



Training nursing home staff to improve residents' end-of-life care: design and baseline findings from a randomized controlled trial

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Key summary points

Aim We present the design, intervention, baseline findings and feasibility of a randomized, controlled trial examining the effectiveness of staff training in palliative care on nursing home residents' hospitalizations and health-related quality-of-life.

Findings Most staff members participated in the training sessions and they gave good feedback. Our patient groups are fairly well balanced in their characteristics.

Message If our further trial shows patient-related benefits, we will have a well-defined model for improving palliative care in nursing homes.

Abstract

Purpose We aim to describe the design, educational intervention, baseline findings and feasibility of our training intervention. Our trial will aim to improve the residents' health-related quality of life (HRQOL) and to reduce unnecessary hospitalizations.

Methods We recruited 340 residents from 20 nursing home wards in Helsinki, and they were randomized into intervention and control groups. At baseline, all the participants were assessed for demographics, medical history, medication, HRQOL, symptoms, hospitalizations, advance care plans, and proxies' satisfaction with care. The staff in the intervention wards were offered four 4-h educational sessions on the principles of palliative care (advance care planning, the adverse effects of hospitalizations, symptom management, communication, giving support to proxies and challenging situations). The sessions were based on constructive learning methods and patient cases.

Results The mean age of residents was 84 years and 76% were women. The intervention and control groups did not differ with respect to demographics, terminal diseases, comorbidities, nutritional status, cognition or the use of palliative medication. However, the control residents were more likely to be bed-bound and to have a do-not-resuscitate order on their medical chart. Of about 180 staff members, 132 completed the educational intervention. The discussions in the training sessions were lively and the participants gave an overall rating of 4.6/5 for the education.

Conclusions We have successfully randomized nursing home wards in this trial and completed staff training with very positive feedback. If our trial shows resident-related benefits, we will have a well-defined model for improving palliative care in nursing homes. The study was registered in the Australian New Zealand Clinical Trials Registry under the intervention code: ACTRN12617001040358.

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Introduction

Developing palliative care and end-of-life care in nursing homes and assisted living facilities has become a topic of increasing interest [1, 2]. It has been suggested that enhanced advance care planning (ACP), the use of advance directives (ADs) and early communication about care preferences yield better quality end-of-life care and concordance of care with residents' preferences, and it may also decrease the incidence of hospital transfers [3, 4]. Interventions enhancing ACP and ADs have used various means such as standardized AD forms [5], external facilitators who discuss issues with residents and their proxies [6, 7], and training staff as well as residents and their surrogates in end-of-life care [8, 9].

Hospitalizations of nursing home residents are abundant even if the health benefits appear to be questionable and they are always burdensome for older residents. Among the ill-effects are delirium, the use of restraints, pressure ulcers, the use of feeding tubes and functional impairment [10–13]. Despite guidelines to the contrary, most older people living in long-term care in Finland die in hospitals and not in their own nursing homes [14].

There have been several trials examining various interventions to promote ACP. ACP seems to decrease the need for hospital care [2] and is associated with a reduction in emotional symptoms related to dying [15]. However, few studies are conducted in nursing home settings [16]. There have been randomized trials investigating how to avoid burdensome hospitalizations among nursing home residents. It is suggested in a few early controlled trials that employing nurse care practitioners [7] and staff training [5, 9, 17] may reduce the incidence of hospitalization. However, later studies have not replicated these findings [18]. The INTERACT project, the aim of which was to reduce hospital transfers, showed a clear reduction following the implementation of a quality-improvement initiative involving staff training, decision-making aids and continuing support [19]. However, these benefits were only observed in the initial feasibility study and were not replicated in the follow-up studies [20–22].

It is reported in several studies that educational interventions focusing on palliative care targeted at nursing home staff may encourage the completion of ADs, enhance discussions on end-of life care and improve staff knowledge, but most studies only report on surrogate rather than patient-related outcomes [23]. We will investigate whether an educational intervention could benefit nursing home patients with respect to their quality-of-life. In doing so, we are carrying out a cluster-randomized educational trial examining whether offering training in palliative care to staff in nursing

homes would (1) improve the residents' health-related quality of life (HRQOL), and (2) reduce burdensome hospitalizations during a 2-year follow-up period, compared to a control group in normal care. The secondary endpoints include pain, other symptoms and satisfaction among proxies. In this article, we describe the design of the study, the intervention and measures in detail, baseline findings of the residents and the feasibility and feedback for the training.

Methods

Study design and participants

This is a single-blinded cluster-randomized trial in which nursing home and assisted living facility wards in Helsinki were randomized into two groups: the staff in the intervention were offered training in palliative and end-of-life care over four afternoons, whereas the staff in the control wards would receive such training after the trial. Assisted living facilities in Finland are like traditional nursing homes offering around-the-clock nursing care but are more home-like. Both types of facility are nurse led; physicians are in a consulting role and the nurses present patients' problems to the physician as needed.

The inclusion criteria for participation were:

1. being Finnish-speaking;
2. being a permanent resident in a nursing home or assisted living facility in the city of Helsinki;
3. having at least one predefined severe disease or condition that was likely to have a less than 12-month prognosis (severe dementia, cancer, heart failure, COPD, renal failure, severe disability, other terminal disease);
4. being a volunteer and able to give informed consent; in cases of moderate to severe cognitive impairment (CDR 2–3), the consent was provided by the closest proxy.

Randomization

We screened all communal nursing home wards in Helsinki using RAI (Resident assessment instrument) measurement data from MDS (Minimum Data Set) [24]. MDS is a widely adopted international scoring system used in almost all nursing homes in Finland. We paired nursing home wards of a similar case mix and then randomly assigned one from each pair to either the intervention or control group. We used computer-generated randomly allocated numbers received by telephone from a randomization center.

Measures

Baseline information for both study groups was assessed between November 2017 and January 2018. Complementing the demographic data, we collected active diagnoses from patient records and computed Charlson comorbidity indexes [25]. The health status and probable prognosis of the residents were assessed according to the diagnoses, malnutrition and disability. We evaluated the most severe terminal condition for each participating resident. Severe dementia was assessed as a score 3 on the Clinical Dementia Rating scale (CDR) [26] and under 11 points on the Mini-Mental State Examination (MMSE) [27].

Nutritional status was determined according to the MNA (Mini-nutritional assessment) [28], and each subject was categorized as having good nutrition (24–30 points), being at risk of malnutrition (17–23.5) or being malnourished (<17). The residents' height and weight were measured and their body mass index (BMI) was calculated accordingly.

The reporting of medications used by the residents is based on the Anatomical Therapeutic Chemical (ATC) classification endorsed by the World Health organization [29]. Here, we report on those that are commonly used in palliative care: opioids N02A, paracetamol (N02BE01) selective and nonselective nonsteroidal anti-inflammatory drugs (NSAID; M01A), antipsychotics N05A, anxiolytics N05B, antiemetics and medicine used for nausea or death rattle A04A or A03A [30].

Data on earlier hospitalizations were retrieved from the residents' medical records. We report here on the proportion of those who were hospitalized during the year before the study began.

Each participant was assessed for a variety of symptoms using Edmonton symptom assessment system (ESAS) [31]. Pain was also evaluated separately on the Pain Assessment in Advanced Dementia (PAINAD)-scale [32].

We used the 15D-instrument to measure health-related quality of life (HRQOL) [33]. It evaluates 15 different dimensions of HRQOL and can be either patient reported or evaluated by means of observation. The instrument has proved capable of detecting change in nursing home settings. We omitted the dimension of sexual function in line with previous practice [34]. Psychosocial well-being (PWB) was assessed on six questions measuring the different dimensions [35]. The extent to which proxies were satisfied with care was assessed using the Satisfaction with Care at the End-of-Life in Dementia scale (SWC-EOLD) [36] presented for the proxies. The range of the scale is from 10 to 40, with higher score indicating higher satisfaction.

Research nurses were responsible for gathering the baseline information from all the assessed residents, those with limited communicative capabilities being assessed with their nurses or proxies when feasible. The research nurses were

blind to the information on random allocation. The follow-up assessments will be made at 6 and 12 months from the intervention. In addition, all use of health care services will be retrieved from medical and central records at the 24-month follow-up.

Educational intervention

Nurses and physicians in the intervention wards were given training over four afternoons that included the basics of good palliative care, advance care planning, good symptom management, communication skills, tailoring end-of-life care, supporting relatives, and confronting challenging situations in end-of-life-care. The theoretical framework for designing the intervention was based on adult learning [37], reflective learning [38], problem-based learning [39] and constructive learning [40]. The nurses and physicians in the intervention wards were sent a questionnaire regarding their learning needs and wishes before the training started. They were also asked to suggest topics for the training, and to describe the challenges associated with palliative care in their everyday work and the kind of support they received. Of the 132 staff members participating in the training, 45 responded to this pre-training questionnaire. The topics acknowledged as learning needs were “confronting patients’ and their relatives anxiety and demands” (89%), “breaking bad news” (87%), “delirium” (82%), “advance care planning” (80%), “futile treatments at the end-of-life” (80%) and “assessment and management of pain” (80%). The intervention education was constructed according to the expressed needs and wishes. We assumed that the motivation for training would be highest if the topics were relevant to the staff members.

Each session was led by a geriatrician from the study team, namely: KP, ML, JL or HF who have long experience working and doing research both in nursing homes and palliative care. Table 1 summarizes the aims, contents and methods of the intervention. We also gathered post-training feedback to help us judge its feasibility: we asked several questions concerning how they felt the intervention had succeeded, assessed on a Likert scale ranging from 1 to 5 (poor...excellent). Free-text items were also included.

Outcome measures in trial analyses

The primary outcome measures will be change in HRQOL according to 15D [33] and the number of hospital days over 24 months from baseline. Secondary outcome measures will include change in symptoms according to ESAS [31] and PAINAD [32]. We will measure the change in PWB [35]. In addition, we will count the number of hospital admissions and care transitions, report total health-care use and costs, and assess proxies' satisfaction according to SWC-EOLD [36]. Finally, we will collect data on advance care plans

Table 1 Contents of the educational intervention

Competence aims	Topics and contents	Learning methods
1st afternoon	<p>How and where do residents die? What is good palliative care?</p> <p>Means of promoting good palliative care in institutions</p> <p>When should palliative care and end-of-life care begin? Signs of approaching death</p> <p>What is ACP and how can we promote it?</p> <p>How and when should we discuss on end-of-life matters with residents and relatives?</p> <p>How do we determine whether hospital transfer is needed? Symptoms and existential challenges related to dying</p>	<p>Small groups (2–4 persons) discussing real-life patient cases and reflecting on their own experiences, feelings and attitudes</p> <p>Making challenges visible by questioning various situations in patient cases</p> <p>Providing learners with materials and extra reading</p>
2nd afternoon	<p>The management and evaluation of symptoms in EOL</p> <p>Choosing acute or palliative care. What are do-not-resuscitate (DNR) and do-not-hospitalize (DNH) orders?</p> <p>The benefits and risks of hospital transfers</p> <p>Specific acute situations: chest pain, dyspnea, stroke, falls and fractures, bleeding, convulsions, pain, delirium, rattle, fever, nausea, constipation, anxiety and fear, dehydration, and nutrition</p> <p>Who should be consulted, and how?</p> <p>Palliative vs. curative medication</p> <p>When should terminal-care decisions be made and how?</p>	<p>Initial pair discussion on the management of each symptom involving real-life patient cases: suggestions related to each symptom/situation were then summarized and discussed with the whole group</p> <p>Brain storming the pros and cons of hospital transfers</p> <p>Providing learners with materials and extra reading</p>
3rd afternoon	<p>Promoting the ACP process</p> <p>How to start a discussion about EOL care with residents and their relatives</p> <p>Discussing care preferences with residents and their loved ones, and formulating EOL treatment plans or ADs</p> <p>AD, LW, POA, DNR, DNH, EOL treatment plans</p> <p>The benefits and risks of AD</p>	<p>Presenting various standardized forms of LWs and ADs and discussing the pros and cons</p> <p>Discussing real-life cases in pairs and small groups</p> <p>Making challenges visible by questioning various situations in patient cases</p> <p>Role playing to discuss EOL with proxies in groups of three and getting feedback</p> <p>Providing learners with materials and extra reading</p>
4th afternoon	<p>Various challenges in EOL (e.g., decisions about tube feeding and intra-venous hydration, relatives' conflicting opinions about EOL, accusations from relatives, symptom management in difficult cases)</p> <p>Existential suffering, ethical dilemmas</p> <p>Acknowledging ones' own relationship with and attitudes toward death and how they affect one's decisions.</p> <p>Working in a team and promoting teamwork</p> <p>Options for consultations?</p>	<p>Discussing the participants' own challenging or thought-provoking patient cases in small groups</p> <p>Addressed topics of special interest</p> <p>Brainstorming principles of good EOL and team work</p> <p>Providing learners with materials and extra readings</p>

during the 12-month follow-up and report mortality during the follow-up period.

Statistical analysis

The power calculation was based on the 15D measure (HRQOL). The sample size was calculated on the assumption of detecting a clinically significant difference of 0.004 in 15D scores between the intervention and the control groups. With an estimated standard deviation of 0.01, a type-I error of 0.05% and 80% power, 120 patients would be needed in each group. Our power calculation hypothesized a 20% drop-out; therefore, we aimed to recruit at least 150 participants in each group.

We used the *t* test, Mann–Whitney, Chi square or Fisher exact test to make statistical comparisons between the groups. In cases of violation of the assumptions (e.g., non-normality), we used a bootstrap-type test. We assessed the normality of the variables by means of the Shapiro–Wilk *W* test. We assigned missing values for the SWC-EOLD scale by means of multiple imputation by chained equations [41] using the *ice* command in Stata [42]. Stata 15.1 (StataCorp LP, College Station, TX, USA) was used for the analysis.

Results

Our pair-matched wards had 494 residents at the start of the recruitment process on 1 September 2017. Baseline assessment was performed on the qualifying 340 residents who gave their informed consent. After randomization, our intervention group consisted of 159 and the control group of 181 residents living in 20 nursing home and assisted living facility wards. More details are given in Fig. 1.

Baseline findings

Average age of the residents was 84 years and 75% were women. There were no significant differences between the two groups in educational background, nutritional status, burden of disease, percentage of inclusion criteria diseases, MMSE, CDR, PWB or 15D.

At baseline, there were more residents with a do-not-resuscitate (DNR) order in their medical charts in the control group than in the intervention group (95.0% vs. 69.6%, $P < 0.001$). Furthermore, those in the control group were slightly less independent in terms of moving and were more likely to be bed-bound. Those in the intervention group were evaluated as experiencing slightly more pain, although there was no notable difference in the use of pain medication between the two groups: in both, 28% were on regular opioid medication and about half were on paracetamol. Earlier

hospitalizations were equally common in both groups, about one-third having been hospitalized during the previous year (see Table 2).

Feasibility of the intervention

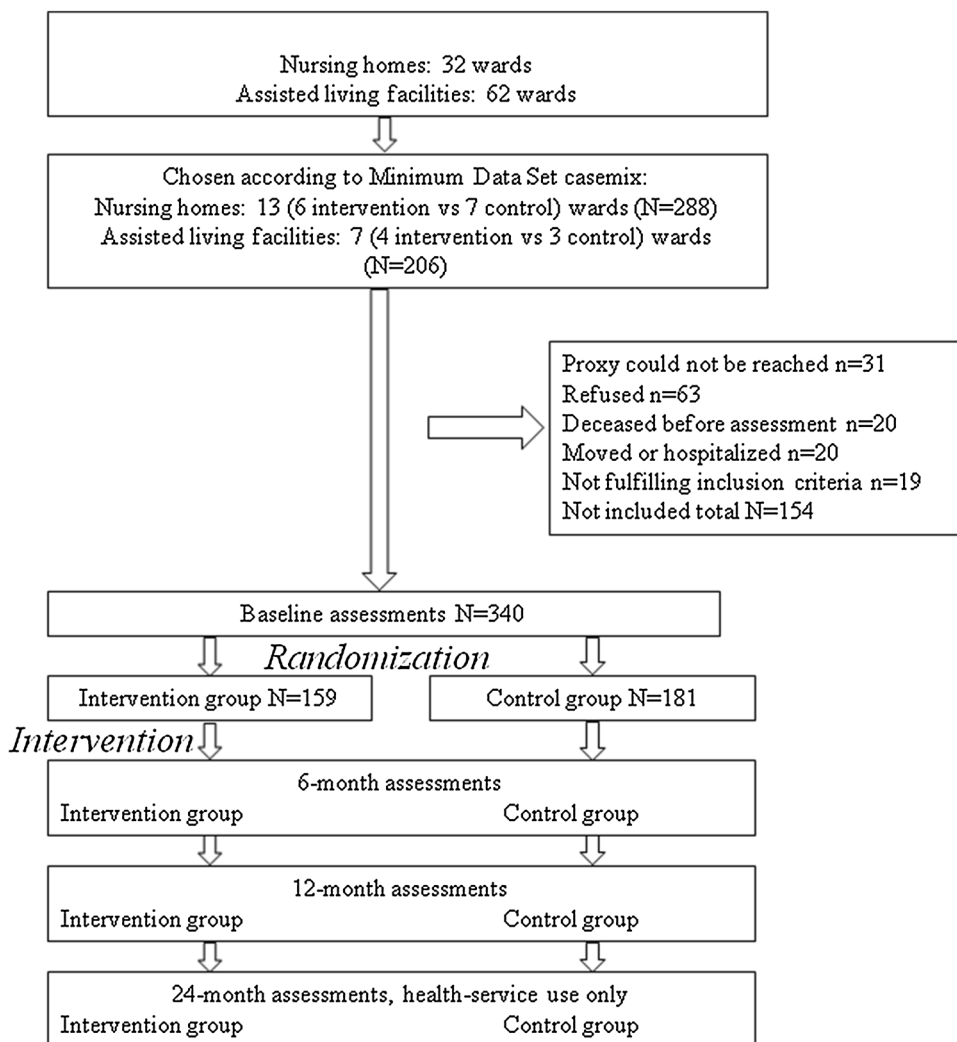
Of the total 180 estimated staff members, 132 completed the intervention training, representing 74% of the total staff, including all five physicians working in the wards. We gathered both numerical and free-text feedback from all participants after the last intervention session. Overall, the feedback was very positive (mean 4.6/5, range 3–5). This high score reflected the lively discussion and the enthusiasm the participants showed during the sessions. The free-text feedback was almost entirely positive. There were three recurring themes to which the staff attached importance in free-text comments: (1) avoiding hospital transfers, (2) promoting advance care planning and communication with relatives, and (3) practical end-of-life care and medication. The possible harmfulness of hospitalization seemed to be deeply thought-provoking and novel notion to many of the participants. The staff members also evaluated how effectively they had learned about various aspects of end-of-life care: these learning objectives were reached with a mean score of 4.3/5 (range 4.0–4.6) (see Table 3 for more information).

Discussion

We successfully randomized nursing home and assisted living wards and their 340 participating residents into intervention and control groups. According to the baseline analysis, the groups seem to be well balanced along most dimensions of health and well-being we evaluated. However, DNR orders were more common in the control wards than in the intervention wards prior to the intervention. We succeeded in training 74% of the staff and all the physicians in our intervention. The training was well received and provided novel insights for the trainees.

Our study has several methodological advantages compared to previous research on this topic. Cluster-randomized designs are rarely used in studies focusing on educational needs in nursing homes [23]. We adopted a rigorous randomized design to ensure that the confounders would be randomly allocated to the intervention and the control groups. To prevent contamination of the intervention, we used cluster randomization. The design of the intervention trial allowed us to optimize the sample size, pair match the wards for case mix, and use more rigorous methods in gathering data. Two thoroughly trained and experienced research nurses blinded to the group assignment gathered the data, with a view to ensuring reliability and minimizing bias.

Fig. 1 Flowchart of the trial



There are several limitations and threats to be considered. The intervention and the control groups differed significantly in some characteristics such as DNR orders, mobility, and pain. These differences should be adjusted for in analyses of changes in the groups during the follow-up. Other threats relate to the real-life setting of the study. Wards of this type typically have high staff turnover, which our participating staff members also confirmed. A high staff turnover rate is a typical diluting factor in this setting. Given that the wards are physically close to one another, it is also possible that a change of workplace during follow-up would cause contamination between the two study groups. There has recently been an increasing tendency on the national level to develop palliative care and advance care planning in Finnish nursing homes and assisted living facilities, and it is quite likely that some of the staff in the control wards had also recently been involved in other projects working toward similar goals as our intervention. Even the increasing public attention to palliative care could easily dilute the effect of our intervention in the follow-up. The marked difference in DNR orders

between the intervention and the control groups could well be a sign of previous educational interventions.

We succeeded in persuading a large proportion of the staff to participate, including all the physicians and most of the registered nurses. It is, therefore, likely that we managed to educate staff members who had been found in previous studies [43] to be opinion leaders, strongly influencing the decision-making cultures of the wards. Decision making in nursing homes on end-of-life care has previously been shown to be based only to some extent on factual knowledge, and to be strongly based on the attitudes and the culture of the working environment [44, 45]. We considered it important to include co-operative and emotion-evoking components and reflection in the training. The good feedback we received implies good feasibility, and the free-text comments on the importance and perceived novelty of avoiding hospitalization suggest the potential for attitude change in the intervention wards that might later result in reduction in avoidable hospitalizations.

Table 2 Baseline findings of the residents

Baseline characteristics	Intervention (<i>N</i> = 159)	Control (<i>N</i> = 181)	<i>P</i> value
Mean age, (SD)	83.5 (7.5)	84.6 (7.8)	0.14
Women, <i>n</i> (%)	120 (75.5)	138 (76.2)	0.87
Education < 8 years, <i>n</i> (%)	76 (48.8)	95 (52.4)	0.53
Main inclusion criteria, <i>n</i> (%)			0.75
Severe dementia	96 (60.4)	118 (65.2)	
Cancer	12 (7.5)	10 (5.5)	
Heart failure	23 (14.5)	20 (11.0)	
COPD	0 (0)	2 (1.1)	
Renal failure	2 (1.3)	2 (1.1)	
Severe disability	21 (13.2)	23 (12.7)	
Other terminal condition	5 (3.1)	6 (3.3)	
CDR, <i>n</i> (%)			0.62
0–1	39 (24.5)	37 (20.5)	
2	35 (22.0)	45 (24.9)	
3	85 (53.5)	99 (54.7)	
MMSE, mean (SD)	10.0 (9.5)	8.5 (9.0)	0.17
MNA, <i>n</i> (%)			0.81
Malnourished < 17	26 (16.4)	34 (18.8)	
At risk of malnutrition 17–23.5	113 (71.1)	123 (68.0)	
Well-nourished > 23.5	20 (12.6)	24 (13.0)	
Needs assistance in ADL, <i>n</i> (%)	133 (83.6)	164 (90.7)	0.054
Mobility, <i>n</i> (%)			0.014
Needs assistance in walking	22 (13.8)	32 (17.7)	
Bed-bound	72 (45.3)	102 (56.4)	
Charlson comorbidity index, mean (SD)	2.8 (1.5)	2.8 (1.7)	0.25
Mean number of medications, (SD)	10.0 (4.0)	9.2 (3.7)	0.15
Mean number of “pro re nata” medications (SD)	4.8 (2.4)	5.1 (2.8)	0.67
Pain medication, <i>n</i> (%)	103 (64.8)	123 (68.0)	0.54
Opioid	44 (27.7)	51 (28.2)	0.92
Weak opioid	32 (20.1)	38 (21.0)	0.84
Strong opioid	13 (8.2)	13 (7.2)	0.73
Paracetamol	76 (47.8)	101 (55.8)	0.14
NSAID	–	–	na
Pregabalin/gabapentin	15 (9.4)	16 (8.8)	0.85
Psychotropic medication, <i>n</i> (%)	98 (47.3)	108 (52.7)	0.79
Antipsychotic	42 (26.4)	41 (22.7)	0.42
Anxiolytics	20 (12.6)	17 (9.4)	0.35
Antiemetic medication, <i>n</i> (%)	1 (0.6)	3 (1.7)	0.38
Opioid as pro re nata, <i>n</i> (%)	53 (33.3)	68 (37.6)	0.58
Psychotropic as pro re nata, <i>n</i> (%)	93 (58.5)	93 (51.4)	0.19
Hospitalized during the previous year, <i>n</i> (%)	56 (35.2)	66 (36.5)	0.81
15D-score, mean (SD) [0–1]	0.596 (0.098)	0.577 (0.103)	0.076
PWB, mean (SD) [0–1]	0.72 (0.024)	0.71 (0.22)	0.95
PAINAD, mean (SD) [0–10]	0.58 (1.1)	0.36 (0.78)	0.037
ESAS, mean (SD) [0–110]	10.4 (8.2)	9.88 (7.76)	0.58
SWC-EOLD, mean (SD) [10–40]	29.0 (4.8)	28.1 (5.0)	0.13
Do-not-resuscitate order, <i>n</i> (%)	110 (69.6)	171 (95.0)	< 0.001

The differences between the groups were tested with the *t* test, Mann–Whitney, a bootstrap-type test, Chi square or Fischer exact test

SD standard deviation, *COPD* chronic obstructive pulmonary disease, *CDR* clinical dementia rating [25], *MMSE* Mini-Mental State Examination [26], *MNA* mini-nutritional assessment [27], *15D* 15-dimensional health-related quality-of-life instrument [32], *PWB* psychological well-being [34], *PAINAD* pain assessment in advanced dementia scale [31], *ESAS* Edmonton Symptom Assessment System [30], *ADL* activities of daily living [23], *SWC-EOLD* satisfaction with Care at the End-of-Life in Dementia scale [35]

Table 3 Participants' ($n = 132$) self-evaluation of their achievement of the educational objectives

Learning objective	Achieving objective, average numerical score (1–5)
Making an end-of life care plan or advance care plan in collaboration with the resident and/or his/her proxy	4.0
Evaluating and treating end-of-life symptoms	4.2
Knowledge of good palliative and symptom care	4.5
Communication skills related to death, palliative care and supporting relatives	4.1
Understanding the consequences of hospital transfers	4.6
Treating acute symptoms and complications	4.1
Understanding the significance of advance planning for solving acute problems	4.4
Understanding the concepts of advance directives, end-of-life care planning and power-of-attorney	4.4
Managing various demanding situations in end-of-life care	4.3
Understanding how one's own experiences and attitudes toward death and dying influence how one treats residents	4.4
Using one's own team and consultations to support palliative care	4.4

Activating learning methods and reflection based on constructive learning theory have previously been shown to result in effective learning in adult education in the medical field [46]. The intervention was designed to be light and suitable for real-life use. We also strived for a well-outlined intervention to enable replication and allow further comparisons between different educational interventions. If our further follow-up shows resident-related benefits, we will have significantly enhanced current knowledge about the planning of future quality-improvement projects related to nursing home residents' end-of-life needs.

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Compliance with ethical standards

Conflict of interest The authors declare they that have no conflicts of interest relevant to this report, and no financial conflicts related to the topic.

Ethical approval The trial was approved by the Ethics Committee of Helsinki University Central Hospital, and the procedures were planned in accordance with the Declaration of Helsinki. Each participating resident and her/his closest proxy were provided with detailed information both orally and in writing, and they gave their informed consent. In cases of moderate-to-severe dementia, the proxy gave the consent on behalf of the resident. The study was registered in the Australian New Zealand Clinical Trials Registry under the intervention code: ACTRN12617001040358.

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