



**Universiteit
Leiden**
The Netherlands

Impact of pain and neuropsychiatric symptoms on activities in nursing home residents (COSMOS trial)

Beek, S.H. van de; Erdal, A.; Husebo, B.S.; Vislapuu, M.; Achterberg, W.P.; Caljouw, M.A.A.

Citation

Beek, S. H. van de, Erdal, A., Husebo, B. S., Vislapuu, M., Achterberg, W. P., & Caljouw, M. A. A. (2024). Impact of pain and neuropsychiatric symptoms on activities in nursing home residents (COSMOS trial). *Journal Of The American Medical Directors Association*, 25(5), 847-852.e3. doi:10.1016/j.jamda.2024.01.012

Version: Publisher's Version
License: [Creative Commons CC BY 4.0 license](https://creativecommons.org/licenses/by/4.0/)
Downloaded from: <https://hdl.handle.net/1887/3764493>

Note: To cite this publication please use the final published version (if applicable).



JAMDA

journal homepage: www.jamda.com

Original Study

Impact of Pain and Neuropsychiatric Symptoms on Activities in Nursing Home Residents (COSMOS Trial)



Sifra H. van de Beek MSc^{a,b,c,*}, Ane Erdal PhD^d, Bettina S. Husebø PhD^{d,e},
 Maarja Vislapuu MSc^d, Wilco P. Achterberg MD, PhD^{f,g}, Monique A.A. Caljouw PhD^{f,g}

^a Department of Internal Medicine, Gerontology and Geriatrics, Leiden University Medical Center, Leiden, the Netherlands

^b Department of Ethics and Law, Leiden University Medical Center, Leiden, the Netherlands

^c Faculty of Medicine, University of Coimbra, Coimbra, Portugal

^d Department of Global Public Health and Primary Care, Center for Elderly and Nursing Home Medicine (SEFAS), Faculty of Medicine, University of Bergen, Bergen, Norway

^e Neuro-SysMed, Department of Global Public Health and Primary Care, Faculty of Medicine, University of Bergen, Bergen, Norway

^f Department of Public Health and Primary Care, Leiden University Medical Center, Leiden, the Netherlands

^g University Network for the Care Sector Zuid-Holland, Leiden University Medical Center, Leiden, the Netherlands

A B S T R A C T

Keywords:
 Dementia
 pain
 behavior
 activity
 nursing homes
 COSMOS study

Objective: This study aims to identify whether pain and dementia-related behavior are associated with different types of activities in nursing home residents, controlled for dementia severity.

Design: Cross-sectional baseline data from the multicomponent cluster randomized controlled COSMOS trial (acronym for Communication, Systematic pain treatment, Medication review, Organization of activities, and Safety).

Setting and Participants: A total of 723 patients from 33 Norwegian nursing homes with 67 units (clusters). Participants aged ≥ 65 years, with a life expectancy of >6 months, and with valid data on activity were eligible for inclusion.

Methods: Activity was operationalized in time (hours per week) and type (cognitive, social, physical, and no activity). Cognitive function was assessed using the Mini-Mental State Examination (MMSE), pain with the Mobilization-Observation-Behavior-Intensity-Dementia-2 Pain Scale (MOBID-2), and behavior with the Neuropsychiatric Inventory Nursing Home version (NPI-NH). Analyses were performed using linear and logistic regression. Sensitivity analyses for dementia severity were performed to account for effect modification.

Results: A total of 289 participants were included (mean age 86.2 [SD 7.6]; 74% female). A higher pain score was associated with less time spent on activity in participants with severe dementia (estimate 0.897, $P = .043$). A higher score for the NPI-NH mood cluster (depression and anxiety) was associated with a higher likelihood of participation in cognitive activities (odds ratio [OR], 1.073; $P = .039$). Apathy (OR, 0.884; $P = .041$) and lack of inhibition (OR, 0.904; $P = .042$) were associated with a lower likelihood of participation in social activities as well as no engagement in activities (apathy OR, 0.880; $P = .042$; lack of inhibition OR, 0.894; $P = .034$).

Conclusion and Implications: Pain and dementia-related behavior may influence the participation in activities in the nursing home. There is an urgent need to investigate what type of activity stimulates people in different stages of dementia.

© 2024 The Authors. Published by Elsevier Inc. on behalf of AMDA – The Society for Post-Acute and Long-Term Care Medicine. This is an open access article under the CC BY license (<http://creativecommons.org/licenses/by/4.0/>).

The COSMOS study was supported by the Research Council of Norway (Sponsor's Protocol Code: 222113) and a grant from Rebekka Ege Hegermann's Foundation. The sponsors had no influence on the trial concept and design, recruitment of patients, analyses and interpretation of data, or preparation of the manuscript.

* Address correspondence to Sifra H. van de Beek, MSc, Department of Ethics and Law, Leiden University Medical Center, Albinusdreef 2, 2300 RC Leiden, the Netherlands.

E-mail address: s.h.van_de_beek@lumc.nl (S.H. van de Beek).

<https://doi.org/10.1016/j.jamda.2024.01.012>

1525-8610/© 2024 The Authors. Published by Elsevier Inc. on behalf of AMDA – The Society for Post-Acute and Long-Term Care Medicine. This is an open access article under the CC BY license (<http://creativecommons.org/licenses/by/4.0/>).

Behavioral disturbances, or neuropsychiatric symptoms (NPSs), are a heterogeneous group of noncognitive symptoms and behaviors frequently observed in people with dementia in nursing homes (NHs). Symptoms may include depression, agitation, or apathy.¹ Prevalence and intensity of NPSs are associated with more severe stages of dementia^{2,3} and lower quality of life, greatly affecting people with dementia and their families.⁴ Ninety-seven percent of people with dementia display NPSs during the course of their disease.⁵

In addition, people with dementia are at high risk of pain^{6,7} because of age-related comorbid conditions that are frequently present in older adults.^{6,8} Up to 40% to 60% of nursing home patients experience acute or chronic pain.⁹ Pain is a subjective experience that may be defined as “an unpleasant sensory and emotional experience associated with, or resembling that associated with, actual or potential tissue damage.”¹⁰

Both pain and NPSs are among the most common clinical symptoms affecting people with dementia^{11,12} and they are interconnected.^{13,14} Social, cognitive, and physical activities may positively affect people with dementia, reduce symptoms, and are important indicators of their quality of life.^{15–22} Activities—tailored to individual needs—are therefore internationally prioritized in health care policy.^{15,23,24} However, activity needs are regularly not met,^{16,25,26} and most NH residents spend their day being considerably inactive.^{27,28} It is known that increased activity can reduce pain or NPSs,^{29–31} but there is limited evidence regarding the relationship among pain, NPSs, and activity participation. We found only 2 studies that focused on the relationship between pain and activities: Lapane et al³² included 9952 participants and found that the presence of pain reduced the time spent on patient-initiated activities. Another cross-sectional study by Zanolchi et al³³ was not able to identify any associations between pain and social activities in 105 NH patients with and without dementia. They also found that pain was associated with less physical activity.³³ To date, the associations between NPSs and different types of activity have not been investigated.

By identifying whether pain or NPSs are associated with less participation in different types of activities (cognitive, social, and physical) and time spent on activities, it may be possible to also identify and reduce barriers to participation in activities. Therefore, this study describes activity in people with dementia in NHs according to severity of dementia. Second, this study examines the association between pain or NPS and participation in activities in NH residents.

Methods

Participants and Settings

This current cross-sectional study includes baseline data from all eligible study participations from the multicomponent, cluster randomized controlled COSMOS study, comprising the implementation of Communication, Systematic assessment and treatment of pain, Medication review, Organization of activities, and Safety.³⁴ Data collection took place between May 2014 and December 2015. In total, 723 Norwegian residents from 67 NH wards in 33 NHs were invited to participate. People with long-term placement and aged 65 or older were considered eligible. People with a life expectancy of ≤ 6 months or people diagnosed with schizophrenia were excluded. More detailed information about the COSMOS study can be found in the protocol article.³⁴

The current study includes participants with valid data on time spent on activities, participation per type of activity, or both.

Study Registration and Ethics

The COSMOS study was approved by the Regional Committee for Medical and Health Research Ethics (2013/1765) and registered in a clinical trial database (clinicaltrials.gov, study identifier NCT02238652). After informing participants, verbal and written consent was asked. If participants were not capable of medical decision making, presumed consent was obtained from legal representatives.³⁴

Outcome Measures

The associations of pain or NPS with “time spent on activities” and “participation per type of activity” were the outcome measures of this study. Activity was assessed through 11 questions administered to NH staff. For this study, activity was operationalized in duration (hours); participation in cognitive (eg, memory games), social (eg, activities involving interaction with others), and physical activity (eg, dancing to music); and participation in any activities based on information from a subset of the interview questions (Supplementary Textboxes 1–3). In the COSMOS study these types of activity were carefully grouped (social, physical, and cognitive), based on literature.

The Neuropsychiatric Inventory, NH-version (NPI-NH) was used to assess NPS.³⁵ The NPI was proxy-rated by staff members, and it determines the severity and frequency of 12 NPSs during the past 4 weeks. Frequency is measured on a scale of 0 to 4 (not present to daily), and severity on a scale of 1 to 3 (higher score equals more severe symptoms). To score each symptom, frequency and severity were multiplied, with the total score ranging from 0 to 12. Per symptom, a score of ≥ 4 is considered clinically relevant.³⁶ The NPI-NH symptoms were analyzed both individually and in clusters. The agitation cluster includes agitation, exhilaration, lack of inhibition, and irritability; the apathy cluster includes apathy and appetite or eating disorders; the psychosis cluster includes delusion, hallucination, deviating motor behavior, and deviating sleep or night-time behavior; and the mood cluster includes depression and anxiety.³⁷

The Mobilization-Observation-Behavior-Intensity-Dementia-2 (MOBID-2) Pain Scale was used to assess pain at the moment of measurement.^{38,39} It distinguishes 2 categories of pain. Part 1 assesses musculoskeletal pain through pain sounds, facial expression, and pain behavior during active movements. Part 2 is focused on pain of the head, skin, and internal organs. Each part consists of 5 items, measured on a scale of 0 to 10 (more severe pain). In addition, a total score (0–10) is provided based on all observations, in which ≥ 3 is considered clinically relevant pain (moderate to severe pain).^{38,39}

Cognitive function was assessed using the Mini-Mental State Examination (MMSE), which includes 30 questions regarding, among other things, recall, language, and complex demands.⁴⁰ The total score ranges from 0 to 30, with higher scores indicating better cognitive function. For descriptive information, participants were stratified according to dementia severity based on their MMSE score: no dementia (≥ 26), mild dementia (21–25), moderate dementia (11–20), and severe dementia (≤ 10).⁴¹

Data Analyses

Analyses were performed using IBM Statistical Package for Social Sciences (SPSS) version 26. Demographic and clinical characteristics were described with the mean and SD or the median and interquartile range (IQR) for non-normally distributed variables where relevant, and the number of participants and percentages for categorical variables. Group comparisons were conducted using the independent samples *t* test, the Pearson χ^2 -test, and the Mann-Whitney *U* test, depending on the data distribution.

The association between pain or NPSs and the time spent on activities was analyzed using multivariate linear regression. Because of non-normal data distribution, the time spent on activities was log-transformed. As log-transformation excludes zero values from the analysis, $\log_{10}(x+1)$ was used. Log-transformed data were back-transformed, as data on a logarithmic scale are less easy to interpret compared with data on the original scale.⁴² After analyses, log-transformed and back-transformed coefficients, confidence intervals (CIs) of 95% and *P* values were reported. Multivariate logistic

regression models were fitted separately for 4 categorical dependent variables: participation in no, social, cognitive, and physical activities. After analysis, the odds ratio (OR), 95% CI, and *P* value were reported.

All 5 models were adjusted for age, sex, marital status, MMSE score, type of NH ward (dementia or somatic), MOBID-2 total score, and NPI-NH clusters. Marital status was categorized as married or unmarried/widowed. Subsequently, univariate analyses were conducted to measure individual associations for every activity measure (dependent). The following independent variables were separately analyzed in these univariate models: all individual NPI-NH items; all NPI-NH clusters; MOBID-2 total score; moderate to severe pain; musculoskeletal pain; other pain. All models were adjusted for age, sex, marital status, MMSE score, and type of NH ward.

Stratified sensitivity analyses were conducted to check whether dementia severity acted as an effect modifier. Participants were stratified according to the presence of severe dementia (MMSE \leq 10; yes/no). Stratified models were adjusted for age, sex, marital status, and type of NH ward. Results with a *P* value of \leq .05 were considered significant in all analyses.

Results

Of the 723 NH residents screened from the participating NH wards, 545 persons from 67 wards participated in the COSMOS study. In total, 289 participants from 37 wards with data on activity were included in the current study (Figure 1). Table 1 reports the characteristics of the study participants. Their mean age was 86.2 years (SD 7.6). Most were female (74.0%), and 61.9% resided in a somatic ward. The mean MMSE score was 12.2 (SD 7.6), and 224 participants (85.4%) had moderate or severe dementia. The mean MOBID-2 total score was 2.9 (SD 2.6), and 120 participants (50.8%) had clinically relevant pain (MOBID-2 total score \geq 3). The median total NPI-NH score was 11.5 (IQR 2–26).

The participants of the included sample (*n* = 289) had significantly higher MMSE scores (*P* < .001); relatively more participants with moderate dementia (*P* = .023) and fewer participants with severe dementia (*P* = .001); and more pain total score (*P* = .002) compared with the COSMOS participants with missing data on activity (data not shown).

Table 1
Baseline Characteristics of the Study Population

Item	Total (n = 289)
Age in years, mean (SD)	86.2 (7.6)
Female, n (%)	214 (74.0)
Married, n (%)	58 (20.8)
Clinical diagnosis (dementia), n (%)	170 (60.5)
MMSE total score, mean (SD)	12.2 (7.6)
No dementia: MMSE \geq 26, n (%)	12 (4.6)
Mild dementia: MMSE 21–25, n (%)	26 (10.0)
Moderate dementia: MMSE 11–20, n (%)	116 (44.6)
Severe dementia: MMSE \leq 10, n (%)	106 (40.8)
Type of ward (dementia), n (%)	110 (38.1)
MOBID-2 total score, mean (SD)	2.9 (2.6)
MOBID-2 moderate to severe pain, n (%)	120 (50.8)
MOBID-2 Part 1 (yes: pain), n (%)	128 (55.2)
MOBID-2 Part 2 (yes: pain), n (%)	94 (39.7)
NPI-NH total score, median (IQR)	11.5 (2–26)
Cluster 1: Agitation (IQR)	2 (0–9)
Cluster 2: Apathy (IQR)	0 (0–3)
Cluster 3: Psychosis (IQR)	2 (0–7)
Cluster 4: Affective (IQR)	1.5 (0–6)
Time spent on activities in hours, mean (SD)	9 (12.8)
Participation in social activities, n (%)	240 (83.0)
Participation in cognitive activities, n (%)	136 (47.1)
Participation in physical activities, n (%)	142 (49.3)
No participation in activities, n (%)	39 (13.5)

Time Spent on Activities

On average, participants spent 9.0 hours on activities per week (SD 12.8). Participants with no dementia spent 10.3 hours (SD 12.7), participants with mild dementia 5.2 hours (SD 9.5), participants with moderate dementia 9.2 hours (SD 14.1), and participants with severe dementia 9.9 hours (SD 13.1) per week on activities. There was no significant association between pain or NPS and time spent on activities (Table 2). No significant associations were found in the univariate linear regression models.

Participation per Type of Activity

In total, 240 participants (83.0%) participated in social, 136 (47.1%) in cognitive, 142 (49.3%) in physical activities, and 39 participants (13.5%) did not engage in any type of activity (Table 1). Participation per type of activity appears to be roughly similar across dementia severity. Only participants without dementia showed a higher participation rate in cognitive activities (66.7%). The group with severe dementia had the relatively smallest proportion of participants who did not engage in any activity (10.4%) (Supplementary Figure 1).

Women were more likely to participate in social activities (OR, 3.395; 95% CI, 1.406–8.199), and more likely to participate in no activity (OR, 3.958; 95% CI, 1.510–10.375). Married participants were less likely to participate in cognitive activities (OR, 0.036; 95% CI, 0.166–0.939). The MOBID-2 total score and NPI-NH clusters were not significantly associated with participation in any type of activity, except for the mood cluster, which was positively associated with more cognitive activities (OR, 1.073; 95% CI, 1.003–1.148) (Table 3). Univariate models of individual NPI-NH items (Supplementary Tables 1–4) showed that, in addition, apathy (OR, 0.884; 95% CI, 0.786–0.995) and lack of inhibition (OR, 0.904; 95% CI, 0.820–0.996) were significantly associated with a lower likelihood of participating in social activities. The same applies to no participation in activities (apathy OR, 0.880; 95% CI, 0.778–0.995; lack of inhibition OR, 0.894; 95% CI, 0.806–0.992).

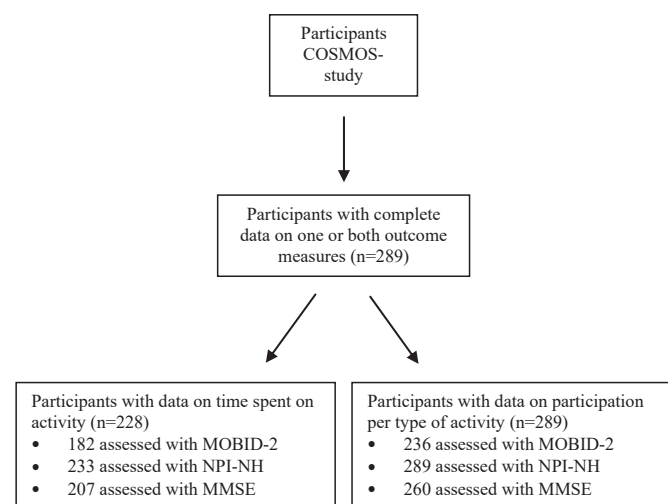


Fig. 1. Flowchart of the included sample in this article. Participants were, first, included according to available activity data (time spent on activity and participation per type of activity; ie, social, cognitive, and physical activity). Subsequently the figure shows how many participants of this sample had available data on the MOBID-2, NPI-NH, and MMSE.

Table 2
Multivariate Linear Regression; Association With Pain or NPSs and Time Spent on Activities at Baseline

Dependent Variable	Independent Variable	Coef.* (B)	Coef. [†] (B)	P [‡]	95% CI [§]	95% CI
Total hours spent on activities per week (n = 149)	Age	0.002	1.002	.649	−0.007 to 0.011	0.984 to 1.026
	Sex (female)	−0.007	0.984	.926	−0.163 to 0.148	0.687 to 1.406
	Marital status (married)	0.023	1.054	.791	−0.147 to 0.192	0.713 to 1.556
	MMSE total score	0.006	1.014	.240	−0.004 to 0.015	0.991 to 1.035
	NH ward (somatic ward)	−0.179	0.662	.020	−0.330 to −0.028	0.468 to .938
	MOBID-2 total score	−0.021	0.953	.091	−0.046 to 0.003	0.899 to 1.007
	NPI-NH Cluster 1: Agitation	−0.006	0.986	.209	−0.015 to 0.003	0.966 to 1.007
	NPI-NH Cluster 2: Apathy	−0.013	0.971	.152	−0.030 to 0.005	0.933 to 1.012
	NPI-NH Cluster 3: Psychosis	0.006	1.014	.276	−0.005 to 0.017	0.989 to 1.04
	NPI-NH Cluster 4: Affective	0.008	1.019	.209	−0.005 to 0.021	0.989 to 1.05

Analysis includes all participants with valid data on time spent on activities.

*Log-transformed coefficient (log₁₀(x + 1)).

[†]Back-transformed coefficient: 10-X.

[‡]Level of significance.

[§]Log-transformed CI (95%).

^{||}Back-transformed CI (95%): 10-X.

Sensitivity Analysis

MMSE scores were initially considered a confounding factor. However, analyses stratified to no severe dementia MMSE ≥11 (n = 154) and severe dementia MMSE ≤10 (n = 106) showed that MMSE scores also functioned as an effect modifier for some

independent variables (ie, total pain score, apathy, lack of inhibition, the apathy cluster). Initially, the total pain score was not associated with time spent on activities. However, in participants with severe dementia, higher total pain scores were significantly associated with less time spent on activities (estimate 0.897; 95% CI, 0.809–0.998). Furthermore, stratified analyses showed that the association between

Table 3
Multivariate Binary Logistic Regression Model for Participation per Type of Activity

Dependent Variable	Independent Variable	OR	95% CI	P
Social activities (n = 196)	Age	0.997	0.943–1.053	.907
	Sex (female)	3.395	1.406–8.199	.007
	Marital status (married)	0.684	0.268–1.746	.427
	MMSE total score	1.027	0.966–1.092	.390
	NH ward (somatic ward)	0.473	0.171–1.307	.149
	MOBID-2 total score	0.952	0.818–1.109	.532
	NPI-NH Cluster 1: Agitation	0.993	0.938–1.052	.814
	NPI-NH Cluster 2: Apathy	0.975	0.875–1.086	.640
	NPI-NH Cluster 3: Psychosis	1.008	0.944–1.078	.806
	NPI-NH Cluster 4: Affective	0.967	0.894–1.046	.400
	Cognitive activities (n = 196)	Age	1.003	0.960–1.047
Sex (female)		1.395	0.665–2.925	.378
Marital status (married)		0.395	0.166–.939	.036
MMSE total score		1.031	0.983–1.080	.211
NH ward (somatic ward)		0.686	0.337–1.399	.301
MOBID-2 total score		1.060	0.941–1.194	.335
NPI-NH Cluster 1: Agitation		0.969	0.924–1.017	.205
NPI-NH Cluster 2: Apathy		0.927	0.848–1.013	.094
NPI-NH Cluster 3: Psychosis		1.015	0.962–1.070	.596
NPI-NH Cluster 4: Affective		1.073	1.003–1.148	.039
Physical activities (n = 195)		Age	1.016	0.973–1.061
	Sex (female)	1.390	0.668–2.895	.379
	Marital status (married)	1.194	0.532–2.679	.668
	MMSE total score	1.022	0.975–1.070	.370
	NH ward (somatic ward)	0.334	0.160–.694	.003
	MOBID-2 total score	1.002	0.892–1.126	.974
	NPI-NH Cluster 1: Agitation	0.974	0.930–1.020	.268
	NPI-NH Cluster 2: Apathy	0.928	0.849–1.015	.100
	NPI-NH Cluster 3: Psychosis	0.998	0.945–1.053	.938
	NPI-NH Cluster 4: Affective	1.053	0.986–1.124	.125
	No activities (n = 195)	Age	0.979	0.917–1.046
Sex (female)		3.958	1.510–10.375	.005
Marital status (married)		0.978	0.489–1.956	.951
MMSE total score		0.989	0.923–1.060	.761
NH ward (somatic ward)		0.611	0.194–1.927	.401
MOBID-2 total score		1.019	0.856–1.212	.834
NPI-NH Cluster 1: Agitation		1.010	0.943–1.083	.770
NPI-NH Cluster 2: Apathy		0.947	0.844–1.062	.352
NPI-NH Cluster 3: Psychosis		0.993	0.923–1.068	.842
NPI-NH Cluster 4: Affective		0.967	0.885–1.057	.464

Analyses included all participants with valid data on participation per type of activity.

apathy and social activities (OR, 0.818; 95% CI, 0.712–0.940), apathy and physical activities (OR, 0.828; 95% CI, 0.708–0.970), and apathy and no activities (OR, 0.853; 95% CI, 0.740–0.982) was only significant in participants with no severe dementia. The association between lack of inhibition and social activities was only significant in participants with severe dementia (OR, 0.867; 95% CI, 0.756–0.995). The apathy cluster was not associated with participation in activities in the original analyses. Stratified analyses, however, found that higher severity of symptoms in the apathy cluster was associated with a lower likelihood of participating in physical activities (OR, 0.864; 95% CI, 0.750–0.996) and no activities (OR, 0.892; 95% CI, 0.802–0.991) only in participants with no severe dementia.

Discussion

The current study explores the pattern of provided activities as well as the associations among pain, NPSs, and participation in activities among NH residents adjusted for dementia status. We found that dementia severity was not associated with time spent engaged in activity. Furthermore, NH residents with severe dementia spent less total time on activities if they had more pain. NH residents with severe dementia experiencing lack of inhibition were also less likely to participate in social activities. Among the group without severe dementia, pain and lack of inhibition were not significantly associated with activity measures, but those having more apathy were significantly less likely to participate in social and physical activity. These results are of key importance for NH residents, as they help clinicians and other stakeholders understand why people do or do not participate in certain activities.

The first aim of the study was to describe the level of activity in people with dementia in NHs according to the severity of dementia. Previous research showed that NH residents are inactive and sedentary more than half of their day.^{27,28} Den Ouden et al²⁷ further specified time spent on activities in Dutch NHs: residents were mainly lying down (29%) or sitting (69%) during the day. Although the current study only measured activity accumulated per week, the reported average of 9.0 hours corresponds to an estimated 1 hour and 17 minutes spent engaged in activity per day. In this study, dementia severity was not significantly associated with time spent on activities. In a comparable cross-sectional analysis with 400 NH residents in the United States, Dobbs et al⁴³ did, however, find that lower activity involvement was more common in NH residents with severe dementia.

Second, this study aimed to investigate whether people with more pain or NPSs participate less in activities. Similar to the results from Lapane et al,³² the current study found a negative association between pain and time spent on activities, but only in people with severe dementia. The current study found that participants with more apathy and lack of inhibition were less likely to participate in social activities, which is not unexpected as both symptoms can influence social behavior.⁴⁴ Apathy and lack of inhibition were associated with a lower likelihood of no engagement in any type of activity. On the other hand, Dobbs et al⁴³ found that behavioral symptoms, depression, and impairment in activities of daily living were associated with lower activity involvement; these effects were, however, diminished in their adjusted model. The comparison with literature, however, needs to be put into perspective. Methods of measuring activity are often not described in depth and there is no uniform definition of activity (and types of activity).

Strengths and Limitations

This is the first study to investigate associations of pain and NPS with both time spent on activities and participation per type of activity. It is based on data in an NH setting, describing a vulnerable

population. Furthermore, the study included NHs from urban as well as rural areas in Norway, increasing the generalizability of the results. To further investigate the generalizability of the data, the included participants were compared with COSMOS participants who were not included in the current study. Except for MMSE scores and pain scores, the groups were comparable, indicating high generalizability of basic participant characteristics and the NPI-NH clusters.

The cross-sectional design of this study limits drawing any causal conclusions. As nonpharmacological interventions, such as activity, are used to manage NPSs, patients with high activity time estimations might experience less NPS. This might influence the results of the current study. There are few relevant studies that have investigated the same associations. In addition, the lack of universally accepted definitions and measures of activity complicates the comparison of literature. Moreover, the validity of staff-reported activity data has not been verified. Organizational differences (regional and international) further complicate interpretation. Last, multiple tests have been executed increasing the chance of Type I errors. Correction for multiple testing using the Bonferroni test has been considered.⁴⁵; however, as this test is criticized for its rigor, and the executed number of tests is not excessive, no correction for multiple tests has been executed. Therefore, there is a chance that some of the findings that are regarded as statistically significant, are random. Nevertheless, we do believe our findings are important and direct further research.

Conclusion and Implications

We found that NH residents spend little of their time engaged in activity per day. Also, pain and neuropsychiatric symptoms influence activity participation in this setting. People with severe dementia who suffered more pain spent less time engaged in any activity. Furthermore, apathy and lack of inhibition were associated with less engagement in social activities.

More research is required to determine how activity can be encouraged in NH residents, such as a prospective investigation of whether treating pain in advanced dementia can increase the ability to participate in meaningful activities. Especially in dementia, pain and behavioral symptoms are difficult to diagnosis and often underestimated. More research on the potential influence of pain and NPSs on activity participation is necessary. To do so properly, there is a need to develop instruments with high validity and reliability to assess and compare activity measurements across study populations and countries.

Disclosure

The authors declare no conflicts of interest.

Acknowledgments

S.H.v.d.B. thanks the Center for Elderly and Nursing Home Medicine, Department of Global Public Health and Primary Care of the University of Bergen in Norway for all their support. B.S.H. thanks the G.C. Rieber Foundation and the Norwegian Government for supporting our work at the Centre for Elderly and Nursing Home Medicine, University of Bergen, Norway.

References

- Selbæk G, Engedal K, Bergh S. The prevalence and course of neuropsychiatric symptoms in nursing home patients with dementia: a systematic review. *J Am Med Dir Assoc*. 2013;14:161–169.
- Tible OP, Riese F, Savaskan E, et al. Best practice in the management of behavioural and psychological symptoms of dementia. *Ther Adv Neurol Disord*. 2017;10:297–309.

3. Thompson C, Brodaty H, Trollor J, et al. Behavioral and psychological symptoms associated with dementia subtype and severity. *Int Psychogeriatr*. 2010;22:300–305.
4. Kales HC, Gitlin LN, Lyketsos CG. Management of neuropsychiatric symptoms of dementia in clinical settings: recommendations from a multidisciplinary expert panel. *J Am Geriatr Soc*. 2014;62:762–769.
5. Steinberg M, Shao H, Zandi P, et al. Point and 5-year period prevalence of neuropsychiatric symptoms in dementia: the Cache County Study. *Int J Geriatr Psychiatry*. 2008;23:170–177.
6. Abdulla A, Adams N, Bone M, et al. Guidance on the management of pain in older people. *Age Ageing*. 2013;42(Suppl 1):i1–i57.
7. Husebo BS, Strand LI, Moe-Nilssen R, et al. Who suffers most? Dementia and pain in nursing home patients: a cross-sectional study. *J Am Med Dir Assoc*. 2008;9:427–433.
8. Achterberg W, Lautenbacher S, Husebo B, et al. Pain in dementia. *Pain Rep*. 2020;5:e803.
9. Osmancevic S, Bauer S. Pain and its associated factors in nursing home residents. *Geriatr Nurs*. 2022;47:13–17.
10. Raja SN, Carr DB, Cohen M, et al. The revised International Association for the Study of Pain definition of pain: concepts, challenges, and compromises. *Pain*. 2020;161:1976–1982.
11. Gaugler JE, Yu F, Krichbaum K, et al. Predictors of nursing home admission for persons with dementia. *Med Care*. 2009;47:191–198.
12. Corbett A, Husebo B, Malcangio M, et al. Assessment and treatment of pain in people with dementia. *Nat Rev Neurol*. 2012;8:264–274.
13. van Kooten J, van der Wouden JC, Sikkes SAM, et al. Pain, neuropsychiatric symptoms, and quality of life of nursing home residents with advanced dementia in The Netherlands: a cross-sectional study. *Alzheimer Dis Assoc Disord*. 2017;31:315–321.
14. Resnick B, Galik E, Kolanowski A, et al. The relationship between pain, function, behavioral, and psychological symptoms of dementia and quality of life. *Pain Manag Nurs*. 2022;23:55–61.
15. Allen JE. *Nursing Home Federal Requirements: Guidelines to Surveyors and Survey Protocols*. Springer Publishing Company; 2014.
16. Smit D, de Lange J, Willemse B, et al. Activity involvement and quality of life of people at different stages of dementia in long term care facilities. *Aging Ment Health*. 2016;20:100–109.
17. Jing W, Willis R, Feng Z. Factors influencing quality of life of elderly people with dementia and care implications: a systematic review. *Arch Gerontol Geriatr*. 2016;66:23–41.
18. Orgeta V, Qazi A, Spector AE, et al. Psychological treatments for depression and anxiety in dementia and mild cognitive impairment. *Cochrane Database Syst Rev*. 2014;2014:Cd009125.
19. McDermott O, Charlesworth G, Hogervorst E, et al. Psychosocial interventions for people with dementia: a synthesis of systematic reviews. *Aging Ment Health*. 2019;23:393–403.
20. Nuzum H, Stickel A, Corona M, et al. Potential Benefits of physical activity in MCI and dementia. *Behav Neurol*. 2020;2020:7807856.
21. Groot C, Hooghiemstra AM, Raijmakers PG, et al. The effect of physical activity on cognitive function in patients with dementia: a meta-analysis of randomized control trials. *Ageing Res Rev*. 2016;25:13–23.
22. Lam FM, Huang MZ, Liao LR, et al. Physical exercise improves strength, balance, mobility, and endurance in people with cognitive impairment and dementia: a systematic review. *J Physiother*. 2018;64:4–15.
23. Europe A. National dementia Strategies: Norway; 2020. Accessed April 27, 2022. <https://www.alzheimer-europe.org/policy/national-dementia-strategies/norway>
24. de Souto Barreto P, Morley JE, Chodzko-Zajko W, et al. Recommendations on physical activity and exercise for older adults living in long-term care facilities: a taskforce report. *J Am Med Dir Assoc*. 2016;17:381–392.
25. Clare L, Rowlands J, Bruce E, et al. The experience of living with dementia in residential care: an interpretative phenomenological analysis. *Gerontol*. 2008;48:711–720.
26. Edvardsson D, Petersson L, Sjogren K, et al. Everyday activities for people with dementia in residential aged care: associations with person-centredness and quality of life. *Int J Older People Nurs*. 2014;9:269–276.
27. den Ouden M, Bleijlevens MH, Meijers JM, et al. Daily (In)Activities of nursing home residents in their wards: an observation study. *J Am Med Dir Assoc*. 2015;16:963–968.
28. Ice GH. Daily life in a nursing home: has it changed in 25 years? *J Aging Stud*. 2002;16:345–359.
29. Stubbs B, Eggermont L, Soundy A, et al. What are the factors associated with physical activity (PA) participation in community dwelling adults with dementia? A systematic review of PA correlates. *Arch Gerontol Geriatr*. 2014;59:195–203.
30. Cheng ST. Cognitive reserve and the prevention of dementia: the role of physical and cognitive activities. *Curr Psychiatry Rep*. 2016;18:85.
31. van der Leeuw G, Eggermont LH, Shi L, et al. Pain and cognitive function among older adults living in the community. *J Gerontol A Biol Sci Med Sci*. 2016;71:398–405.
32. Lapane KL, Quilliam BJ, Chow W, et al. The association between pain and measures of well-being among nursing home residents. *J Am Med Dir Assoc*. 2012;13:344–349.
33. Zancocci M, Maero B, Nicola E, et al. Chronic pain in a sample of nursing home residents: prevalence, characteristics, influence on quality of life (QoL). *Arch Gerontol Geriatr*. 2008;47:121–128.
34. Husebo BS, Flo E, Aarmland D, et al. COSMOS—improving the quality of life in nursing home patients: protocol for an effectiveness-implementation cluster randomized clinical hybrid trial. *Implement Sci*. 2015;10:131.
35. Selbaek G, Kirkevold O, Sommer OH, et al. The reliability and validity of the Norwegian version of the Neuropsychiatric Inventory, nursing home version (NPI-NH). *Int Psychogeriatr*. 2008;20:375–382.
36. C.J.L. Neuropsychiatric Inventory Nursing Home Version (NPI-NH): Comprehensive Assessment of Psychopathology in Patients with Dementia Residing in. *Nursing Homes*. 2009:npITEST.
37. Bergh S, Holmen J, Saltvedt I, et al. Dementia and neuropsychiatric symptoms in nursing-home patients in Nord-Trøndelag County. *Tidsskr Nor Laegeforen*. 2012;132:1956–1959.
38. Husebo BS, Strand LI, Moe-Nilssen R, et al. Mobilization-Observation-Behavior-Intensity-Dementia Pain Scale (MOBID): development and validation of a nurse-administered pain assessment tool for use in dementia. *J Pain Symptom Manage*. 2007;34:67–80.
39. Husebo BS, Ostelo R, Strand LI. The MOBID-2 pain scale: reliability and responsiveness to pain in patients with dementia. *Eur J Pain*. 2014;18:1419–1430.
40. Strobel C, Engedal K. MMSE-NR—Norsk revidert mini men-tal status evaluering. Revidert og utvidet manual, *Nasjonalkompetansenetjeneste for Aldring og Helse*. 2008:1–6.
41. Perneczky R, Wagenpfel S, Komossa K, et al. Mapping scores onto stages: mini-mental state examination and clinical dementia rating. *Am J Geriatr Psychiatry*. 2006;14:139–144.
42. West RM. Best practice in statistics: the use of log transformation. *Ann Clin Biochem*. 2022;59:162–165.
43. Dobbs D, Munn J, Zimmerman S, et al. Characteristics associated with lower activity involvement in long-term care residents with dementia. *Gerontol*. 2005;45:81–86.
44. Jenkins LM, Wang L, Rosen H, et al. A transdiagnostic review of neuroimaging studies of apathy and disinhibition in dementia. *Brain*. 2022;145:1886–1905.
45. Armstrong RA. When to use the Bonferroni correction. *Ophthalmic Physiol Opt*. 2014;34:502–508.

Supplementary Textboxes 1–3**Textbox 1. Questionnaire on Activity Administered to NH Staff**

Question	Answer Options
Have there been major changes in patient's activity offerings in the last 4 weeks?	Yes/No/Not applicable
The reason for changes?	The patient's state of health/resources/other
Other reasons for changes?	Open question
Does the patient have a customized weekly schedule with the activity?	Yes/No/Not applicable
Has the patient participated in activities involving physical exercise/movement?	Yes/No/Not applicable
Has the patient participated in activities involving thinking, memory, or reflection?	Yes/No/Not applicable
Has the patient participated in social activities?	Yes/No/Not applicable
Approximately how much time is spent weekly on activities (hours)?	X hours
Approximately how much time is spent weekly on activities (minutes)?	X minutes
Approximately how much of this time was under the auspices of relatives (hours)?	X hours
Approximately how much of this time was under the auspices of relatives (minutes)?	X minutes

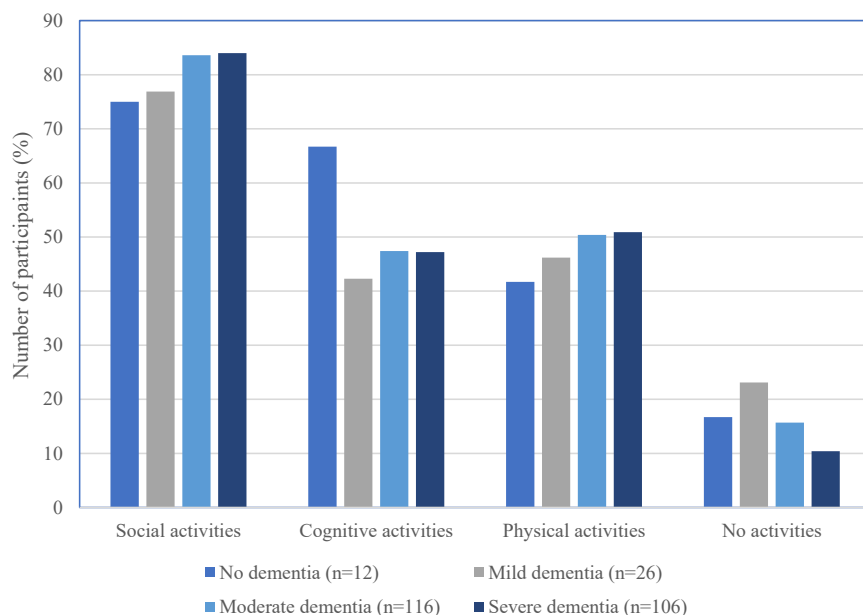
Textbox 2. Interview Questions on Time and Type of Activity–COSMOS

	Question	Answering Option
1.	Has the patient participated in activities involving physical exercise/movement?	Yes/No/Not applicable
2.	Has the patient participated in activities involving thinking, memory, or reflection?	Yes/No/Not applicable
3.	Has the patient participated in social activities?	Yes/No/Not applicable
4.	Approximately how much time is spent weekly on activities (hours)?	X (hours)
5.	Approximately how much time is spent weekly on activities (minutes)?	X (minutes)

Textbox 3. Examples of Activity Types

- Cognitive activities:
 - Group tasks (eg, memory groups)
 - Games (ie, brain teasers)
 - Charades (eg, memory therapy)
 - Occupation-/hobby-related activities with cognitive component
- Social activities:
 - Activities involving interaction with others
- Physical activities:
 - Exercise (eg, walking, exercises with physiotherapist)
 - Dance to music
 - Occupation-/hobby-related activities with physical component

Supplementary Figure 1



Supplementary Fig. 1. Participation per type of activity according to dementia severity.

Supplementary Tables 1–4

Supplementary Table 1

Univariate Binary Logistic Regression Models; Association of Pain or NPS With Participation in Social Activities at Baseline Adjusted for Age, Sex, Marital Status, MMSE Score, and NH Wards

Dependent Variable	Independent Variable	OR	95% CI	P*
Social activity	MOBID-2 Total score	0.936	0.809–1.083	.376
	MOBID-2 Dichotomous	0.798	0.368–1.729	.568
	MOBID-2 Part 1	0.691	0.307–1.556	.372
	MOBID-2 Part 2	1.492	0.666–3.346	.331
	NPI-NH Total score	0.990	0.974–1.005	.182
	NPI-NH Cluster 1: Agitation	0.980	0.946–1.015	.250
	NPI-NH Cluster 2: Apathy	0.940	0.866–1.021	.142
	NPI-NH Cluster 3: Psychosis	0.983	0.943–1.025	.426
	NPI-NH Cluster 4: Affective	0.968	0.919–1.019	.214
	NPI-NH Delusions	0.932	0.847–1.025	.147
	NPI-NH Hallucinations	0.974	0.852–1.113	.695
	NPI-NH Agitation	0.970	0.879–1.070	.543
	NPI-NH Depression	0.982	0.894–1.079	.705
	NPI-NH Anxiety	0.925	0.847–1.010	.083
	NPI-NH Exhilaration	0.992	0.807–1.221	.942
	NPI-NH Apathy	0.884	0.786–0.995	.041
	NPI-NH Lack of inhibition	0.904	0.820–0.996	.042
	NPI-NH Irritability	0.963	0.880–1.053	.404
	NPI-NH Deviating motor behavior	0.981	0.866–1.112	.766
	NPI-NH Disturbed sleep behavior	1.000	0.894–1.118	.999
NPI-NH Appetite disorder	0.992	0.851–1.157	.920	

Analyses included all participants with valid data on participation per type of activity.

*Level of significance $P \leq .05$.

Supplementary Table 2

Univariate Logistic Regression Models; Association of Pain or NPSs With Participation in Cognitive Activities at Baseline Adjusted for Age, Sex, Marital Status, MMSE Score, and NH Wards

Dependent Variable	Independent Variable	OR	95% CI	P*
Cognitive activity	MOBID-2 Total score	1.068	0.955–1.194	.248
	MOBID-2 Dichotomous	1.541	0.866–2.741	.141
	MOBID-2 Part 1	1.451	0.810–2.601	.211
	MOBID-2 Part 2	1.197	0.658–2.178	.557
	NPI-NH Total score	1.000	0.987–1.013	.977
	NPI-NH Cluster 1: Agitation	0.994	0.965–1.024	.711
	NPI-NH Cluster 2: Apathy	0.961	0.897–1.029	.252
	NPI-NH Cluster 3: Psychosis	1.009	0.974–1.044	.623
	NPI-NH Cluster 4: Affective	1.038	0.994–1.084	.089
	NPI-NH Delusions	0.999	0.924–1.079	.970
	NPI-NH Hallucinations	0.968	0.866–1.083	.570
	NPI-NH Agitation	0.985	0.910–1.065	.698
	NPI-NH Depression	1.056	0.980–1.137	.151
	NPI-NH Anxiety	1.062	0.986–1.144	.112
	NPI-NH Exhilaration	0.900	0.742–1.092	.286
	NPI-NH Apathy	0.965	0.870–1.071	.508
NPI-NH Lack of inhibition	0.985	0.904–1.073	.724	
NPI-NH Irritability	1.002	0.932–1.076	.965	
NPI-NH Deviating motor behavior	1.014	0.914–1.126	.788	
NPI-NH Disturbed sleep behavior	1.064	0.972–1.163	.177	
NPI-NH Appetite disorder	0.939	0.841–1.049	.267	

Analyses included all participants with valid data on participation per type of activity.

*Level of significance $P \leq .05$.

Supplementary Table 3

Univariate Logistic Regression Models; Association of Pain or NPSs With Participation in Physical Activities at Baseline Adjusted for Age, Sex, Marital Status, MMSE Score, and NH Wards

Dependent Variable	Independent Variable	OR	95% CI	P*
Physical activity	MOBID-2 Total score	0.984	0.881–1.099	.779
	MOBID-2 Dichotomous	0.892	0.498–1.596	.700
	MOBID-2 Part 1	0.771	0.425–1.398	.392
	MOBID-2 Part 2	0.925	0.506–1.688	.799
	NPI-NH Total score	0.995	0.982–1.008	.422
	NPI-NH Cluster 1: Agitation	0.991	0.962–1.020	.528
	NPI-NH Cluster 2: Apathy	0.935	0.871–1.004	.065
	NPI-NH Cluster 3: Psychosis	0.995	0.961–1.030	.786
	NPI-NH Cluster 4: Affective	1.014	0.972–1.058	.527
	NPI-NH Delusions	0.988	0.915–1.068	.764
	NPI-NH Hallucinations	0.912	0.807–1.030	.137
	NPI-NH Agitation	0.969	0.896–1.049	.441
	NPI-NH Depression	1.014	0.943–1.091	.707
	NPI-NH Anxiety	1.026	0.953–1.104	.498
	NPI-NH Exhilaration	0.906	0.762–1.077	.264
	NPI-NH Apathy	0.912	0.818–1.017	.097
	NPI-NH Lack of inhibition	0.966	0.887–1.053	.429
	NPI-NH Irritability	1.013	0.943–1.089	.717
	NPI-NH Deviating motor behavior	1.019	0.918–1.130	.726
NPI-NH Disturbed sleep behavior	1.022	0.936–1.116	.628	
NPI-NH Appetite disorder	0.936	0.839–1.045	.237	

Analyses included all participants with valid data on participation per type of activity.

*Level of significance $P \leq .05$.

Supplementary Table 4

Univariate Logistic Regression Models; Association of Pain or NPS With Participation in No Activities at Baseline Adjusted for Age, Sex, Marital Status, MMSE Score, and NH Wards

Dependent Variable	Independent Variable	OR	95% CI	P*
No activity	MOBID-2 Total score	0.990	0.840–1.167	.905
	MOBID-2 Dichotomous	1.051	0.449–2.457	.909
	MOBID-2 Part 1	0.865	0.350–2.139	.754
	MOBID-2 Part 2	0.967	0.420–2.228	.938
	NPI-NH Total score	0.989	0.973–1.006	.212
	NPI-NH Cluster 1: Agitation	0.980	0.943–1.018	.291
	NPI-NH Cluster 2: Apathy	0.921	0.846–1.002	.057
	NPI-NH Cluster 3: Psychosis	0.974	0.932–1.017	.234
	NPI-NH Cluster 4: Affective	0.969	0.917–1.024	.262
	NPI-NH Delusions	0.910	0.823–1.007	.067
	NPI-NH Hallucinations	0.947	0.825–1.088	.443
	NPI-NH Agitation	0.949	0.854–1.054	.324
	NPI-NH Depression	0.986	0.891–1.091	.780
	NPI-NH Anxiety	0.923	0.839–1.015	.099
	NPI-NH Exhilaration	1.145	0.791–1.657	.474
	NPI-NH Apathy	0.880	0.778–0.995	.042
	NPI-NH Lack of inhibition	0.894	0.806–0.992	.034
	NPI-NH Irritability	0.968	0.876–1.068	.513
	NPI-NH Deviating motor behavior	0.953	0.834–1.090	.484
NPI-NH Disturbed sleep behavior	1.003	0.888–1.132	.966	
NPI-NH Appetite disorder	0.939	0.811–1.088	.403	

Analyses included all participants with valid data on participation per type of activity.

*Level of significance $P \leq .05$.