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Pain and its consequences in dementia: Observing the complex relationship between pain, behaviour and ADL in nursing home residents

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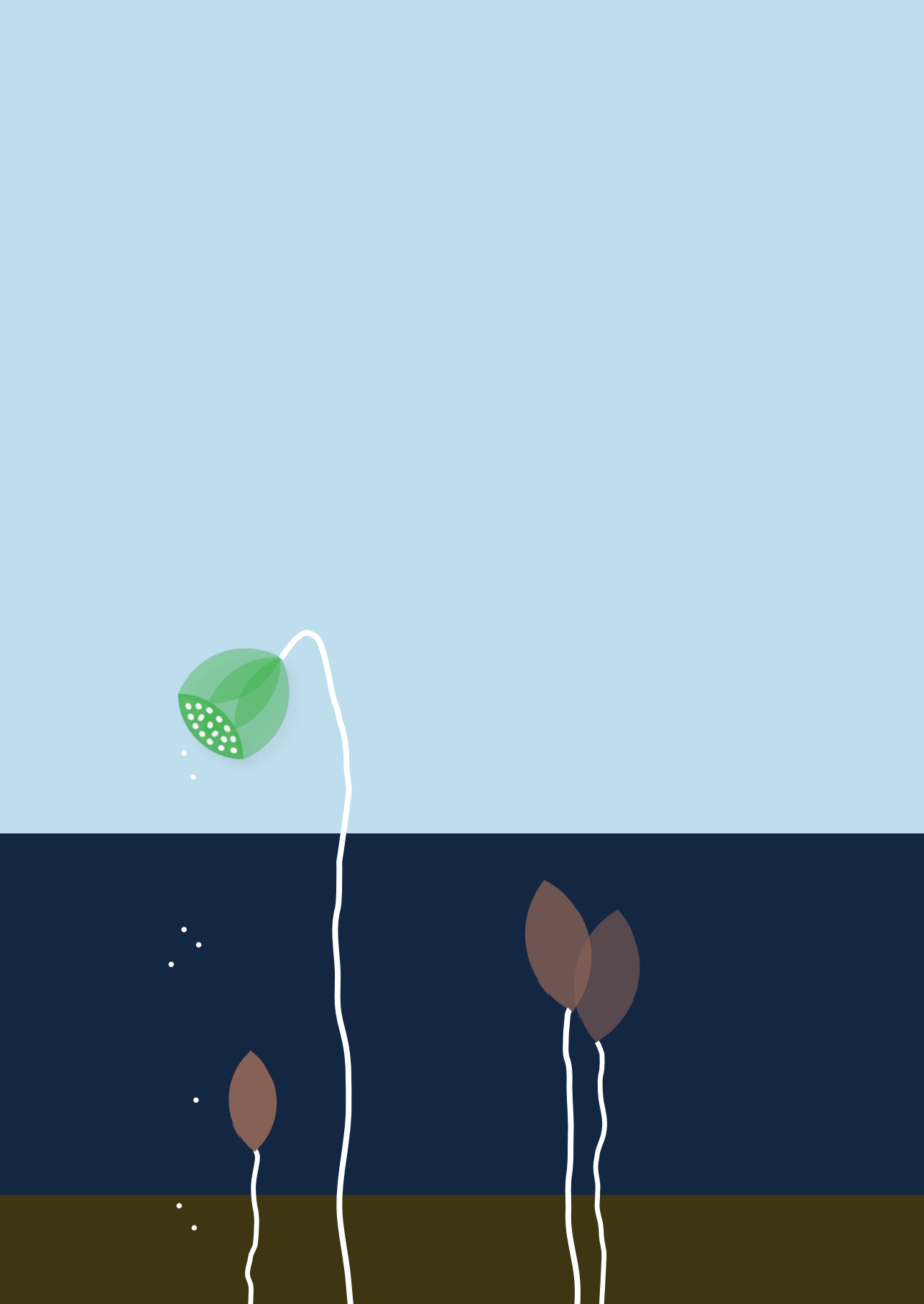
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CHAPTER 4

The impact of pain on the course of ADL functioning in patients with dementia

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Abstract

Background

Understanding if and how pain influences activities of daily living (ADL) in dementia is essential to improving pain management and ADL functioning. This study examined the relationship between the course of pain and change in ADL functioning, both generally and regarding specific ADL functions.

Methods

Participants were Dutch nursing home residents ($n=229$) with advanced dementia. ADL functioning was assessed with the Katz ADL scale, and pain with the Dutch version of the Pain Assessment Checklist for Seniors with Limited Ability to Communicate (PACSLAC-D). Changes of PACSLAC-D and Katz ADL scores were computed based on the difference in scores between baseline, 3-month and 6-month follow-up. Multivariate linear regression models were used to assess the relationships between change in pain score, change in total ADL score and specific ADL item scores during follow-up.

Results

At baseline, residents had a median ADL score of 18 (interquartile range 13-22, range 6-24) and 48% of the residents were in pain (PACSLAC-D ≥ 4). Residents with pain were more ADL dependent than residents without pain. A change in pain score within the first 3 months was a significant predictor for a decline in ADL functioning over the 6-month follow-up ($B=0.10$, $SE=0.05$, $P=0.045$), and specifically, a decline on the items 'transferring' over the 6-month follow-up and 'feeding' during the first 3 months of follow-up.

Conclusions

Pain is associated with ADL functioning cross-sectionally, and a change in pain score predicts a decline in ADL functioning, independent of dementia severity. Awareness of (changes in) ADL activities is clearly important and might result in both improved recognition of pain and improved pain management.

Keywords:

dementia, pain, activities of daily living, nursing home, longitudinal study, older people

Key points:

- Recognition of pain in dementia is challenging and often leads to undertreatment, with negative consequences for quality of life
- Persons with dementia and pain were more ADL dependent compared with residents without pain
- Pain and change in pain affect ADL functioning in dementia, independent of dementia severity
- Pain affects overall ADL functioning as well as specific ADL activities such as transferring and feeding
- Changes in ADL functioning could serve as a red flag for the presence of pain

Introduction

In dementia, activities of daily living (ADL) are challenged by the progressive nature of the neuropathological changes that cause dementia. Consequently, a decline in ADL is to be expected, especially in the more advanced stages of dementia¹. However, functional decline in dementia is a complex phenomenon and besides dementia itself, various (indirect) causes can lead to functional impairment. Examples include age-related diseases, such as osteoporosis and arthritis, depression, apathy, and the use of medication such as psychotropic drugs²⁻⁴. Furthermore, pain might even be an independent cause of decline in ADL^{5,6}, although few studies have described a relationship between pain and ADL functioning in persons with moderate to severe dementia⁷. Some studies have described positive associations between pain and instrumental ADL impairment, and between pain and specific ADL functions such as bathing and transfers^{8,9}, but ADL functioning was often not the main topic of these studies, and use of valid measurement instruments to measure pain and ADL functioning was frequently lacking⁷. Despite the paucity of studies investigating this relationship, understanding the impact of pain on ADL functioning is of the utmost importance. Impairment of ADL has a significant impact on the quality of life of persons with dementia and hampers social interactions and wellbeing¹⁰, representing a burden not only for patients but also for caregivers and society as a whole^{11,12}.

In order to study the relationship between pain, a change in pain score, and change in ADL functioning in general and in specific ADL activities, prospectively collected data were used in addition to cross-sectional data. Our hypothesis was that pain, and especially a change in pain, predicts a general decline in ADL functioning and a decline in specific ADL functions in persons with moderate to severe dementia.

Methods

Setting and study population

The present study was conducted within the framework of the STA-OP! trial, a single-blinded, cluster-randomised controlled trial in Dutch nursing homes¹³.

The STA-OP! trial has been approved by the Medical Ethics Review Committee of the VU University Medical Center, Amsterdam (registration number 2009/119).

Within 12 nursing homes (with 21 units), residents were included with moderate to severe cognitive impairment (Reisberg Global Deterioration Scale (GDS) stage 5, 6, 7), and no chronic psychiatric diagnosis other than a dementia-related diagnosis¹³.

A total of 288 residents were included and randomly assigned to the intervention (n=148) or to usual care (n=140). For the purposes of the longitudinal analyses in this study, we included 229 residents, excluding residents who died (n=58) or were transferred to another facility (n=1) during the 6-month follow-up period.

Assessments

Demographic characteristics (age, gender, marital status and length of stay), dementia severity, ADL functioning and pain were collected by trained research assistants (psychologists) through face-to-face interviews with healthcare professionals familiar with the patient. Medication use was derived from daily logs of registered nurses and from pharmacists' electronic patient records. The MDS-RAI comorbidity index was used to collect data on comorbidity and was completed by the attending elderly care physician.

ADL functioning

The primary outcome measure for this study was ADL functioning measured with the Katz ADL scale¹⁴. This version of the Katz ADL scale is commonly used in Belgian nursing home care¹⁵, and the scale consists of six items: 1) bathing, 2) dressing, 3) transferring, 4) going to the toilet, 5) continence, and 6) feeding. The range of the total score per item level is 1-4, with higher scores indicating a higher level of dependency: 1) independent, 2) requires some assistance, 3) requires full assistance, and 4) completely dependent. The total Katz-ADL score indicates the degree of dependency, with higher scores indicating a higher level of dependency.

Pain

Pain was assessed using the Dutch version of the Pain Assessment Checklist for Seniors with Limited Ability to Communicate (PACSLAC-D)^{16,17}. This is an observational pain assessment instrument consisting of 24 items. Reliability and validity have been established^{16,18}.

A score of ≥ 4 is considered indicative of the presence of pain¹⁸.

The PACSLAC-D was based on the most recent care moment with the resident, with a maximum time span of 24h.

Dementia severity

The Reisberg GDS was used to assess dementia severity¹⁹. The GDS rates the clinically identifiable stages of cognitive decline on a 7-point rating scale. Scores range from 1) 'no cognitive decline' to 7) 'very severe cognitive decline'. The scores reflect both cognitive and functional performance testing. Interrater reliability was high ($r=.82$), as was validity ($r=.62$)^{20,21}. The GDS was completed by the attending elderly care physician.

Statistical analyses

Descriptive statistics were used to examine the demographics and clinical characteristics of the study population. Data were expressed as means with standard deviations (SD) or medians with interquartile range (IQR), as appropriate. For the non-normally distributed variables, differences between groups were analyzed using the Mann-Whitney U-test.

To assess the course of ADL functioning, differences in Katz ADL scores between 6-month follow-up and baseline (T2-T0), between 3-month follow-up and baseline (T1-T0), and between 6-month follow-up and 3-month follow-up (T2-T1) were computed. A change of PACSLAC-D scores was also computed as the difference in score between 3-month follow-up and baseline (T1-T0).

Multivariate linear regression models were used to analyse whether a change in pain score in the first 3 months (independent variable) was a predictor for: 1) a decline in ADL functioning during the 6-month follow-up period, 2) decline in ADL functioning in the first 3 months of follow-up, and 3) decline in ADL functioning in the last 3 months of follow-up (dependent variables). These models also included baseline ADL score, pain at baseline (PACSLAC-D ≥ 4 yes/no), and dementia severity (GDS ≥ 7 yes/no) as independent predictors. Consequently, B-values can be interpreted as the independent contribution of each variable, with a value of 1 representing 1-point change in Katz ADL score per unit of the independent variable. R^2 represents the percentage of the variation of the dependent variable that a linear model (all variables together) explains. We further adjusted for intervention assignment, marital status, length of stay, co-morbidity, and use of medication known to have an impact on ADL functioning and/or pain (opioids, paracetamol, antipsychotics, anxiolytics, sedative/hypnotics, antidepressants, and anti-dementia drugs).

Analyses were performed with IBM SPSS statistics for Windows version 25.0.

Results

Resident characteristics

The majority of residents were female (72.5%), the mean age was 83.1 (range 59-103 years), and almost 90% had advanced dementia (Reisberg GDS score 6-7) (Table 1, Figure 1). At baseline, the median length of stay in the nursing home was 22.9 months. Almost half (48%) of the residents were experiencing pain (PACSLAC-D score ≥ 4).

Table 1. Characteristics of the study population (n=229) at baseline

Age (years), mean	83.1 (SD 7. 2)
Gender	
Male	63 (27.5%)
Female	166 (72.5%)
Marital status	
Single	157 (68.6%)
Significant other	72 (31.4%)
Length of stay (months), median	22.9 (IQR 11-43)
Dementia severity (GDS), mean	6.2 (SD 0.6)
GDS 5 (moderate-severe)	28 (12.2%)
GDS 6 (severe)	134 (58.5%)
GDS 7 (very severe)	67 (29.3%)
Pain (PACSLAC-D), mean	4.4 (SD 4.41)
Pain No (PACSLAC-D <4)	119 (52.0%)
Pain Yes (PACSLAC-D ≥ 4)	110 (48.0%)
Physical function (Katz ADL score), median	18.0 (IQR 13-22)
Co-morbidity	
Diseases of circulatory system	115 (50.2%)
Diseases of musculoskeletal system	58 (25.3%)
Diseases of nervous system	35 (15.3%)
Diseases of respiratory system	23 (10.0%)
Clinical diagnosis depression	22 (9.6%)
Cancer	8 (3.5%)
Medication (missing, n=3)	
Paracetamol	92 (40.7%)
Anxiolytics	81 (35.8%)
Antipsychotics	76 (33.6%)
Antidepressants	53 (23.5%)
Sedatives/hypnotics	46 (20.4%)
Anti-dementia	20 (8.8%)
Opioids	11 (4.9%)

SD: Standard Deviation; GDS: Global Deterioration Scale; IQR: Inter Quartile Range

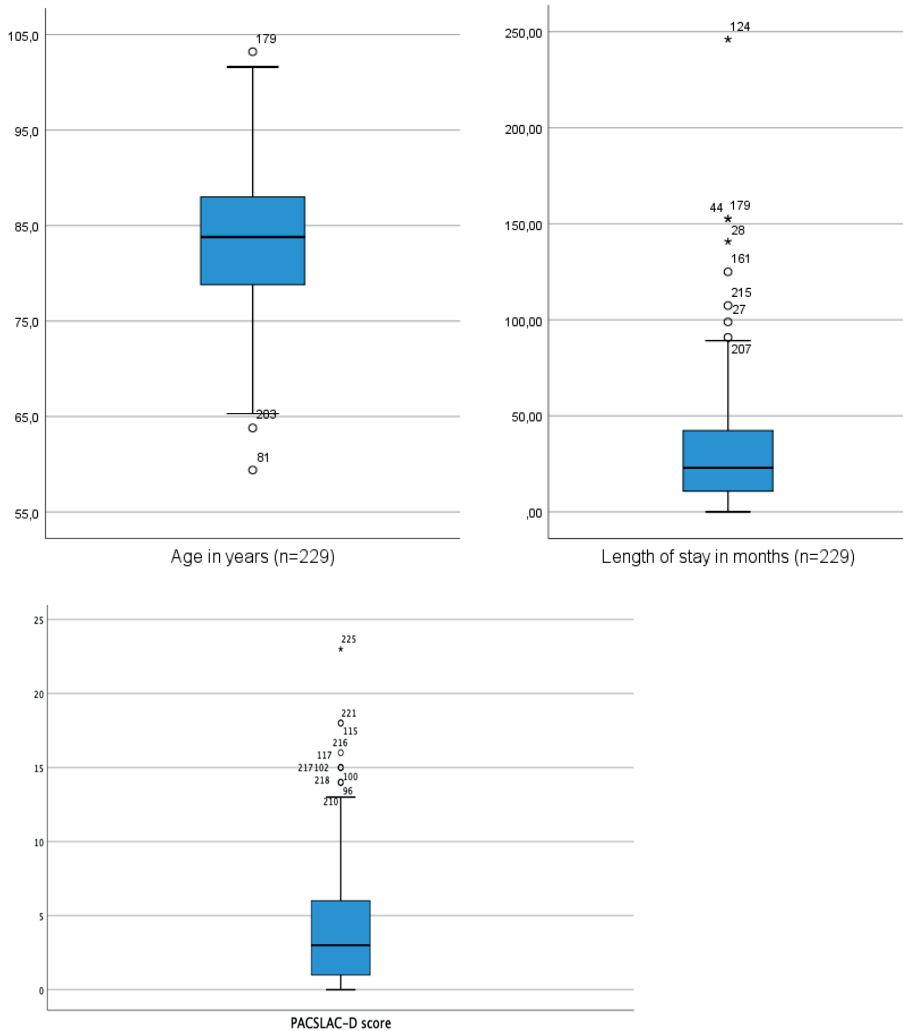


Figure 1. Boxplots baseline characteristics

Cross-sectional relationships between ADL functioning and presence of pain at baseline showed that the median ADL score was higher in residents with pain compared to residents without pain: 20 (IQR 16-23) and 16 (IQR 11-19), respectively ($p < 0.001$), indicating higher levels of dependency in those with pain (Table 2). This was also true for median scores on the ADL items; in residents with pain all items were scored significantly higher compared to residents without pain. In residents with pain, the items 'bathing', 'dressing' and 'continence' had the highest scores, again indicating higher levels of dependency.

Table 2. ADL functioning at baseline in residents without and with pain

	Pain: No (n=119) (PACSLAC-D <4)	Pain: Yes (n=110) (PACSLAC-D ≥4)	P-value
Baseline Katz ADL total score	16.0 (11-19)	20.0 (16-23)	< 0.001
Katz ADL score on item level			
- Bathing	3.0 (2-4)	4.0 (3.8-4)	< 0.001
% Independent*	6.7	1.8	
- Dressing	3.0 (2-4)	4.0 (3.8-4)	< 0.001
% Independent	10.1	2.7	
- Transferring	2.0 (1-2)	3.0 (1.8-4)	< 0.001
% Independent	47.1	24.5	
- Going to the toilet	3.0 (1-3)	3.0 (3-4)	< 0.001
% Independent	25.2	13.6	
- Continence	3.0 (2-4)	4.0 (2-4)	< 0.001
% Independent	21.8	10.9	
- Feeding	2.0 (1-3)	2.5 (2-4)	< 0.001
% Independent	45.4	23.6	

Numbers represent median (IQR). *Indicates the number of residents who are completely independent on that specific item.

Predictors of the course of ADL functioning: total ADL score

Multivariate linear regression analyses (Table 3) showed that a change in pain score within the first 3 months was a significant predictor of a decline in ADL functioning over the 6-month follow-up period ($B=0.10$, $SE=0.05$, $P=0.045$), and especially during the first 3 months of follow-up ($B=0.09$, $SE=0.4$, $P=0.02$). Pain at baseline was not a significant predictor of a decline in the ADL total score throughout the 6-month follow-up period ($B=-0.14$, $SE=0.46$, $P=0.76$), during the first 3 months of follow-up ($B=-0.08$, $SE=0.36$, $P=0.82$) or during the last 3 months of follow-up ($B=-0.06$, $SE=0.43$, $P=0.88$). A higher score on the GDS, indicating more advanced dementia, was a significant predictor of a decline in ADL functioning over the 6-month follow-up period ($B=1.16$, $SE=0.51$, $P=0.02$).

Table 3. Predictors of change in the Katz ADL score over 6 months of follow-up (multivariate analyses, n=229)

Patient characteristics	6-month follow-up			First 3-month follow-up			Last 3-month follow-up		
	B	SE	P-value	B	SE	P-value	B	SE	P-value
Age	0.02	0.03	0.54	0.01	0.02	0.68	0.01	0.03	0.75
Gender, female	0.78	0.48	0.10	0.43	0.37	0.24	0.35	0.44	0.42
Dementia severity, GDS 7	1.16	0.51	0.02	0.44	0.39	0.26	0.72	0.47	0.12
Baseline Katz ADL score*	-0.23	0.05	<0.001	-0.10	0.04	0.09	-0.13	0.04	0.003
Pain at baseline	-0.14	0.46	0.76	-0.08	0.36	0.82	-0.06	0.43	0.88
Change in pain score in first 3 months	0.10	0.05	0.045	0.09	0.40	0.02	0.01	0.05	0.77

Adjusted for intervention assignment, marital status, length of stay, co-morbidity, and medication use. R^2 6-month follow-up: 0.22, R^2 first 3-month follow-up: 0.18, R^2 last 3-month follow-up: 0.11. * Higher scores indicate higher level of dependency. Bold values represent significant values.

Predictors of the course of ADL functioning at the item level

A change in pain score within the first 3 months was a significant predictor for a decline in the ADL item 'transferring' over 6 months of follow-up ($B=0.03$, $SE=0.01$, $P=0.04$), but it did not reach significance during the first 3 months of follow-up ($B=0.02$, $SE=0.01$, $P=0.12$) or during the last 3 months of follow-up ($B=0.01$, $SE=0.01$, $P=0.32$) (Table 4). Furthermore, a change in pain score within the first 3 months was a significant predictor for a decline in the ADL item 'feeding' during the first 3 months of follow-up ($B=0.02$, $SE=0.01$, $P=0.04$). None of the other ADL items were significantly affected by a change in pain score within the first 3 months. In addition, pain at baseline was not a predictor for a decline in ADL scores for any item after 6 months of follow-up, although pain at baseline was a significant predictor for a decline in the item 'bathing' at 3-month follow-up ($B=0.18$, $SE=0.09$, $P=0.04$). All items were significantly affected by baseline ADL score on item level over 6 months of follow-up.

Table 4. Predictors of change in the Katz ADL score on item level over 6 months of follow-up (multivariate analysis, n=229)

Patient characteristics	Bathing			Dressing		
	B	SE	p-value	B	SE	p-value
6-month follow-up						
Age	0.01	0.01	0.03	0.01	0.01	0.24
Gender, female (reference=male)	0.10	0.10	0.34	0.05	0.11	0.65
Dementia severity, GDS 7 (reference=GDS 5/6)	0.29	0.10	0.004	0.32	0.11	0.01
Baseline Katz ADL score item level	-0.37	0.05	<0.001	-0.48	0.06	<0.001
Pain at baseline	0.06	0.10	0.54	0.09	0.11	0.41
Change in pain score in first 3 months	0.01	0.01	0.17	0.02	0.01	0.07
First 3-month follow-up						
Age	0.002	0.01	0.76	0.01	0.01	0.28
Gender, female (reference=male)	0.03	0.09	0.75	0.05	0.10	0.62
Dementia severity, GDS 7 (reference=GDS 5/6)	0.13	0.09	0.13	0.14	0.10	0.15
Baseline Katz ADL score item level	-0.30	0.05	<0.001	-0.24	0.05	<0.001
Pain at baseline	0.18	0.09	0.04	0.05	0.09	0.60
Change in pain score in first 3 months	0.02	0.01	0.10	0.01	0.01	0.22
Last 3-month follow-up						
Age	0.01	0.01	0.07	0.002	0.01	0.80
Gender, female (reference=male)	0.07	0.11	0.53	0.004	0.12	0.97
Dementia severity, GDS 7 (reference=GDS 5/6)	0.16	0.11	0.15	0.18	0.12	0.13
Baseline Katz ADL score item level	-0.07	0.06	0.20	-0.24	0.06	<0.001
Pain at baseline	-0.12	0.11	0.27	0.04	0.11	0.70
Change in pain score in first 3 months	-0.001	0.01	0.96	0.01	0.01	0.46

Adjusted for, intervention assignment, marital status, length of stay, co-morbidity, and medication use. R² 6-months follow-up: bathing: 0.30, dressing: 0.34, transferring: 0.19, going to toilet: 0.29, continence: 0.28, feeding: 0.29. R² first 3 months follow-up: bathing: 0.24, dressing: 0.22, transferring: 0.19, going to toilet: 0.16, continence: 0.20, feeding: 0.29. R² last 3 months follow-up: bathing: 0.10, dressing: 0.12, transferring: 0.12, going to toilet: 0.12, continence: 0.12, feeding: 0.11. * Higher scores indicate higher level of dependence. Bold values represent significant values.

Transferring			Going to toilet			Continence			Feeding		
B	SE	p-value	B	SE	p-value	B	SE	p-value	B	SE	p-value
-0.01	0.01	0.53	-0.01	0.01	0.03	0.01	0.01	0.58	0.01	0.01	0.45
0.19	0.14	0.17	0.17	0.10	0.08	0.22	0.13	0.10	0.09	0.13	0.50
0.37	0.13	0.01	0.19	0.10	0.05	0.22	0.13	0.09	0.39	0.15	0.01
-0.23	0.05	<0.001	-0.32	0.05	<0.001	-0.35	0.05	<0.001	-0.38	0.06	<0.001
-0.05	0.13	0.69	0.06	0.09	0.50	0.12	0.71	0.62	-0.04	0.12	0.75
0.03	0.01	0.04	0.02	0.01	0.09	-0.001	0.01	0.93	0.01	0.01	0.55
-0.002	0.01	0.75	-0.003	0.01	0.62	0.01	0.01	0.36	-0.004	0.01	0.59
0.02	0.11	0.88	0.03	0.09	0.73	0.24	0.12	0.05	0.11	0.12	0.32
0.32	0.10	0.002	0.15	0.09	0.10	0.11	0.12	0.39	0.31	0.14	0.02
-0.16	0.04	<0.001	-0.17	0.04	<0.001	-0.25	0.05	<0.001	-0.30	0.06	<0.001
-0.08	0.10	0.42	-0.04	0.09	0.68	0.15	0.12	0.19	0.09	0.11	0.42
0.02	0.01	0.12	0.001	0.01	0.91	0.01	0.01	0.70	0.02	0.01	0.045
-0.003	0.01	0.67	-0.01	0.01	0.07	-0.002	0.01	0.75	0.01	0.01	0.25
0.17	0.12	0.15	0.14	0.09	0.15	-0.02	0.12	0.88	-0.03	0.14	0.84
0.05	0.12	0.67	0.04	0.10	0.68	0.11	0.13	0.36	0.08	0.16	0.61
-0.07	0.05	0.11	-0.14	0.04	0.001	-0.10	0.05	0.04	-0.08	0.07	0.26
0.03	0.12	0.79	0.10	0.09	0.28	-0.03	0.12	0.77	-0.13	0.13	0.33
0.01	0.01	0.32	0.02	0.01	0.10	-0.01	0.01	0.64	-0.02	0.01	0.28

Discussion

To the best of our knowledge, this is the first study to examine the longitudinal relationship between pain and ADL functioning in persons with moderate to severe dementia.

A change in pain score predicted a decline in ADL functioning during the 6-month follow-up period, as well as during the first 3 months of follow-up, independent of dementia severity. In particular, the items 'transferring' (6-month follow-up) and 'feeding' (first 3 months) were affected by a change in pain score during the first 3 months. A change in pain score within the first 3 months did not affect any ADL item during the last 3 months of follow-up. This remained true after controlling for co-morbidity, length of stay in the nursing home, and medication use.

The cross-sectional findings were in line with the few similar studies available, which reported that pain is related to poorer ADL function in persons with dementia ^{8,9,22}.

Interestingly, this longitudinal study suggests that it is not so much the presence of pain, but rather the change in pain score that is related to a decline in ADL functioning. Labus et al. showed that the relation between pain behaviour, such as the slower performance of certain activities, and the experience of pain is stronger in acute pain compared to persistent pain ²³. In the present study, pain was measured using the PACSLAC-D and was based on the most recent care moment with the resident. This implies that the PACSLAC-D may have captured both acute and chronic pain. In theory, a change in pain score might represent either worsening or improvement. However, in this study a change in pain score is more likely to represent acute pain, and the largest effect on ADL functioning may be during the acute phase of pain. Furthermore, the PACSLAC-D does not provide information on pain location. Although this might be important knowledge, persons with dementia are often non-verbal, which hampers them to identify pain locations. Observation of pain related behaviour/pain severity is the key.

Additionally, this study shows that ADL functions deteriorate with the progression of dementia ^{2,10,24,25}. This was to be expected, especially as the GDS also includes ADL (feeding, toileting) and psychomotor skills (e.g., ability to walk) that measure dementia severity. Nevertheless, the present study shows that a change in pain score within the first 3 months significantly predicts a decline in ADL functioning, regardless of dementia severity. This is an important finding that can be applied in daily practice, as a decline in ADL functioning may serve as a red flag for the presence of pain.

This study had several strengths, including the longitudinal study design, ADL functioning as a primary outcome measure and a focus on individual ADL items instead of solely focussing on the total ADL score. This is important because it is possible that the way ADL scores are interpreted might aid understanding of the complexity of the relationship between pain and ADL functioning. Whereas a total ADL score provides information on the degree of overall ADL dependency, scores on item level tell us which ADL functions are most affected. An example is the cross-sectional study by Lin et al., in which pain was observed immediately following routine care and a higher prevalence of pain was noted in patients during bathing (46%) and during assisted transfer (51%) compared to patients in self-transfer situations (3%) ⁸. The present study also provides insight into which ADL functions are most affected by pain, i.e., transferring and feeding (rather than bathing,

dressing, going to toilet, and continence). However, B-values for both transferring and feeding were small (transferring: $B=0.03$; bathing: $B=0.02$), and one could question the clinical significance of these results. Furthermore, the item feeding might also capture appetite, as a resident with a loss of appetite might be reluctant to eat, behaviour that could be interpreted by the nurse as a need for assistance during dinner. Nevertheless, this information is important to health care workers as it may assist in clinical management and raise awareness of pain as a potential cause. Possible limitations of this study should also be considered. The 6-month follow-up period might appear brief, but appears less so when one considers that the median length of stay after admission to a psychogeriatric ward is only two years²⁶. Furthermore, the fluctuation of ADL functioning and pain over time makes it difficult to capture all changes in these items, and although longitudinal analysis facilitated examination of time-related changes in ADL functioning, we did not include the onset of ADL decline or disability, unlike (for example) Eggermont et al.⁵. One could also argue that an ADL scale might not be the best instrument to measure ADL functioning and explore the complex relationship between pain and ADL functioning. Measuring care dependency with, for example the Care Dependency Scale (CDS)²⁷ might better reflect ADL functioning and especially ADL dependency. The CDS consists of 15 items, including items on ADL functioning (eating, drinking and getting (un)dressed), social activities, communication, and mobility²⁸. Together these 15 items capture a much broader view of ADL functioning because they are not restricted to only the basic ADL activities. Finally, it would be most interesting to investigate the causal relationship between pain and ADL functioning in dementia. However, the present study was nested in the STA-OP! trial²⁹ and therefore not designed to test for causality between pain and ADL functioning. This is also true for investigating the effect of pain medication on ADL impairment. Interestingly, a randomised double-blind, placebo-controlled crossover trial by van Dam et al, aims to evaluate the scheduled effect of pain medication on ADL functioning and care dependency³⁰.

Conclusion

The results of this study suggest that pain, and change in pain, in nursing home residents with dementia is related to a decline in ADL functions, independent of dementia severity. Recognizing a decline in ADL functioning, both in general and in specific ADL activities, may serve as an important cue for the presence of pain. Consequently, we urge health-care workers to focus on regular assessment of pain and ADL functions, for example every 3 months. When assessing ADL functioning it is important that the separate items of the Katz ADL scale or other measurement tools, such as the Barthel Index or the CDS, should be considered^{27 31}. This approach might facilitate tailored (non)pharmacological interventions^{25 32}. In addition, regular assessment of both pain and ADL functions should assist in improving pain management in persons with dementia and help to decelerate, or even avoid, functional loss.

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Conflict of interest

None of the authors have conflicts of interest or dual commitments.

References

1. Hiroyuki T, Yuma N, Daiki I, et al. Clinical factors associated with activities of daily living and their decline in patients with severe dementia. *Psychogeriatrics* 2019 doi: 10.1111/psyg.12502 [published Online First: 2019/12/29]
2. Helvik AS, Engedal K, Benth JS, et al. A 52 month follow-up of functional decline in nursing home residents- degree of dementia contributes. *BMC Geriatr* 2014;14(1):45. doi: 1471-2318-14-45 [pii];10.1186/1471-2318-14-45 [doi]
3. Shah RC, Buchman AS, Boyle PA, et al. Musculoskeletal pain is associated with incident mobility disability in community-dwelling elders. *J Gerontol A Biol Sci Med Sci* 2011;66(1):82-88. doi: glq187 [pii];10.1093/gerona/glq187 [doi]
4. Tormalehto S, Martikainen J, Bell JS, et al. Use of psychotropic medications in relation to neuropsychiatric symptoms, cognition and functional performance in Alzheimer's disease over a three-year period: Kuopio ALSOVA study. *Int Psychogeriatr* 2017;29(10):1723-33. doi: 10.1017/S1041610217001090 [published Online First: 2017/06/20]
5. Eggermont LH, Leveille SG, Shi L, et al. Pain characteristics associated with the onset of disability in older adults: the maintenance of balance, independent living, intellect, and zest in the Elderly Boston Study. *J Am Geriatr Soc* 2014;62(6):1007-16. doi: 10.1111/jgs.12848 [doi]
6. Hirase T, Kataoka H, Nakano J, et al. Impact of frailty on chronic pain, activities of daily living and physical activity in community-dwelling older adults: A cross-sectional study. *Geriatr Gerontol Int* 2018;18(7):1079-84. doi: 10.1111/ggi.13314 [published Online First: 2018/03/28]
7. van Dalen-Kok AH, Pieper MJ, de Waal MW, et al. Association between pain, neuropsychiatric symptoms, and physical function in dementia: a systematic review and meta-analysis. *BMC Geriatr* 2015;15(1):49. doi: 10.1186/s12877-015-0048-6
8. Lin PC, Lin LC, Shyu YIL, et al. Predictors of pain in nursing home residents with dementia: a cross-sectional study. *Journal of Clinical Nursing* 2011;20(13-14):1849-57.
9. Shega JW, Weiner DK, Paice JA, et al. The association between noncancer pain, cognitive impairment, and functional disability: an analysis of the Canadian study of health and aging. *J Gerontol A Biol Sci Med Sci* 2010;65(8):880-86. doi: glq039 [pii];10.1093/gerona/glq039 [doi]
10. Giebel CM, Sutcliffe C, Stolt M, et al. Deterioration of basic activities of daily living and their impact on quality of life across different cognitive stages of dementia: a European study. *Int Psychogeriatr* 2014;26(8):1283-93. doi: 10.1017/S1041610214000775
11. Reich JW, Olmsted ME, van Puymbroeck CM. Illness uncertainty, partner caregiver burden and support, and relationship satisfaction in fibromyalgia and osteoarthritis patients. *Arthritis Rheum* 2006;55(1):86-93. doi: 10.1002/art.21700 [doi]
12. Chibnall JT, Tait RC, Harman B, et al. Effect of acetaminophen on behavior, well-being, and psychotropic medication use in nursing home residents with moderate-to-severe dementia. *J Am Geriatr Soc* 2005;53(11):1921-29. doi: JGS53572 [pii];10.1111/j.1532-5415.2005.53572.x [doi]

13. Pieper MJ, Francke AL, van der Steen JT, et al. Effects of a Stepwise Multidisciplinary Intervention for Challenging Behavior in Advanced Dementia: A Cluster Randomized Controlled Trial. *J Am Geriatr Soc* 2016;64(2):261-9. doi: 10.1111/jgs.13868
14. Katz S, Akpom CA. A measure of primary sociobiological functions. *IntJHealth Serv* 1976;6(3):493-508.
15. Roelands M, Van OP, Depoorter A, et al. A social-cognitive model to predict the use of assistive devices for mobility and self-care in elderly people. *Gerontologist* 2002;42(1):39-50.
16. Fuchs-Lacelle S, Hadjistavropoulos T. Development and preliminary validation of the pain assessment checklist for seniors with limited ability to communicate (PACSLAC). *Pain ManagNurs* 2004;5(1):37-49. doi: S152490420300122X [pii]
17. Zwakhalen SM, Hamers JP, Berger MP. Improving the clinical usefulness of a behavioural pain scale for older people with dementia. *JAdvNurs* 2007;58(5):493-502. doi: JAN4255 [pii];10.1111/j.1365-2648.2007.04255.x [doi]
18. Zwakhalen SM, Hamers JP, Berger MP. The psychometric quality and clinical usefulness of three pain assessment tools for elderly people with dementia. *Pain* 2006;126(1-3):210-20. doi: S0304-3959(06)00353-8 [pii];10.1016/j.pain.2006.06.029 [doi]
19. Reisberg B, Ferris SH, de Leon MJ, et al. The Global Deterioration Scale for assessment of primary degenerative dementia. *Am J Psychiatry* 1982;139(9):1136-9.
20. Rikkert MG, Tona KD, Janssen L, et al. Validity, reliability, and feasibility of clinical staging scales in dementia: a systematic review. *Am J Alzheimers Dis Other Demen* 2011;26(5):357-65. doi: 10.1177/1533317511418954 [published Online First: 2011/09/15]
21. Gottlieb GL, Gur RE, Gur RC. Reliability of psychiatric scales in patients with dementia of the Alzheimer type. *Am J Psychiatry* 1988;145(7):857-60. doi: 10.1176/ajp.145.7.857 [published Online First: 1988/07/01]
22. Plooi B, Scherder EJ, Eggermont LH. Physical inactivity in aging and dementia: a review of its relationship to pain. *JClinNurs* 2012;21(21-22):3002-08. doi: 10.1111/j.1365-2702.2011.03856.x [doi]
23. Labus JS, Keefe FJ, Jensen MP. Self-reports of pain intensity and direct observations of pain behavior: when are they correlated? *Pain* 2003;102(1-2):109-24.
24. Caljouw MA, Cools HJ, Gussekloo J. Natural course of care dependency in residents of long-term care facilities: prospective follow-up study. *BMC Geriatr* 2014;14:67. doi: 10.1186/1471-2318-14-67
25. Sverdrup K, Bergh S, Selbaek G, et al. Trajectories of physical performance in nursing home residents with dementia. *Aging Clin Exp Res* 2020 doi: 10.1007/s40520-020-01499-y [published Online First: 2020/02/16]
26. van der Steen JT, Ribbe MW, Deliens L, et al. Retrospective and prospective data collection compared in the Dutch End Of Life in Dementia (DEOLD) study. *Alzheimer Dis Assoc Disord* 2014;28(1):88-94. doi: 10.1097/WAD.0b013e318293b380
27. Dijkstra A, Tiesinga LJ, Plantinga L, et al. Diagnostic accuracy of the care dependency scale. *J Adv Nurs* 2005;50(4):410-6. doi: 10.1111/j.1365-2648.2005.03406.x [published Online First: 2005/04/22]
28. Allen RS, Thorn BE, Fisher SE, et al. Prescription and dosage of analgesic medication in relation to resident behaviors in the nursing home. *JAmGeriatrSoc* 2003;51(4):534-38. doi: jgs51164 [pii]

29. Pieper MJC, van der Steen JT, Francke AL, et al. Effects on pain of a stepwise multidisciplinary intervention (STA OP!) that targets pain and behavior in advanced dementia: A cluster randomized controlled trial. *Palliat Med* 2018;32(3):682-92. doi: 10.1177/0269216316689237 [published Online First: 2017/02/02]
30. van Dam PH, Achterberg WP, Gussekloo J, et al. Quality of life and paracetamol in advanced dementia (Q-PID): protocol of a randomised double-blind placebo-controlled crossover trial. *BMC Geriatr* 2018;18(1):279. doi: 10.1186/s12877-018-0974-1 [published Online First: 2018/11/16]
31. Mahoney FI, Barthel DW. Functional Evaluation: The Barthel Index. *Md State Med J* 1965;14:61-5.
32. Pieper MJ, van Dalen-Kok AH, Francke AL, et al. Interventions targeting pain or behaviour in dementia: A systematic review. *Ageing ResRev* 2013 doi: S1568-1637(13)00024-X [pii];10.1016/j.arr.2013.05.002 [doi]