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Effects of a Multidisciplinary Intervention on the Presence of Neuropsychiatric Symptoms and Psychotropic Drug Use in Nursing Home Residents WithYoung-Onset Dementia: Behavior and Evolution of Young-Onset Dementia Part 2 (BEYOND-II) Study

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ABSTRACT

Objective: *The effect of an intervention on neuropsychiatric symptoms (NPS), particularly agitation and aggression, and psychotropic drug use (PDU) in institutionalized people with young-onset dementia (YOD) was evaluated.* ***Methods:*** *A randomized controlled trial was conducted using a stepped wedge design. Thirteen YOD special care units were randomly assigned to three*

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groups, which received the intervention at different time points. Four assessments took place every 6 months during a period of 18 months. Two hundred seventy-four people with YOD who resided in YOD special care units participated, of whom 131 took part in all assessments. The intervention consisted of an educational program combined with a care program, which structured the multidisciplinary process of managing NPS. The care program included the following five steps: evaluation of psychotropic drug prescription, detection, analysis, treatment, and evaluation of treatment of NPS. The Cohen-Mansfield Agitation Inventory and the Neuropsychiatric Inventory-Nursing Home version were used to assess NPS. Data on PDU were retrieved from residents' medical files. Multilevel models were used to evaluate the effect of the intervention, which accounted for clustering of measurements in clients within units. ***Results:*** *No significant differences were found in agitation, aggression, other NPS, or PDU after crossing over to the intervention condition.* ***Conclusion:*** *We found no evidence that the intervention for management of NPS in nursing home residents with YOD was more effective in reducing agitation, aggression, other NPS, or PDU compared with care as usual.* (Am J Geriatr Psychiatry 2019; 27:581−589)

INTRODUCTION

When dementia occurs before the age of 65, this is most commonly referred to as young-onset dementia (YOD). Of the nursing home (NH) residents with YOD, 90% show one or more neuropsychiatric symptoms (NPS).[1] These high rates are troublesome given the serious negative health outcomes associated with NPS in dementia, such as loss of quality of life of the NH resident, high workload and distress of professional caregivers, and increased costs of care.[2−7] Comorbidity is less common in people with young-onset Alzheimer disease than in people with late-onset Alzheimer disease, suggesting that people with YOD are less frail.[8] As a consequence, NPS in YOD might be more severe compared with late-onset dementia (LOD) because of increased physical fitness, such as walking speed and strength. Indeed, a recent study by van Duinen-van den IJssel et al.[7] showed that NH staff caring for people with YOD experience more distress related to NPS compared with NH staff caring for people with LOD. Psychotropic drug use (PDU) is common in the management of NPS in NH residents with LOD and YOD.[9,10] PDU is associated with poor health outcomes, such as stroke, increased mortality, and reduced quality of life.[3,11,12] However, between 76.9% and 87.6% of NH residents with YOD use one or more psychotropic drugs.[4,9] Those rates are higher compared with PDU in NH residents with LOD.[9]

The high prevalence rates of NPS and PDU stress the need for the development and evaluation of nonpharmacologic interventions in YOD. To successfully manage NPS, many models emphasize that the underlying causes of NPS need to be identified and treated.[13] One of these models is the unmet needs framework, in which NPS are perceived as behaviors through which the person with dementia might indirectly communicate an underlying need.[13] Needs can be medical (e.g., physical illness, pain, and mobility), psychosocial (e.g., life habits and premorbid personality), or environmental (e.g. under/overstimulation and behavior of NH staff/other residents).[14,15] People with YOD have specific age-related care needs regarding daytime activities, social interaction, intimate relationships, and information that are often unmet.[16] With knowledge of the underlying causes of NPS, an intervention can be individualized to the specific needs of residents instead of suppressing behavior with the use of psychotropic drugs, concealing behavior through which the person with dementia might indirectly communicate an underlying need.[14,17,18]

In the current study, the effect of a multidisciplinary intervention for the management of NPS in NH residents with YOD was evaluated.[19,20] The intervention was based on the "Grip on Challenging

Behavior" care program that has been effective in the management of NPS in LOD.[19–22] The aims of the study are to 1) evaluate the effect of the intervention on the prevalence of NPS, particularly agitation and aggression, compared with care as usual; and 2) evaluate the effect of the intervention on PDU.

METHODS

This cluster randomized controlled trial is part of the Behavior and Evolution of Young-Onset Dementia Part 2 (BEYOND-II) study.[23] Process data were assessed to be able to interpret the outcomes of this randomized controlled trial.[24] The process data showed sufficient internal and external validity, allowing for further effect analyses.[24,25]

Setting and Subjects

In this study, 13 YOD special care units (SCUs)—units delivering specialized treatment and support for people with YOD—participated.[24] The YOD SCUs were recruited through NHs affiliated with the Dutch YOD Knowledge Center. Residents with a dementia diagnosis with a symptom onset before the age of 65 who resided on the YOD SCU for at least 1 month were eligible for inclusion in the study. The exclusion criteria were lack of informed consent provided by the legal representative and dementia caused by human immunodeficiency virus, traumatic brain injury, Down syndrome, Korsakoff syndrome, or Huntington disease. Diagnoses of dementia subtypes were made before inclusion according to internationally accepted criteria for diagnosing dementia subtypes and were retrieved from medical files.[26–31] Newly admitted residents were recruited at the end of the study, replacing deceased residents and residents who moved to another care unit during the study.

Intervention

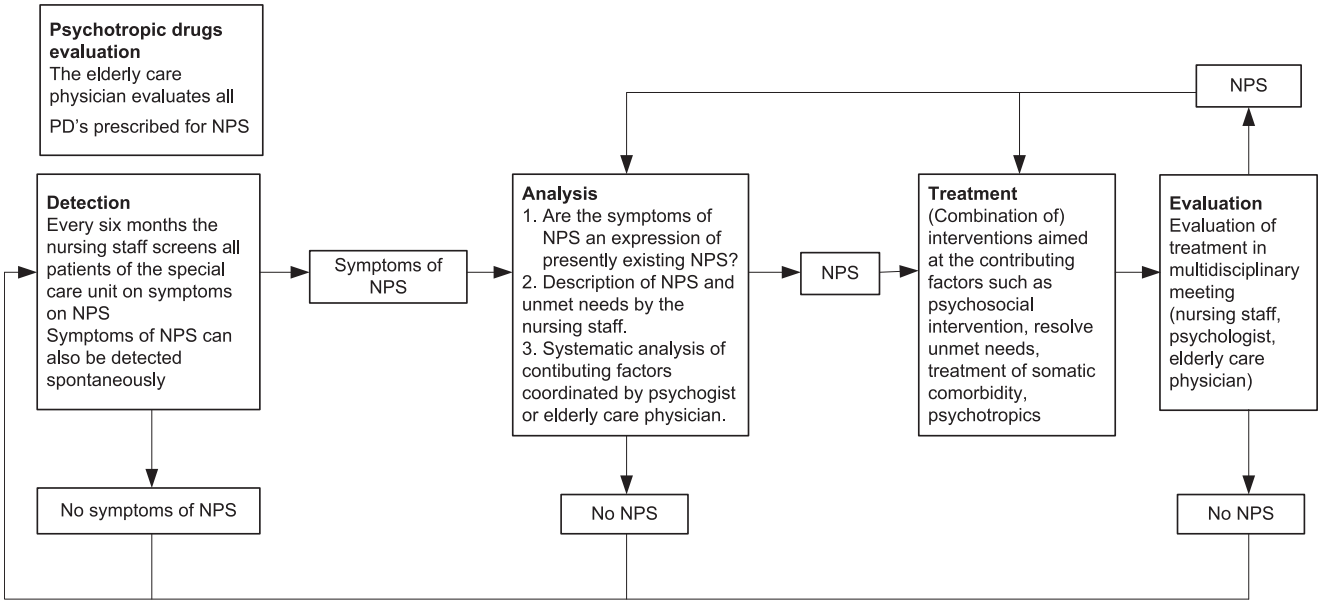
The development of the intervention "Grip on NPS in Institutionalized People with YOD" is described in detail by Zwijsen et al.[20] To increase implementation, the NH staff received an educational program that consisted of two training sessions (2.5 and 1.5 hours). In the educational program, causes and mechanisms of NPS were discussed with the NH staff, and the use and relevance of the care program were explained. After receiving the educational program, the care program on the management of NPS was implemented (Fig. 1). The care program provided guidance for the multidisciplinary team involved in the management of NPS in Dutch NHs to structure the process of detection, analysis, treatment, and evaluation of NPS. This care program consisted of five steps, which were consecutive and formed a cycle, except for the evaluation of appropriateness of psychotropic drug prescription. This separate step was a tool for the evaluation of appropriateness of psychotropic drug prescription by the elderly care physician.[32,33] The tool was performed for all residents (with or without NPS) in the first 2 months after the SCU was enrolled in the intervention condition. After the initial screening, the tool was used at the physician's own discretion. The other four consecutive steps of the care program had a circular structure (Fig. 1).

Detection of NPS occurred through usual observations of the multidisciplinary team or with the systematic use of a screening tool every 6 months by a vocational nurse. When NPS were detected, a structured analysis of possible causes of the NPS observed was conducted by the (vocational) nurse. This analysis included a tool for the detection of unmet needs possibly underling the NPS.[34] When necessary, the elderly care physician and/or the psychologist continued the analysis. After this analysis, treatment options were discussed within the multidisciplinary team, and a treatment plan was established by the elderly care physician and/or the psychologist. The care program did not prescribe a specific intervention. The choice of intervention relied on the hypothesized causes of the NPS, the preferences of the resident, and the available options in the NH. However, psychosocial treatments were preferred, with PDU only if other treatments had little or no effect. The treatment outcomes were evaluated by the multidisciplinary team, and if unsatisfactory, other treatments were considered or the analysis performed again. All tools of the care program were fully digitized and contained automatic reminders.

Design

To evaluate the effect of the intervention, a stepped wedge design was used (Table 1). This design allowed the YOD SCUs to cross over from the control

FIGURE 1. The five steps of the care program "Grip on NPS in institutionalized people with YOD."[23] Reprinted with permission. PD: psychotropic drugs. NPS: neuropsychiatric symptoms.



to the intervention condition over time, assuring that all YOD SCUs received the intervention.[35] The 13 YOD SCUs were randomly assigned to 3 groups. Every 6 months, a new group entered the intervention condition. The control condition consisted of care as usual, without the educational program and use of the care program. Four assessments took place every 6 months during a period of 18 months (September 2015 to April 2017).

Data Collection and Ethical Considerations

The BEYOND-II study protocol was approved by the Medical Ethics Committee region Arnhem/Nijmegen (file number 2015-1558) and registered in the Dutch Trial Register (ID NTR5018). This research project was conducted according to the principles of the Declaration of Helsinki, version November 2013 (www.wma.net), and in agreement with the laws regarding medical-scientific research in humans.

Written informed consent was obtained from the legal representative of each resident. After receiving informed consent, trained researchers and research assistants collected data from the residents' medical files and through structured interviews with nursing staff.

TABLE 1. Stepped Wedge Design

	Group 1	Group 2	Group 3
T0	0[a]	0	0
T1	1[b]	0	0
T2	1	1	0
T3	1	1	1

Notes: Reprinted with permission.[23] There are four twice yearly assessments, and each group consists of four or five YOD SCUs. T0: assessment 0; T1: assessment 1; T2: assessment 2; T3: assessment 3.
[a] 0 = control condition.
[b] 1 = intervention condition.

Primary Outcome

The Dutch version of the Cohen-Mansfield Agitation Inventory was used to assess agitation and aggression.[14,36] The Cohen-Mansfield Agitation Inventory (CMAI) has a well-established validity and reliability and assesses 29 agitated or aggressive behaviors.[36] The frequency of each symptom is rated on a seven-point frequency scale (range: 1–7), ranging from never to several times an hour. We used CMAI factors based on a previous study of LOD in which three factors in a large NH sample were found:

physically nonaggressive behaviors (range: 7−49), physically aggressive behaviors (range: 8−56), and verbally agitated behaviors (range: 4−28).[37]

Secondary Outcomes

To determine effects of the care program on other NPS, the Dutch version of the Neuropsychiatric Inventory-Nursing Home version (NPI-NH) was used. The NPI-NH has a high inter-rater reliability and is found to be a valid instrument for the assessment of a wide range of NPS in dementia.[38] The NPI-NH measures 12 neuropsychiatric symptoms: delusions, hallucinations, agitation/aggression, depression, anxiety, euphoria, apathy, disinhibition, irritability, aberrant motor behavior, nighttime behavior disturbances, and eating disturbances. For each symptom, a screening question is used to determine whether the symptom is present. If the symptom is present, frequency (F) and severity (S) are rated on four-point (range: 1−4) and three-point (range: 1−3) Likert scales, respectively, for each symptom. Scores for each symptom are calculated as $F \times S$ (range: 1−12). A symptom score of at least four is considered clinically relevant.[39]

PDU was derived from the NHs' pharmacists' electronic files and was classified according to the Anatomical Therapeutic Chemical classification system as antipsychotics, anxiolytics, hypnotics, antidepressants, antiepileptics, antidementia drugs, and any psychotropic medication.[40] As needed medications, which are medications not taken according to a fixed schedule but given only in the prescribed dosage if needed, were not included because it was unclear if and how often these drugs were actually used. Furthermore, antiepileptics used by residents with epilepsy were not registered as PDU.

Other Measurements

Medical and demographic data were extracted from the residents' medical files. Data on dementia subtype, age, sex, length of stay at the SCU, and date of inclusion were recorded. Dementia severity was assessed with the Global Deterioration Scale (GDS).[41] The GDS describes seven different stages of dementia on a seven-point scale (range: 1−7), ranging from "subjectively and objectively normal cognition" to "severe cognitive decline."

Process data showed that the fidelity of the intervention differed between SCUs.[24] Therefore, fidelity was conceptualized into an implementation score consisting of three components. A score was calculated for the step detection based on the number of times the step was completed with regard to the number of residents residing on the SCU (score of two if used at least once every 6 months for 75%−100% of all residents, score of one if used for 50%−74%, and score of zero if used in <50%).[24] In addition, the NH staff rated the percentages of cases with challenging behavior on which they worked according to the care program on a questionnaire (score of two if used in 75%−100% of cases, score of one if used in 50%−74%, and score of zero if used in <50%). Finally, two authors closely involved in the implementation (JCLD and BA) separately rated it based on their communication with the SCUs about its progress (range: 0−2). Disagreements were resolved by discussion. The scores on the three components were summed, resulting in a total implementation score (range: 0−6).

Statistical Analysis

All analyses were performed using SPSS 22 (IBM, Armonk, NY). Demographic variables of the NH residents at the time of enrollment in the study were described by means or proportions.

Multilevel model analyses were used to adjust for the clustering of residents in the 13 different SCUs (random effect for SCU) and the correlation of the repeated measures within the residents (random effect for resident, nested within SCU). Time and interaction of time with treatment were included as a fixed effect to model time trend (in absence of treatment) and the effect of treatment, respectively. Multilevel models were fitted with the restricted maximum likelihood method, and the 95% confidence intervals and p values of the coefficients in the model were based on Wald tests and t distributions, with Satterthwaite approximation of df. The 12 symptom scores on the NPI-NH were dichotomized into clinically relevant symptoms (symptom score: ≥4) or no clinically relevant symptoms (symptom score: <4). Data on PDU were also dichotomized (present or absent) for each category. In case of binary variables, the fit for logistic and linear mixed model logistic regression was compared by comparing the observed and predicted profiles of SCUs over time. In the case

of an equal or better fit, we used linear regression instead of logistic regression, as this allows direct interpretation in terms of change of percentage over time.

In a previous study evaluating the effect of the intervention on LOD, dementia severity and time being exposed to the intervention had an influence on the intervention effect.[21] In addition, differences in fidelity between SCUs could influence the intervention effect.[24] Therefore, to investigate whether the intervention effect was different for residents with more advanced dementia (GDS score <5 mild, score = 5 moderate, or score ≥6 severe) or residents exposed to the intervention for a longer period of time (0−6 months, 6−12 months, or 12−18 months), or for higher fidelity (implementation score), interaction effects between the intervention and these variables were investigated. In all analyses, a p value <0.05 was considered statistically significant.

RESULTS

In total, 274 NH residents with YOD participated in this study. Table 2 provides demographic and clinical characteristics of the NH residents at time of inclusion. Seventy-six residents were lost to follow-up because they moved to another care unit or died before the end of the study. Sixty-seven newly admitted residents were included after T0. Baseline data on outcome variables are presented in Table 3.

TABLE 2. Demographic and Clinical Characteristics of Nursing Home Residents at Time of Inclusion

	n (%)	Mean (SD) [Range]
Age		63.86 (5.91) [39−78]
Sex (male)	138 (50.4)	
Length of stay at SCU (months)[a]		28.65 (32.10) [1−259]
Dementia severity (GDS)[b]		
Mild (2, 3, 4)	43 (15.7)	
Moderate (5)	57 (20.8)	
Severe (6, 7)	172 (62.8)	
Dementia subtype		
Alzheimer disease	120 (43.8)	
Vascular dementia	29 (10.6)	
Frontotemporal dementia	80 (29.2)	
Mixed		
Alzheimer's/vascular	14 (5.1)	
Lewy body/Parkinson's	5 (1.8)	
Alcohol-related dementia	6 (2.2)	
Other	20 (7.3)	

Notes: n = 274. SD: standard deviation.
[a] 1 missing.
[b] 5 missing.

TABLE 3. Baseline Data on Outcome Variables at Time of Inclusion

	n (%)	Mean (SD)
CMAI factor scores		
Physically aggressive behaviors		13.02 (6.41)
Physically nonaggressive behaviors		14.86 (7.90)
Verbally agitated behaviors		8.46 (5.90)
Clinically relevant NPI-NH		Mean F × S[a] (SD)
Delusions	29 (12.8)	8.45 (2.87)
Hallucinations	29 (12.8)	6.86 (3.01)
Agitation/aggression	95 (41.9)	7.27 (2.80)
Depression	42 (18.5)	7.29 (3.08)
Anxiety	33 (14.5)	8.18 (3.02)
Euphoria	23 (10.1)	8.04 (3.14)
Apathy	93 (41.0)	8.52 (3.28)
Disinhibition	69 (30.4)	8.07 (3.00)
Irritability	84 (37.0)	7.63 (2.63)
Aberrant motor behavior	89 (39.2)	8.47 (3.30)
Nighttime behavior disturbances	37 (16.3)	7.57 (2.97)
Eating disturbances	43 (18.9)	7.56 (2.86)
PDU		
Antipsychotics	71 (31.3)	
Anxiolytics	60 (26.4)	
Hypnotics	34 (15.0)	
Antidepressants	80 (35.2)	
Antiepileptics	22 (9.7)	
Antidementia drugs	12 (5.3)	
Any psychotropic medication	152 (67.0)	

Notes: n = 227; only scores for residents included at T0, T1, or T2 who had not yet been exposed to the intervention are shown. SD: standard deviation.
[a] Mean F × S = mean frequency × severity scores of clinically relevant NPI-NH scores.

For all variables (including binary variables), linear multilevel regression models were used because these models had a better or equally good fit and, in case of binary variables, were consistent with the logistic multilevel models in terms of the predicted percentage in each of the institutions at each of the time points or better. In the face of this consistency, we chose the linear mixed model, as this has an easier interpretation of absolute difference in percentages. The analyses showed no significant effect of the intervention on physically aggressive behaviors (estimate: 0.495; p = 0.303), physically nonaggressive behaviors (estimate: −0.137; p = 0.825), or verbally agitated behaviors (estimate: −0.176; p = 0.697) (Table 4). Additionally, no effect of the intervention on other NPS or PDU was found (Table 4).

TABLE 4. Effects of Intervention on NPS and PDU

	Estimate	p	95% CI	
			Lower Bound	Upper Bound
CMAI Factor Scores				
Physically nonaggressive behaviors	−0.137	0.825	−1.358	1.074
Physically aggressive behaviors	0.495	0.303	−0.448	1.438
Verbally agitated behaviors	−0.176	0.697	−1.065	0.713
Clinically Relevant NPI-NH				
Delusions	−0.048	0.136	−0.111	0.015
Hallucinations	0.044	0.135	−0.014	0.101
Agitation/aggression	−0.001	0.975	−0.090	0.087
Depression	0.022	0.560	−0.052	0.096
Anxiety	0.034	0.318	−0.033	0.102
Euphoria	0.031	0.338	−0.033	0.095
Apathy	0.051	0.320	−0.051	0.154
Disinhibition	0.077	0.092	−0.013	0.167
Irritability	0.000	0.999	−0.087	0.087
Aberrant motor behavior	0.049	0.284	−0.041	0.139
Nighttime behavior disturbances	0.050	0.180	−0.023	0.122
Eating disturbances	0.044	0.253	−0.031	0.118
PDU				
Antipsychotics	−0.002	0.956	−0.064	0.060
Anxiolytics	−0.033	0.301	−0.095	0.029
Hypnotics	−0.021	0.459	−0.078	0.035
Antidepressants	−0.057	0.066	−0.117	0.004
Antiepileptics	0.029	0.126	−0.008	0.067
Antidementia drugs	−0.005	0.781	−0.045	0.044
Any psychotropic medication	−0.023	0.505	−0.090	0.044

Notes: Estimate (i.e., regression coefficient) from multilevel model analyses with random effect for SCU and random effect for resident nested within SCU. The p values and 95% CIs were based on Wald tests and *t* distributions, with Satterthwaite approximation of df. CI: confidence interval.

No significant interaction effects between dementia severity and fidelity and the intervention effect were found. With regard to the prevalence of delusions, a significant interaction effect for the effect of the intervention and the time a resident was exposed to the intervention was found (p = 0.024). After being exposed for a longer period of time to the intervention, it became more effective in decreasing delusions, with an estimated intervention effect of −0.06 (p = 0.056) for SCUs that worked 0−6 months with the intervention to −0.06 + 2 × −0.06 (estimated intervention effect: −0.18; p = 0.08) for SCUs that worked 12−18 months with the intervention.

DISCUSSION

To our knowledge, this is the first study to evaluate the effects of a multidisciplinary intervention on the management of NPS, particularly agitation and aggression, and PDU in NH residents with YOD. We found no evidence that the intervention was more effective in reducing agitation, aggression, other NPS, or PDU compared with care as usual.

An intervention for the management of NPS and PDU in LOD, on which our intervention was based, was able to diminish NPS and PDU.[21] An explanation for the differences in effects between the original intervention and the adapted intervention for YOD might be that all participating SCUs in our study were recruited through NHs that were affiliated with the Dutch YOD Knowledge Center. Only care organizations offering specialized care for people with YOD are affiliated with the center. Therefore, they might had already (to some degree) developed effective working methods for the management of NPS in YOD before implementation of our intervention. Indeed, the process evaluation revealed that NH staff experienced overlap between the intervention and their current working methods.[24] In addition, although most NH staff were satisfied with the overall content of the care program, some steps of the intervention (like the detection tool for monitoring PDU) were often rated as irrelevant.[24] This suggests

that users of the intervention did not expect that these steps would be more effective in diminishing NPS and PDU than care as usual in YOD SCUs. In YOD SCUs, there was possibly less need for an intervention that structured the management of NPS compared with LOD care units. The needs of one setting (LOD care units) cannot be completely generalized to another (YOD SCUs).

Despite adding a tool to the intervention for monitoring PDU, no significant decrease in PDU after implementation of the intervention was found. A possible explanation could be that the current policy that favors limiting the prescription of psychotropic drugs has already positively influenced the prescription pattern to some degree, leaving less room for improvement. Indeed, when comparing the PDU rates in our study (68.6% using at least one drug) with the rates in NH residents with YOD approximately 10 years ago (87.6% using at least one drug), the rates in our study appear considerably lower.[4]

Our results suggest that after working longer with the intervention, it became more effective in decreasing delusions. However, not even a trend toward increasing or decreasing effectiveness was found for other NPS. Therefore, we expected that this interaction effect might have been a result of multiple testing.

An important strength of this study was that we were able to include a large sample size of NH residents, resulting in sufficient study power (80% for an effect of 0.4 × standard deviation).[23] This is an advantage, especially in research on YOD, because the prevalence of NH residents with YOD is much lower compared with LOD. Some limitations of this study should also be considered. The presence of NPS was based on the observations of nurses who could not be blinded. Awareness of being in the intervention or control condition might have influenced their ratings to some degree. Furthermore, no assessment instruments are available that take into account the specific characteristics of younger individuals with dementia. Therefore, we chose to measure NPS with assessment instruments designed and validated for use in NH residents with LOD.[36,38] However, the CMAI does not extensively assess behavior associated with frontal lobe dysfunction, which might be more likely to occur in younger NH residents with dementia because of the higher prevalence of frontotemporal dementia.[1] Finally, we decided not to include as needed medications in the effect analysis because in our study we did not collect data on how often these drugs were actually used. Therefore, we could not establish the influence of the intervention on the admission of medication as needed.

CONCLUSION

We found no evidence that the intervention was more effective in reducing agitation, aggression, other NPS, or PDU compared with care as usual. The perceived overlap between the intervention and current working methods and lower PDU rates compared with approximately 10 years ago suggests that YOD SCUs had already (to some degree) developed effective working methods for structuring the management of NPS in YOD before implementation of our intervention, diminishing the intervention effect. In future studies, more research on the specific needs and context of YOD SCUs during the development phase of an intervention is important to improve the relevance and effectiveness of the intervention in this specific context.

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