

# Nursing Staff Distress Associated With Neuropsychiatric Symptoms in Young-Onset Dementia and Late-Onset Dementia

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## Original Study

# Nursing Staff Distress Associated With Neuropsychiatric Symptoms in Young-Onset Dementia and Late-Onset Dementia



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## A B S T R A C T

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 neuropsychiatric symptoms  
 long-term care

**Objective:** The aims of this study were (1) to investigate the relationship between different neuropsychiatric symptoms (NPS) and the level of distress experienced by nurses caring for residents with young-onset dementia (YOD) and (2) to compare these findings with those for nurses caring for residents with late-onset dementia (LOD).

**Design/Setting:** This is a retrospective study conducted in Dutch long-term care facilities. Data were used from the Behavior and Evolution of Young-ONset Dementia studies (BEYOND) Parts I and II and the WAAL Behavior in Dementia-II (Waalbed-II) study.

**Participants:** A total of 382 nursing home residents with YOD and 261 nursing home residents with LOD were included.

**Measurements:** The Neuropsychiatric Inventory, nursing home version, was used to assess nursing staff distress and the frequency (F) and severity (S) of NPS. Multilevel logistic regression analysis was used to investigate the relationships between nursing staff distress related to NPS and YOD and LOD care units, the  $F \times S$  score per symptom, gender, dementia subtype, and dementia severity.

**Results:** Nurses working in YOD care units rated sleep and nighttime behavior disorders, delusions, and agitation/aggression most often as highly distressing and euphoria most often as not distressing. Multivariate analyses indicated that the frequency and severity of NPS were significantly associated with staff distress in all symptoms, except for apathy. Comparison of the 2 groups of nurses demonstrated that the odds for distress related to sleep and nighttime behavior disorders were higher for nurses in YOD care units than for nurses in LOD units. For both the YOD and LOD nurses, irritability in male residents had higher impact than similar behavior in female residents.

**Conclusion:** This study provides important insight into distress related to individual NPS and the interaction with residents' characteristics. All NPS result in distress. The frequency and severity of the

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behavior is an important predictor. Sleep and nighttime behavior disorders are more likely to result in distress in YOD nurses than in LOD nurses. The amount of distress related to NPS emphasizes the urgent need for adequate management of NPS and the support of professional caregivers.

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Caring for nursing home residents with dementia can be a demanding and challenging job. In particular, the presence of neuropsychiatric symptoms (NPS) is considered burdensome for nurses.<sup>1,2</sup> For example, the burdens of NPS lead to sick days, lower quality of general health, increased workload, reduced work ability, and high burnout levels, likely leading to an increase in staff turnover.<sup>2–4</sup> NPS are common in nursing home residents with dementia, even more so in people with young-onset dementia (YOD) in whom the first symptoms develop before the age of 65.<sup>5</sup> A large Dutch study on YOD nursing home residents concluded that nearly 90% of residents displayed NPS, with agitation/aggression and apathy being the most prevalent.<sup>6</sup> Despite this high prevalence rate, research focusing on the impact of various NPS in YOD residents on nursing staff remains lacking.

Research on late-onset dementia (LOD) on this particular issue has primarily focused on the relation between aggressive behaviors and nursing staff stress. Aggression and the staff's perception of having little control over the behavior or the unpredictability of the behavior were most difficult to address.<sup>7</sup> In addition, high caregiver burden was related to aggression that was perceived as threatening, verbal abuse, excessive demands, ill-natured denials, quarrelling, and screaming.<sup>8,9</sup> Miyamoto et al. argued that in cases of aggressive behavior, nurses must manage this behavior while simultaneously protecting the other residents.<sup>8</sup> Earlier studies found associations between aggressive and hostile behavior and the male gender.<sup>10,11</sup> Furthermore, extreme agitation and aggressive behaviors appear more likely to occur in men below the age of 70.<sup>12</sup> For YOD, half of the residents are male, compared with a quarter in LOD. It is therefore likely that nurses caring for YOD residents must manage (extreme) aggressive behavior more often than nurses caring for residents with LOD.

Other NPS, such as disinhibition and irritability, are also distressing for nurses whereas apathy is most often considered the least distressing.<sup>2</sup> Disinhibition is highly prevalent in YOD.<sup>6</sup> This may be related to the prevalence of frontotemporal dementia (FTD), which is associated with disinhibition, wandering and stereotyping.<sup>13–15</sup> NPS in people with YOD may have different effects because of increased physical fitness, such as walking speed, strength, and verbal abilities and because of the more emotional effect of the disease at a relatively young age. In YOD, there may be less acceptance of the decline and the shortened life expectancy by family or staff members. Furthermore, in YOD, there is more heterogeneity in diagnoses,<sup>6</sup> and nurses may be confronted with more variation in NPS and dementia severity and be required to switch strategies and work routines, which may increase their workload, compared to nurses caring for LOD residents.

Over the past 10 years, increased attention to the specific needs of people with YOD led to the development of a national YOD care program by the Dutch YOD Knowledge Center (DKC). This resulted in the development of special care units (SCUs) with dedicated care for people with YOD.<sup>16</sup> Therefore, in the Netherlands, there is a unique opportunity to investigate YOD nursing staff distress and compare their stress with the stress levels of the LOD nursing staff.

The aims of this study were (1) to investigate the relations between different NPS and the level of distress experienced by nurses caring for YOD nursing home residents and (2) to compare these findings with the distress experienced by nurses caring for people with LOD. This comparison may help design specific interventions to increase nursing staff knowledge and skills concerning NPS and thereby reduce distress and absenteeism and increase work ability in YOD SCUs.

## Methods

### Study Design

This study used baseline data from the Behavior and Evolution of Young-onset Dementia (Beyond) Parts I<sup>14</sup> and II<sup>17</sup> studies as well as baseline data from the WAAL Behavior in Dementia-II study.<sup>18</sup> The Beyond-I study and the Waalbed-II study are descriptive studies investigating the characteristics and course of dementia and NPS in institutionalized people with YOD and people with LOD, respectively.<sup>14,18</sup> The Beyond-II study is an intervention study focused on improving the management of NPS.<sup>17</sup>

The study protocols were all reviewed and approved by the Medical Ethics Committee region Arnhem/Nijmegen. All studies were conducted according to the principles of the Declaration of Helsinki (version November 2013, [www.wma.net](http://www.wma.net)). In all 3 studies, informed consent was obtained from the first legal representative or legal guardian.

### Participants

In the Beyond-I and Beyond-II studies, YOD nursing home residents were recruited from the YOD SCUs of nursing homes affiliated with the DKC. People were included in the study if they had an established dementia diagnosis with symptom onset before the age of 65 years and had been residing in the SCU for at least 1 month. Diagnoses of dementia subtype were made according to regular criteria and retrieved from the medical files.<sup>19–24</sup> The exclusion criteria were lack of informed consent, dementia caused by human immunodeficiency virus (HIV), traumatic brain injury, Down syndrome, Korsakov syndrome, alcohol-related dementia, or Huntington disease. Some YOD SCUs participated in the Beyond-I as well as the Beyond-II study. When residents had the same gender, date of birth, and diagnosis, one of them was randomly excluded from either the Beyond-I or Beyond-II study to prevent duplication.

The LOD comparison group was selected from a historical cohort, the Waalbed-II study. Identical inclusion and exclusion criteria were applied as in the YOD group. Furthermore, residents from the LOD group were only included if they had an established symptom onset after the age of 65 or were older than 70 years at the time of institutionalization or at the time of inclusion in the Waalbed-II study. This regulation was enacted to reduce the risk of YOD residents being part of the LOD group.

### Data Collection Procedure

All data were gathered by interviews with vocational nurses specifically assigned to the resident. Trained researchers and research assistants collected the data.

### Primary Outcome

Distress was assessed using the occupational disruptiveness scale of the Dutch version of the Neuropsychiatric Inventory, Nursing Home version (NPI-NH).<sup>25–27</sup> The NPI-NH assesses 10 behavioral symptoms: delusions, hallucinations, agitation/aggression, anxiety, depression, euphoria, apathy, disinhibition, irritability, aberrant motor behavior, and 2 neurovegetative symptoms: sleep and nighttime behavior disorders and appetite and eating changes. The NPI-NH has a high

interrater reliability and is considered to be a valid measure for NPS.<sup>26</sup> The occupational disruptiveness scale assesses the increase in work, effort, time or distress related to NPS on a 6-point scale, ranging from not disruptive at all to very severely to extremely disruptive (0–5).<sup>25,27</sup> The total distress score can be calculated by totaling the 12 distress scores, range 0–60.

### Independent Variables

The NPI-NH was also used to assess the frequency (*F*) and severity (*S*) of NPS on a 4-point (1–4) and 3-point (1–3) Likert-type scale, respectively.<sup>25–27</sup> A total NPI-NH score can be calculated by multiplying *F* by *S*; the *F* × *S* scores range from 0 (symptom was absent) to 12.

The severity of dementia was assessed with the Global Deterioration Scale (GDS).<sup>28</sup> The GDS is a validated 7-point scale that describes 7 different stages of dementia ranging from no cognitive decline (1) to very severe cognitive decline (7). Stages 4 and higher are considered to represent subsequent dementia stages. The GDS is a widely used instrument and has been validated against behavioral, neuroanatomic, and neuropsychological measures.<sup>28</sup> The residents' year of first symptoms of dementia, age, gender, and dementia subtype were obtained from the medical file.

### Data Analysis

Analyses were conducted using the Statistical Package for Social Sciences, version 22.<sup>29</sup> Before analysis, data were checked for missing values, outliers, duplicates, linearity, and normality. Residents with missing scores on the NPI-NH or GDS were excluded from the analysis. Only residents with an *F* × *S* score ≥ 1 on at least one of the NPI items were included in the analysis because only then could a distress score be obtained. Demographic variables of the YOD and the LOD groups were described using means or frequencies. The distribution of distress ratings among nurses caring for YOD and LOD residents were categorized as low (score 0–1), medium (score 2–3), and high distress (score 4–5).<sup>30</sup> Mean total distress scores in the YOD and LOD groups were calculated and compared with the independent samples *t* test.

Because the distress scores were not normally distributed, a multilevel logistic model was used to compare distress related to NPS in nurses caring for YOD and nurses caring for LOD residents. For this analysis the dependent variable distress was dichotomized into no distress (0–1) and distress (2–5). Odds ratios were calculated for group (YOD/LOD), *F* × *S* score, gender, dementia severity (GDS: 2–5, 6–7), and dementia subtype (Alzheimer's disease, Vascular/Mixed and Other [comprising of FTD, Lewy body dementia, Parkinson dementia, neurosyphilis, and dementia not otherwise specified]). The multilevel model corrected for clustering of residents within nursing homes. Additional subgroup analyses were performed to explore whether the effect of the group (YOD or LOD) was different by dementia subtype, gender, *F* × *S* scores and dementia severity. Therefore, the interaction terms group\*gender, group\*dementia subtype, group\**F* × *S* score and group\*dementia severity were added to the multilevel logistic model and manually analyzed using backward selection. Only significant interactions were included in the final analysis. All analyses were 2-tailed, and a *P* value of <.05 was considered statistically significant.

## Results

### Sociodemographic Characteristics

In this study, a total of 382 residents with YOD and 261 residents with LOD were included. Approximately half of the YOD residents were male compared with nearly one-quarter of the LOD residents

**Table 1**  
Demographic and Clinical Characteristics of YOD and LOD Residents

	YOD (n = 382)	LOD (n = 261)
Resident age at inclusion		
Mean (SD)	62.7 (6.9)	84.9 (5.9)
Range	39.3–78.2	70.4–102.2
Gender, male, n (%)	193 (50.5)	59 (22.6)
Dementia subtype, n (%)		
Alzheimer's disease	41.9	43.7
Vascular dementia and mixed dementia	16.5	16.9
Frontotemporal dementia	24.6	3.1
Other	17	36.4
Dementia severity (GDS), n (%)		
Mild (2–4)	16	5.7
Moderate (5)	21.5	23.4
Severe (6)	35.9	42.9
Very severe (7)	26.7	28
NPI-NH <i>F</i> × <i>S</i> score, mean (SD)		
Delusions	6.42 (4.0)	5.10 (3.2)
Hallucinations	5.34 (3.5)	3.49 (2.1)
Agitation/aggression	6.44 (3.4)	5.23 (3.4)
Depression	5.32 (3.4)	4.45 (2.8)
Anxiety	6.77 (3.5)	5.47 (3.0)
Euphoria	5.57 (3.2)	4.31 (2.0)
Apathy	8.28 (3.4)	7.18 (3.6)
Disinhibition	6.82 (3.8)	6.06 (3.3)
Irritability	6.27 (3.2)	5.56 (3.3)
Aberrant motor behavior	8.77 (3.5)	7.55 (3.2)
Sleep and nighttime behavior disorders	6.19 (3.3)	4.96 (3.1)
Appetite and eating changes	8.05 (3.5)	6.65 (2.8)

(Table 1). The mean age of the YOD group was 62.7 years [standard deviation (SD) 6.9] and 84.9 years (SD 5.9) in the LOD group. The prevalence of Alzheimer's dementia, vascular dementia, and mixed dementia was nearly equal in both groups. However, FTD was more prevalent in YOD residents (24.6% vs 3.1%). Most residents in both groups had (very) severe dementia (GDS score 6 or higher). However, in the YOD group, more residents had mild dementia (16%) compared with the LOD group (5.7%). In YOD and LOD, the mean *F* × *S* (SD) score was highest for aberrant motor behavior [8.8 (3.5) and 7.55 (3.2)], followed by apathy at 8.28 (3.4) and 7.18 (3.6) and appetite and eating changes at 8.05 (3.5) and 6.65 (2.8). In YOD, the mean *F* × *S* score was lowest for depression at 5.32 (3.4), whereas in LOD, this was lowest for hallucinations at 3.49 (2.1).

### NPS and Distress in YOD and LOD Nursing Staff

In both YOD and LOD residents, agitation/aggression, apathy, and irritability were the most common behavioral symptoms (Table 2). All separate NPS caused medium or high distress in a larger majority of nurses caring for YOD residents (Table 2). Approximately 45% of the nurses rated sleep and nighttime behavior disorders, agitation/aggression, and delusions as highly distressing, and a nearly equal percentage rated these behaviors to be medium distressing. Euphoria was most often rated as not distressing. However, more than half of the nurses experienced some level of distress because of euphoria. Furthermore, although distress related to hallucinations was often rated as absent or minimal, a similar percentage rated hallucinations as medium distressing. All other symptoms were most often rated as medium distressing by nurses in YOD care units.

As in YOD, all symptoms cause distress in LOD. However, for all symptoms, the absolute rates of high distress are lower for LOD, and the rates of no/low distress are higher for LOD. When distress was experienced, it was for all symptoms most often rated as medium distressing. More than half of the nurses caring for LOD residents rated anxiety, irritability, and appetite and eating changes to be medium distressing. More than half of the nurses experienced no/low distress related to hallucinations, euphoria, and apathy. Comparison of the

**Table 2**  
Prevalence of Individual NPS in YOD and LOD Residents and Corresponding Distribution (Percentages) of Nursing Staff Distress

Symptoms	n (%)	No/Low Distress, %	Medium Distress, %	High Distress, %
Delusions				
YOD	59 (15.4)	16.9	39	44.1
LOD	49 (18.8)	30.6	38.8	30.6
Hallucinations				
YOD	56 (14.7)	41.1	42.9	16.1
LOD	39 (14.9)	53.8	33.3	12.8
Agitation and aggression				
YOD	201 (52.6)	10.9	44.8	44.3
LOD	111 (42.5)	25.2	46.8	27.9
Depression				
YOD	117 (30.7)	21.4	49.6	29.1
LOD	74 (28.4)	36.5	47.3	16.2
Anxiety				
YOD	84 (22)	15.5	51.2	33.3
LOD	70 (26.8)	20	58.6	21.4
Euphoria				
YOD	61 (16)	45.9	41	13.1
LOD	16 (6.1)	62.5	31.3	6.3
Apathy				
YOD	200 (52.5)	36	49	15
LOD	92 (35.2)	51.2	41.3	7.6
Disinhibition				
YOD	136 (35.7)	22.1	38.2	39.7
LOD	49 (18.8)	30.6	44.9	24.5
Irritability				
YOD	193 (50.6)	14	54.9	31.1
LOD	105 (40.2)	22.9	51.4	25.7
Aberrant motor behavior				
YOD	161 (42.3)	29.2	40.4	30.4
LOD	73 (28)	42.5	37	20.5
Sleep and nighttime behavior disorders				
YOD	74 (19.4)	10.8	43.2	45.9
LOD	52 (19.9)	36.5	36.5	26.9
Appetite and eating changes				
YOD	76 (19.9)	13.2	52.6	34.2
LOD	55 (21.1)	25.5	61.8	12.7

mean total distress between YOD and LOD nursing staff indicated that nurses caring for YOD residents experienced significantly [ $t(608.236) = 5.157, P = .0001$ ] more distress ( $M = 10.0, SD = 8.6$ ) than nurses caring for LOD residents ( $M = 6.8, SD = 7.4$ ).

**Table 3**  
ORs and 95% CIs of the Relationship Between the Independent Variables and Distress of the Individual Neuropsychiatric Symptoms

	Delusions	Hallucinations	Agitation/Aggression	Depression	Anxiety	Euphoria
	OR (95% CI)	OR (95% CI)				
Group (ref: LOD)	2.30 (0.50-10.69)	0.92 (0.24-3.54)	1.49 (0.72-3.08)	2.38 (0.95-5.98)	1.03 (0.38-2.75)	1.06 (0.20-5.76)
F × S score	<b>1.47 (1.16-1.86)</b>	<b>1.40 (1.15-1.7)</b>	<b>1.55 (1.34-1.80)</b>	<b>1.45 (1.23-1.72)</b>	<b>1.38 (1.15-1.64)</b>	<b>1.56 (1.19-2.03)</b>
Gender (ref: female)	0.74 (0.22-2.46)	1.43 (0.51-3.99)	1.53 (0.73-3.23)	0.49 (0.21-1.11)	1.06 (0.34-3.24)	1.23 (0.33-4.60)
Dementia severity (ref: 6-7)	0.52 (0.14-1.97)	0.72 (0.15-3.46)	1.41 (0.67-2.96)	0.63 (0.30-1.36)	1.61 (0.51-5.11)	0.64 (0.17-2.39)
Dementia subtype (ref: AD)						
Vasc./mixed	1.65 (0.19-14.56)	0.89 (0.21-3.79)	1.23 (0.47-3.23)	1.47 (0.55-3.91)	0.96 (0.27-3.37)	0.24 (0.04-1.58)
Other	0.64 (0.18-2.25)	0.61 (0.18-2.05)	0.63 (0.29-1.34)	1.11 (0.47-2.65)	0.54 (0.19-1.51)	2.03 (0.52-7.98)
	Apathy	Disinhibition	Irritability	Aberrant Motor Behavior	Sleep and Nighttime Behavior Disorders	Appetite and Eating Changes
	OR (95% CI)	OR (95% CI)				
Group (ref: LOD)	1.34 (0.58-3.10)	1.37 (0.57-3.29)	0.98 (0.38-2.49)	1.49 (0.61-3.64)	<b>3.93 (1.37-11.3)</b>	1.81 (0.58-5.60)
F × S score	1.02 (0.94-1.11)	<b>1.55 (1.32-1.82)</b>	<b>1.59 (1.34-1.87)</b>	<b>1.30 (1.18-1.43)</b>	<b>1.56 (1.24-1.95)</b>	<b>1.36 (1.13-1.63)</b>
Gender (ref: female)	1.06 (0.62-1.82)	1.02 (0.46-2.29)	<b>2.57 (1.15-5.76)</b>	0.82 (0.42-1.60)	0.95 (0.33-2.71)	1.92 (0.56-6.64)
Dementia severity (ref: 6-7)	1.07 (0.55-2.12)	1.14 (0.49-2.62)	1.36 (0.62-3.01)	0.61 (0.29-1.30)	0.96 (0.30-3.04)	0.67 (0.24-1.82)
Dementia subtype (ref: AD)						
Vasc./Mixed	0.67 (0.31-1.45)	0.75 (0.24-2.33)	0.50 (0.19-1.33)	0.86 (0.31-2.39)	1.86 (0.44-7.83)	0.55 (0.12-2.48)
Other	1.20 (0.68-2.11)	1.22 (0.49-3.01)	0.60 (0.25-1.42)	1.41 (0.70-2.85)	1.49 (0.44-7.83)	0.41 (0.12-1.34)

AD, Alzheimer's disease; Vasc., vascular dementia. Bold indicates significant result with  $P < .05$ .

The multilevel logistic regression analyses (Table 3) indicated that the odds of experiencing distress related to sleep and nighttime behavior disorders was significantly higher for the YOD nursing staff than for the LOD nursing staff [sleep and nighttime behavior disorders odds ratio (OR): 3.93, 95% confidence interval (CI): 1.37-11.3;  $P = .012$ ]. For all other symptoms, no significant differences were found between YOD and LOD nursing staff.

Our analysis also indicated that after controlling for group (YOD vs LOD), gender, dementia subtype, and dementia severity, for every 1-point increase in the F × S score, nurses were more likely to experience distress. This was found for all symptoms with the exception of apathy (Table 3). The OR was lowest for aberrant motor behavior (OR: 1.30, 95% CI: 1.18-1.43;  $P = .0001$ ) and highest for irritability (OR: 1.59, 95% CI: 1.34-1.87,  $P = .0001$ ).

Additionally, in this model we found an association between gender and distress related to irritability (OR: 2.57, 95% CI: 1.15 - 5.76;  $P = .022$ ). In both groups of nurses, the odds of experiencing distress related to irritability increased when male residents were compared with female residents. No significant effects were identified between dementia severity and distress and dementia subtype and distress.

Additional subgroup analysis (not shown) revealed no interaction effects between group and gender, dementia subtype, dementia severity, and F × S score.

## Discussion

This study is the first to address nursing staff distress related to NPS in YOD and to compare these figures with the LOD nursing staff. We found that all NPS affect nurses caring for YOD residents as well as nurses caring for LOD residents. Most YOD nurses experienced medium or high levels of distress for all symptoms, which indicates that according to the NPI-NH, NPS are quite disruptive and upsetting to staff and a major time infringement.<sup>25,27</sup> LOD nurses also experienced distress related to all different symptoms, although they less often appeared to experience high levels of distress. In both YOD and LOD residents, sleep and nighttime behavior disorders, agitation/aggression, and delusions were the most distressing NPS. In YOD, these symptoms were most often rated as highly distressing by nurses, whereas in LOD these symptoms were most often rated as medium distressing. Consistent with earlier studies, we found that agitation/aggression and sleep and nighttime behavior disorders in

particular appeared to cause distress in nurses.<sup>2,8,9</sup> Sleep and nighttime behavior disorders and delusions, although in our sample relatively low in prevalence rate, caused high levels of distress in YOD nurses. Matsumoto et al. concluded that even if the frequency and severity of symptoms were low, they nevertheless caused substantial distress.<sup>31</sup>

Consistent with earlier studies, we found that the likelihood of experiencing distress increased when the frequency and/or severity of NPS increased.<sup>2</sup> We did not identify a relation between the  $F \times S$  score for apathy and the corresponding distress score, despite the high prevalence of apathy and high mean apathy scores in both groups. Zwijsen et al. argued that apathy most likely does not distress nurses.<sup>2</sup> Indeed, it is likely that nurses are not required to intervene or change their work routines because of apathy in residents. However, it is possible that apathy influences the quality of life of the resident. A recent study related apathy in YOD to a lower quality of life.<sup>32</sup> Other researchers found that the relationship between apathy in people with dementia and quality of life depended on the level of cognitive functioning and only was associated with quality of life in nursing home residents with better cognitive functioning.<sup>33,34</sup> This suggests that health care professionals should evaluate for each case individually whether or not a person with dementia experiences a lower quality of life as a result of apathy.

We found that distress related to sleep and nighttime behavior disorders was specifically dependent on YOD or LOD, after correction for other factors. The NPI-NH subscale Sleep and Nighttime Behavior Disorders assesses behaviors such as wandering, pacing, waking up too early, and going to other rooms.<sup>25,27,30</sup> From a clinical perspective, people with YOD are more physically fit and are more often able to get out of bed compared with people with LOD. Therefore, nighttime behavior in YOD may be more disturbing to the social environment. In most nursing homes, only a few nurses work during the evening and night; consequently, managing this behavior requires changing their work routine and can be time-consuming and therefore particularly burdensome for nurses. Multivariate analysis in our study did not show differences in nursing staff distress related to agitation/aggression between nurses caring for either YOD or LOD residents. This is surprising, given the fact that health care professionals in clinical practice report that being hit by a young person is perceived differently than being hit by an older person, probably because younger people are more vital and strong. Maybe not the younger age per se but the physical characteristics of the younger person might be more important such as strength, vitality, mobility, and body size of the person with dementia. Future research should take this into account.

The likelihood of experiencing irritability as distressing was higher when presenting in males than in females. This is partially consistent with a study in which residents' irritability was found to be distressing for nurses,<sup>2</sup> and a study associating irritability in community-dwelling people with dementia with informal caregiver distress.<sup>31</sup> However, those studies did not discriminate by gender. One study on LOD found that males became annoyed more easily than females although that study did not investigate nursing staff burden.<sup>10</sup> Future research should further investigate this phenomenon.

Our study is unique in that to our knowledge, we included the largest group of institutionalized people with YOD and their nurses and directly compared our data with a similar LOD study sample. However, there are also some limitations that must be discussed. First, we dichotomized distress scores for statistical reasons, which results in a loss of information. Consequently, we were not able to compare nurses who rated NPS as non-, medium, or highly distressing. In addition, some NPS were displayed only by a few YOD and/or LOD residents; thus, we had to collapse groups to increase power, reducing dementia severity to only 2 groups. Furthermore, we asked the vocational nurses specifically assigned to the residents to rate the behavior and the effects of the behavior. It is possible that the degree

to which a nurse was distressed by NPS influenced the ratings of the frequency and severity of NPS. Finally, we combined 3 datasets, of which the Beyond-I and Waalbed-II studies were of the same cohort and the Beyond-II study was of a newer cohort.<sup>14,17,18</sup> This may have caused an unwanted cohort effect because in recent years, nursing homes have paid more attention to the recognition and treatment of NPS. However, because we chose multilevel analysis in which we corrected for the nursing home, we partially corrected for this.

Future research should focus on using a combination of quantitative and qualitative measurement instruments because some symptoms can be emotionally difficult to address whereas other symptoms lead to an increased workload. For deeper understanding of the emotional impact of NPS on nurses, structured interviews could be used to investigate the experiences of nurses concerning the resident's behavior. This should include the actual moment residents exhibit a certain behavior but also the period thereafter, because some behaviors can have a lasting impact. Furthermore, characteristics of the nurses should be considered. Hazelhof et al. demonstrated that distress related to NPS was also influenced by the characteristics of the nurses.<sup>1</sup> Knowledge regarding the content of distress and the influence of nurses' characteristics renders it possible to develop specific interventions aimed at decreasing distress.

## Conclusion

This explorative study illustrates the effect on nursing staff of NPS in residents with YOD. Nurses experienced distress related to NPS, and a fair number of nurses experienced high levels of distress related to agitation/aggression, delusions, and sleep and nighttime behavior disorders. Nurses on YOD care units must be better supported in addressing residents' sleep and nighttime behaviors. In addition, interventions can be developed to focus on increasing the night rest of the residents. Addressing NPS is a major portion of nurses' daily jobs, and the amount of distress related to NPS emphasizes the urgent need for adequate management of NPS and support for professional caregivers. Moreover, psychosocial interventions as treatment of NPS are mostly conducted by nurses. Distress in nurses can affect the quality of care and maybe even increase NPS in the resident. Therefore, nursing staff distress should be part of the treatment of NPS. Finally, some symptoms cause little distress in nurses, such as apathy and euphoria. However, because they can affect the quality of life of the resident, it is important to be aware of the signs of these NPS.

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