

**Original Article**

# Staff Distress Improves by Treating Pain in Nursing Home Patients With Dementia: Results From a Cluster-Randomized Controlled Trial

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**Abstract**

**Context.** Most people with dementia develop neuropsychiatric symptoms (NPSs), which are distressing for their carers. Untreated pain may increase the prevalence and severity of NPSs and thereby staff burden.

**Objectives.** We investigated the association between NPSs and the impact of individual pain treatment on distress in nursing home staff.

**Methods.** Nursing home (NH) units were cluster-randomized to an intervention group (33 NH units;  $n = 175$ ) or control group (27 NH units;  $n = 177$ ). Patients in the intervention group received individual pain treatment for eight weeks, followed by a four-week washout period; control groups received care as usual. Staff informants ( $n = 138$ ) used the Neuropsychiatric Inventory–NH version (including caregiver distress) as primary outcome to assess their own distress. Other outcomes were pain (Mobilization-Observation-Behavior-Intensity-Dementia-2 Pain Scale) and cognitive functioning (Mini–Mental State Examination).

**Results.** Using hierarchical regression analysis, all NPS items at baseline were associated with staff distress ( $P < 0.01$ ) apart from euphoria; agitation had the largest contribution ( $\beta = 0.24$ ). Using mixed models, we found significantly lower staff distress in the intervention group compared to the control group. Moreover, we also found significantly reduced distress in the control group, and there were still effects in both groups throughout the washout period.

**Conclusion.** Individual pain treatment reduced staff distress in the intervention group compared to control group especially in regard to agitation-related symptoms and apathy. Furthermore, our results indicated a multifactorial model of staff distress, in which enhanced knowledge and understanding of NPSs and pain in people with advanced dementia may play an important role. *J Pain Symptom Manage* 2016;■:■–■. © 2016 The Authors. Published by Elsevier Inc. on behalf of American Academy of Hospice and Palliative Medicine. This is an open access article under the CC BY-NC-ND license (<http://creativecommons.org/licenses/by-nc-nd/4.0/>).

**Key Words**

Staff distress, staff education, nursing home, dementia, neuropsychiatric symptoms, pain

**Introduction**

Approximately 35 million people worldwide and 10 million people in Europe suffer from dementia, a progressive and terminal condition.<sup>1</sup> During the first years

of the disease, the majority of patients live at home with their family; consequently, a vast number of people with informal caregiving responsibilities are indirectly affected by the condition.<sup>2</sup> As the dementia progresses, people lose their independence and 90%

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develop neuropsychiatric symptoms (NPSs) such as agitation, psychosis, and sleep disturbances.<sup>2,3</sup> These symptoms are distressing, not only for the patients but also for the carers, and lead to institutionalization as reflected in the nursing home (NH) population, 80% of whom have dementia.<sup>4</sup>

Distressing symptoms do not recede with NH admission, and the care for these patients is found to affect formal carers, both emotionally and physically, leading to depression, anxiety, and sleep problems.<sup>5</sup> The societal consequences are significant: burnout, sick leave, turnover, and increased economic costs.<sup>2,6,7</sup> Interestingly, only a few and mostly cross-sectional studies specifically investigate the differential effect of discrete NPSs on distress in NH staff.<sup>2,6,8,9</sup> Interviews with licensed nurses and certified nursing aides ( $n = 24$ ) demonstrated that aggression and agitation were more distressing than other NPSs such as euphoria and nonaggressive behaviors.<sup>2</sup> Results are supported by 445 formal caregivers in Japan who experienced the presence of disruptive behaviors such as aggression and screaming as most burdensome.<sup>6</sup> To handle NPSs, psychotropic drugs are often used as a first-line therapy and are prescribed to approximately 75% of people with dementia in NHs.<sup>4</sup> A placebo-controlled trial with risperidone in older people with dementia ( $N = 279$ ) demonstrated a significant reduction in NH staff distress.<sup>10</sup> Another intervention study using the cognitive enhancer memantine in people with dementia and behavioral disturbances also found supplementary amelioration of staff distress.<sup>11</sup>

Although the etiology of NPSs is largely unknown, undiagnosed, and untreated, pain may be an important trigger for the increased prevalence of NPSs<sup>12–14</sup> and is thereby, indirectly, an important concern for staff distress. Recently, our research group completed a cluster-randomized controlled trial (RCT) that included people with advanced dementia and agitation who received either individual pain treatment (intervention) or care as usual (control). Beneficial effects were found in relation to several NPSs.<sup>15–17</sup> Study results also suggested that a Hawthorne effect can be of matter because NPSs improved in both intervention and control groups, possibly related to training and staff support. Increased knowledge may empower staff to cope with difficult symptoms in contrast to being helpless witnesses of the suffering with untreated pain in patients.<sup>7,18</sup> These complex issues have not yet been addressed.

In the present study, the objectives may be divided into three stages: 1) a prestage investigating the nature of staff distress and patient symptoms, 2) the main objectives as a second stage, 3) and a third stage investigating secondary effects of the study protocol.

- 1) We aimed to investigate the association between different NPSs and level of staff distress at baseline as we hypothesized that different NPSs would not all be equally distressing to staff.
- 2) We have already shown that pain treatment reduces NPSs in NH patients and that this effect was reverted during washout.<sup>15,17</sup> Thus, the main aim of this study was to investigate if the introduction of a systematic pain treatment also had an effect on staff distress. In particular, we wished to investigate 1) whether the level of distress was reduced in the intervention as compared to control group after eight weeks of systematic pain treatment and 2) whether staff distress increased after the analgesic washout period in intervention group vs. control group. We hypothesized that introducing individual pain treatment would reduce staff distress but did not have any scientific grounds to suggest if the effect was large enough to detect change after washout.
- 3) Because both the intervention and control groups received education regarding pain, neuropsychiatric symptoms, and received training in several assessment tools, we also aimed to investigate the effect of the study intervention within both the intervention and control groups. We hypothesized that the mere participation in a study would entail positive effects also for the control group.

## Methods

This study is based on secondary data analyses from a cluster-RCT including 352 long-term care patients from 18 NHs in Western Norway. The study was conducted between October 2009 and June 2010. Participants were included from 60 NH units (1 NH unit = 1 cluster), randomized to control (27 NH units;  $n = 177$ ) or intervention (33 NH units;  $n = 175$ ). Inclusion criteria were as follows: age 65 years or more, expected survival of more than six months, advanced dementia (Mini-Mental State Examination [MMSE], score  $<20$ ), and high levels of agitation (Cohen-Mansfield Agitation Inventory score  $\geq 39$ ).

### NH Staff Participation

Primary caregivers ( $n = 138$ ) who knew the patient and had direct patient contact for at least four weeks participated as proxy raters (informants). The informants in both the intervention and control groups received a half-day specific training in clinical

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