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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

Keywords:

Nursing staff
 distress
 young-onset dementia
 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

This study was funded by the Netherlands Organization for Health Research and Development (ZonMW, no. 733050402), the Archipel Care Group in the Netherlands, the Florence Care Group in the Netherlands, the Dutch YOD Knowledge Center, and the Dutch Alzheimer Society.

The authors declare no conflicts of interest.

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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.^{1,2} 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.^{2–4} 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 65.⁵ 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.⁶ 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.⁷ In addition, high caregiver burden was related to aggression that was perceived as threatening, verbal abuse, excessive demands, ill-natured denials, quarrelling, and screaming.^{8,9} Miyamoto et al. argued that in cases of aggressive behavior, nurses must manage this behavior while simultaneously protecting the other residents.⁸ Earlier studies found associations between aggressive and hostile behavior and the male gender.^{10,11} Furthermore, extreme agitation and aggressive behaviors appear more likely to occur in men below the age of 70.¹² 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.² Disinhibition is highly prevalent in YOD.⁶ This may be related to the prevalence of frontotemporal dementia (FTD), which is associated with disinhibition, wandering and stereotyping.^{13–15} 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,⁶ 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.¹⁶ 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 I¹⁴ and II¹⁷ studies as well as baseline data from the WAAL Behavior in Dementia-II study.¹⁸ 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.^{14,18} The Beyond-II study is an intervention study focused on improving the management of NPS.¹⁷

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). 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.^{19–24} 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).^{25–27} 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

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