based.

The fact that NRS ratings were based on a larger period of time, namely the whole activity, and the observed behaviors on two minutes of this activity is a methodological weakness that can be held responsible for the small correlations.

A major advantage of our study is the fact that it was performed in six different nursing homes improving the external validity of the findings.

Conclusion

In conclusion, REPOS appears to be promising for identifying pain in a broad range of nursing homes residents. This is one of the first studies evaluating possible differences in pain behavior between types of dementia.

To improve pain management, we determined a cut-off score indicating pain and provide a step-by-step decision tree. As the scale is concise, we expect good usefulness in daily practice, provided that caregivers are adequately instructed. In a next phase, we will perform a pilot implementation of REPOS.

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