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Original Study

Signs of Imminent Dying and Change in Symptom Intensity During Pharmacological Treatment in Dying Nursing Home Patients: A Prospective Trajectory Study

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A B S T R A C T

Objectives: To investigate whether it is possible to determine signs of imminent dying and change in pain and symptom intensity during pharmacological treatment in nursing home patients, from day perceived as dying and to day of death.
Design: Prospective, longitudinal trajectory trial.
Setting: Forty-seven nursing homes within 35 municipalities of Norway.
Participants: A total of 691 nursing home patients were followed during the first year after admission and 152 were assessed carefully in their last days of life.
Measurements: Time between admission and day of death, and symptom severity by Edmonton symptom assessment system (ESAS), pain (mobilization-observation-behavior-intensity-dementia-2), level of dementia (clinical dementia rating scale), physical function (Karnofsky performance scale), and activities of daily living (physical self-maintenance scale).
Results: Twenty-five percent died during the first year after admission. Increased fatigue (logistic regression, odds ratio [OR] 1.8, $P = .009$) and poor appetite (OR 1.2, $P = .005$) were significantly associated with being able to identify the day a person was imminently dying, which was possible in 61% of the dying (n = 82). On that day, the administration of opioids, midazolam, and anticholinergics increased significantly ($P < .001$), and was associated with amelioration of symptoms, such as pain (mixed-models linear regression, 60% vs 46%, $P < .001$), anxiety (44% vs 31%, $P < .001$), and depression (33% vs 15%, $P < .001$). However, most symptoms were still prevalent at day of death, and moderate to severe dyspnea and death rattle increased from 44% to 53% ($P = .040$) and 8% to 19% ($P < .001$), respectively. Respiratory symptoms were not associated with opioids or anticholinergics.
Conclusion: Pharmacological treatment ameliorated distressing symptoms in dying nursing home patients; however, most symptoms, including pain and dyspnea, were still common at day of death. Results emphasize critical needs for better implementation of guidelines and staff education.
Trial registration: ClinicalTrials.gov NCT01920100.

The rapidly aging population, combined with substantial urban changes in the society, makes the role of institutional care increasingly important for the dying old. Every year, approximately 20% of all dying UK citizens[1] and almost 50% of the dying Norwegian population, die in a nursing home.[2]

The authors declare no conflicts of interest.

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More than 80% of all nursing home patients have dementia, a chronic, usually progressive and incurable disease, with increased risk of neuropsychiatric symptoms and mortality.[3,4] To enhance advance care planning and end-of-life care in nursing homes, mid- and short-term prognostication[5] and pain and symptom management are key responsibilities for the clinician.[6,7] According to the newest National Institute for Health and Care Excellence (NICE) guidelines, *Care of dying adults in the last days of life*, the recognition and weighing up of factors that may indicate that someone is imminently dying are complex and underestimated.[8] Challenges are even more urgent in nursing home patients and people with dementia.[9] Mitchell et al[10] demonstrated that pneumonia, repeated episodes of fever, and eating problems increased the 6-month mortality risk in people with dementia. In the last 3 months of life, dyspnea, pain, and pressure ulcers were identified to be the most common and distressing symptoms in these individuals. However, many nursing home patients die unexpectedly and suddenly because signs and symptoms for prognostication of the imminent death are not yet established, leading to increased suffering of the individual.[11] A Dutch observational study reported that identifying a patient as terminally ill was possible only when the person died within the next 3 days.[12] Patients in this study were recognized as imminent dying by the lack of fluid and nutrition intake, general weakness, dyspnea, and somnolence. Another nursing home study found significant decrease of pain and distressing symptoms during the last 2 days of life, by retrospective observation.[13] Contrary to these findings, pain, agitation, and dyspnea were found in 6% to 71% of affected patients, in the last week and days before death.[14]

Better predictability and treatment of these symptoms may contribute to the overall end-of-life care in nursing homes, and most recent recommendations emphasized the importance of prospective studies in elderly patients and people with dementia.[15] Few studies have, however, assessed prospectively the change of pain and symptom intensity alongside pharmacological treatment, from the day when the patient was imminently dying and to the day of death.

We identified, prospectively, typical signs and symptoms prevalent on the day when the patient was imminently dying and the day of

Table 1
Measurement Tools Used in the Study

	What Does the Tool Measure?	Tool Characteristics and Psychometric Properties	Time Point for Measurement
ESAS	Pain and distressing symptoms (fatigue, drowsiness, nausea, appetite disturbances, dyspnea, depression, anxiety, and well-being)	Edmonton symptom assessment system (ESAS) evaluates subitem intensity on an 11-point Likert scale (range 0–10). Intensity is grouped as none to mild (0–2), mild to moderate (3–6), and moderate to severe (7–10).[37] ESAS has shown good psychometric properties, and has been used in dying people with dementia.[15–17]	Baseline
ESAS	Pain and distressing symptoms (fatigue, drowsiness, nausea, appetite disturbances, dyspnea, depression, anxiety, sleep, vomiting, delirium, agitation, death rattle, and constipation)	ESAS evaluates subitem intensity on an 11-point Likert scale (range 0–10). Intensity is grouped as none to mild (0–2), mild to moderate (3–6), and moderate to severe (7–10).[37] ESAS has shown good psychometric properties, and has been used in dying people with dementia.[15–17]	Day perceived as dying, day of death
CDR	Cognitive staging tool	Clinical dementia rating (CDR) consists of 5 steps (0–3) distributed as follows: no dementia (0 and 0.5), mild dementia (1), moderate dementia (2), severe dementia (3). CDR is a reliable, valid, and feasible tool, validated in the Norwegian language.[27]	Baseline
KPS	Functional performance status	Karnofsky performance status scale (KPS) is an 11-step rating scale from normal function (100), to dead (0). KPS demonstrates good psychometric properties in patients with cancer and in elderly people.[21]	Baseline, day perceived as dying
MMSE	Cognitive staging tool with 8 domains (orientation to time and place, short-term recall, attention, and calculation, long-term recall, language, repetition, and complex commands)	Mini-mental state examination (MMSE) is a 30-point questionnaire (0–30); severe impairment (0–11), moderate impairment (12–17), mild impairment (18–23), and no impairment (24–30). MMSE is widely used and demonstrates good validity and reliability.[23–26]	Baseline
MOBID-2	Pain intensity and pain location from musculoskeletal pain (Part 1), and pain from internal organs, head, and skin (Part 2)	Mobilization-observation-behavior-intensity-dementia-2 Pain Scale (MOBID-2) assesses pain intensity and pain location based on patient's pain behavior during standardized, guided movements. The 10 items are scored on a 0–10 numerical rating scale (0 = no pain, 10 = severe pain). Based on all observations, the patient's overall pain intensity is rated again on a 0–10 scale. MOBID-2 has excellent reliability, validity, and good responsiveness.[18]	Baseline, day perceived as dying day of death
PSMS	Activities of daily living are assessed by 6 domains (toileting, eating, dressing, grooming, transfer, and bathing)	Lawton and Brody physical self-maintenance scale (PSMS) has 6 domains, each scored on a scale from 1–5 (range 6–30). Increasing numbers means increasing dependence in daily functioning. Good reliability and validity, and sensitive to change in severe dementia.[19,20]	Baseline
RAI-PC	Distressing symptoms, care and treatment provided	Residents Assessment Instrument for Palliative Care (RAI-PC) consists of 8 domains (symptoms, communication, mood, functional status, preferences, social relations, spirituality, and treatments), of which we included items for mouth care, bedsores, and nutrition.[22]	Baseline, day perceived as dying, day of death