Original Article

Training Staff in Long-Term Care Facilities—Effects on Residents' Symptoms, Psychological Well-Being, and Proxy Satisfaction

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Abstract

Context. Long-term care facility (LTCF) residents have unmet needs in end-of-life and symptom care.

Objectives. This study examines the effects of an end-of-life care staff training intervention on LTCF residents' pain, symptoms, and psychological well-being and their proxies' satisfaction with care.

Methods. We report findings from a single-blind, cluster randomized controlled trial featuring 324 residents with end-of-life care needs in 20 LTCF wards in Helsinki. The training intervention included four 4-hour educational workshops on palliative care principles (advance care planning, adverse effects of hospitalizations, symptom management, communication, supporting proxies, challenging situations). Training was provided to all members of staff in small groups. Education was based on constructive learning methods and included participants' own resident cases, role-plays, and small-group discussions. During a 12-month follow-up we assessed residents' symptoms with the Edmonton Symptom Assessment Scale (ESAS), pain with the PAINAD instrument and psychological well-being using a PWB questionnaire. Proxies' satisfaction with care was assessed using the SWC-EOLD.

Results. The change in ESAS symptom scores from baseline to 6 months favored the intervention group compared with the control group. However, the finding was diluted at 12 months. PAINAD, PWB, and SWC-EOLD scores remained unaffected by the intervention. All follow-up analyses were adjusted for age, gender, do-not-resuscitate order, need for help, and clustering.

Conclusion. Our rigorous randomized controlled trial on palliative care training intervention demonstrated mild effects on residents' symptoms and no robust effects on psychological well-being or on proxies' satisfaction with care. J Pain Symptom Manage 2021;62:e4—e12.

Key Words

Palliative care, training, long-term care, randomized controlled trial, pain, well-being

Key Message

Our rigorous RCT examined the effects of a feasible long-term care facility staff training intervention focusing on end-of-life and symptom care. The intervention demonstrated mild effects on residents' symptoms and no clear effects on psychological well-being or on proxies' satisfaction with care over a 12-month follow-up.

Trial registration: The study was registered in the Australian New Zealand Clinical Trials Registry: ACTRN12617001040358.

Introduction

Residents in long-term care facilities (LTCFs) are known to have unmet needs in symptom management.

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Pain and other physical and psychological symptoms are common, as this older population is often faced with multimorbidity and dementia. Difficulties in mobility, communication, and a range of neuropsychological symptoms challenge the staffs' skills in both managing changing situations and communicating with residents and their proxies.[1,2]

Palliative care aims to relieve physical, emotional and spiritual symptoms related to diseases, especially life-limiting diseases.[3] LTCF residents are living their last phase of life with estimated median survival from admission being around 2 years from admission in Western countries.[4,5] However, formal palliative care consultations are uncommon in this setting compared to other populations with similar prognosis.[2,6] Expert opinion considers a palliative or comfort-oriented path suitable for the majority of these residents.[1,7] Residents have unmet care needs, with previous studies highlighting common and varying symptoms such as pain[8] and neuropsychological symptoms,[9] and suggesting a need for timely management of common medical conditions such as heart failure.[10] Interventions to reduce the burden of symptoms have been targeted to improve end-of-life care or to enhance the quality of life of residents. Proxies' satisfaction with care has been considered a marker of care quality and resident comfort as well as a marker of the quality of communication between staff and relatives.[11] Several interventions have aimed at improving resident-related outcomes in LTCFs. A previous systematic review noted that these interventions were mostly without effect and were often complicated or relying on continuous external support.[12] Less complicated staff training interventions have not been rigorously evaluated, with earlier studies reporting mainly staff-related outcomes.[13]

We performed a single-blind, cluster randomized controlled trial. Our aim was to explore the effects of a feasible staff-training workshop intervention on palliative care. Selected outcomes were quality of end-of-life care from the residents' and proxies' perspectives. This study reports the secondary outcomes of the trial: symptoms using Edmonton Symptom Assessment Scale (ESAS) and Pain Assessment in Advanced Dementia (PAINAD), psychological well-being, and proxy satisfaction with care.

Methods

Our previously published article provides details on the design and baseline findings of this trial.[14] Outcomes of health-related quality of life and hospital service use are reported separately. This trial was registered in the Australian New Zealand Clinical Trials Registry (ACTRN1261700104035) and approved by the Ethics Committee of Helsinki University Hospital.

Study Design and Participants

The trial was designed as a single-blind, cluster randomized controlled trial with a two-year follow-up for the primary outcomes and a 1-year follow-up for the secondary outcomes presented in this article. Whole wards were recruited from nursing homes (NHs) and assisted living facilities (ALFs) managed by the City of Helsinki. We had Resident Assessment Instrument/Minimum Data Set (RAI/MDS)[15] information available for 94 LTCF wards. Considering sample size requirements and available resources, wards with similar MDS case-mix were matched and a total of 13 NH wards and 7 ALF wards were included in the sample. The following variables from MDS were used for pair-matching: gender, age, any degenerative brain disease, Cancer, CPS = 5–6 (poor cognition), ADLh = 5–6 (major difficulties in Activities of Daily Living), CHESS > 0 (instability of health indicators), Hospitalized within three months, and emergency department visit without hospitalization. We included all permanent Finnish-speaking residents who provided informed consent personally or via proxy and were judged likely to have a prognosis of less than 12 months.

In our country LTCFs provide care for older people who are unable to reside at home despite intensive home-care. NHs and ALFs have rather similar resident-mix and both LTCFs provide round-the-clock care with a registered nurse being in charge of the ward. ALFs are more home-like and can provide service for example to people with dementia needing more assistance in ADL. Both settings typically take care of their residents until death.[16] Both ALFs and NHs can utilize local hospital-at-home type services for more intensive care needs.

Randomization

Randomization was carried out with random allocation numbers provided by a separate randomization center. One of each facility-pair was assigned to an intervention group, while the other acted as a control. See Fig. 1 for a flowchart of the trial.

Intervention

The intervention consisted of four afternoons of training in small groups using various techniques to cover the topics. The main techniques were short discussion-activating lectures, group discussions on clinical cases, role-plays, and reflection. All staff members were invited to take part in the training and facility managers facilitated participation. Intervention trainings were started in November 2017 and for the last facilities ended in March 2018.

We used constructivist learning theory[17] and adult learning[18] as learning theories to construct our education. As methods we used learner centered approaches and reflective learning to enhance participants'

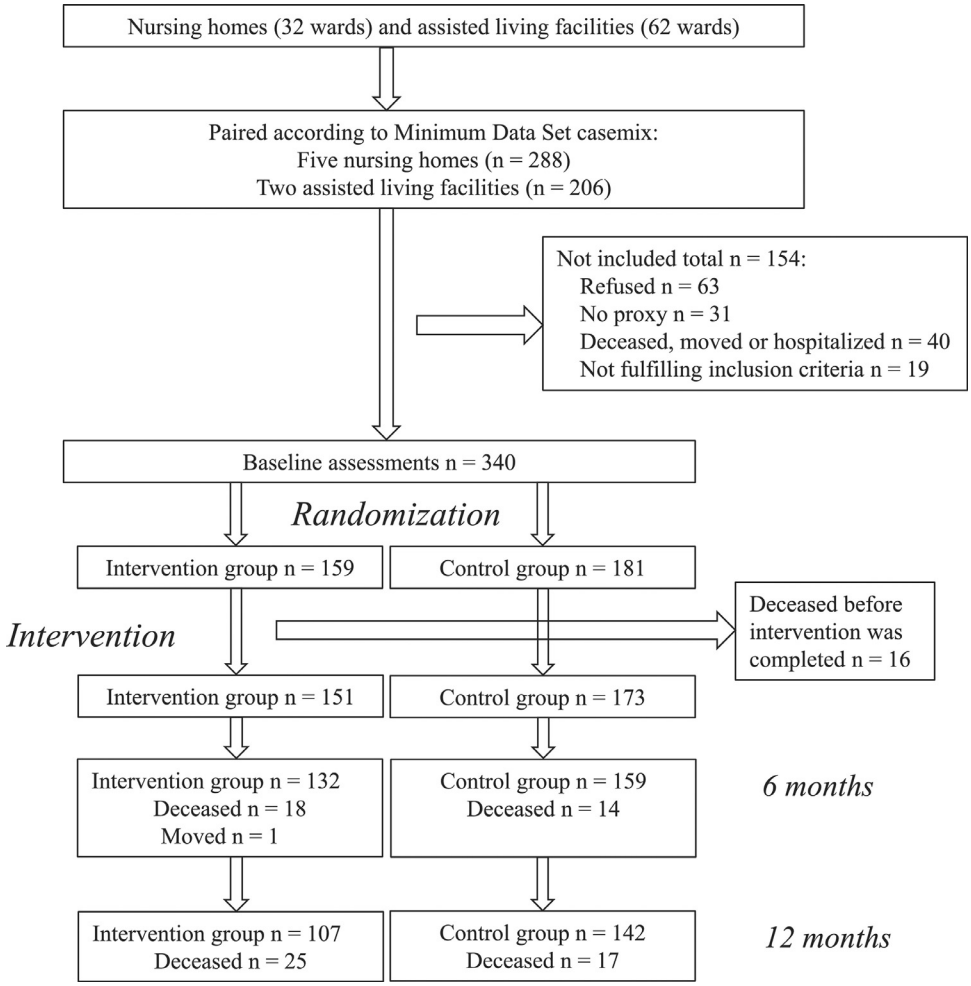

Fig. 1. Flowchart of the trial.

competence.[19–21] We assumed that practical and everyday-relevant topics would be most motivating for the participants. Therefore, we conducted a survey on learning needs for the participants in the planning phase of the intervention. The survey was based on expert opinion and recent recommendations and served to clarify the topics emphasized in the trainings.[6] The topics handled in the four sessions were basics of good palliative care, advance care planning and leading discussions with patients and their relatives, good symptom management, adverse effects of hospitalizations, communication skills, tailoring end-of-life care, supporting relatives, and confronting challenging situations in end-of-life care. The sessions were largely based on resident cases from the instructors and from participants. We also used role-plays, reflections, and small-group discussions as practical techniques.[19] We managed to train all five physicians working in the intervention wards and about three quarters of all staff members (registered nurses and assistant nurses). The aims, contents and learning methods of intervention are described in *Supplementary Table 1*. We aimed to keep the intervention rather short and simple so that it could be easily disseminated into practice. According to feedback, the workshops were well-received, felt feasible, and the themes were considered important.[14]

Measures

All resident measures and baseline information were collected by trained study nurses blinded from group allocation. Collection of demographic data, diagnoses, and cognitive and nutritional evaluation was performed before the start of intervention. Repeated assessments for the secondary outcomes addressed in this article were carried out at 6 and 12 months post-intervention.

Symptoms were assessed using the Edmonton Symptom Assessment Scale (ESAS) and Pain Assessment in Advanced Dementia (PAINAD). ESAS was originally developed for repeated symptom assessment of palliative patients with cancer.[22] Being widely adopted to clinical practice, it evaluates a set of symptoms, each on an 11-point Likert scale from “none” (0) to “worst

possible" (10). Several versions of the scale are currently used, as the scale has undergone various developments over the years.[23] We used a Finnish version that includes 11 domains/questions: pain at rest, pain at effort, fatigue, shortness of breath, lack of appetite, nausea, dry mouth, constipation, depression, anxiety, and overall well-being.

Pain assessment with PAINAD is carried out by an external observer, noting behavioral cues considered to imply possible pain. These cues derive from five domains: breathing, vocalization, facial expression, body language, and consolability. Each domain is rated between 0 and 2, yielding a total maximum score of 10. According to original developers, scores of 7-10 are considered severe pain, 4−6 moderate pain, and 0-3 mild pain.[24] Later studies have suggested with scores of 2 or more that increasing pain treatment be considered.[25]

Psychological well-being (PWB) was assessed using a six-item questionnaire.[26] These six questions focus on areas considered important in PWB[27] and have shown good test−retest reliability[28] and prognostic validity.[29] The questions consider 1) life satisfaction, 2) feeling needed, 3) having plans for the future, 4) having zest for life, 5) feeling depressed, and 6) suffering from loneliness. Questions 1−4 are graded no/yes (0/1 points) and questions 5−6 as seldom or never/sometimes/often or always (0/0.5/1). The average of all questions forms a PWB score, where a score of 1 indicates the best psychological well-being and 0 the poorest.

The Satisfaction with Care in End-of-Life in Dementia (SWC-EOLD) assessment tool was used to evaluate proxies' satisfaction with care. The scale is part of a set of tools to evaluate end-of-life care for people with advanced dementia.[30] It comprises 10 questions with each rated on a scale from 1 to 4, with the total score of 40 implying complete satisfaction.

Statistical Analysis

Our sample size was estimated based on detecting a clinically significant change in health-related quality of life using the 15D instrument, which was one of the primary outcomes of the trial. We used Student's t-test, Chi-square, or Fischer's 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. Repeated measures of the changes in primary and secondary outcomes were compared between the intervention and the control with mixed-effects models and an unstructured covariance structure (Kenward-Roger method for calculating the degrees of freedom). Fixed effects included group, time, and group × time interactions. Models included age, gender, DNR order, and need for help according to the Clinical Dementia Rating (CDR) as a covariate. The repeated measurements were taken at three time points: at baseline and at 6 and 12 months. All analyses were intention-to-treat. Mixed models allowed analysis of unbalanced datasets without imputation; therefore, we analyzed all available data with the full analysis set. The models accounted for clustered data by random effect modeling with an unstructured covariance pattern. Normal distributions were evaluated graphically and with the Shapiro−Wilk W test. All analyses were performed in Stata 16.1 (StataCorp LP; College Station, TX, USA).[22,24,26,30−33]

Results

We recruited 340 residents to the trial. Altogether 16 were deceased before the intervention started, leaving 324 participating residents in the LTCFs, including 151 residents in intervention wards and 173 in control wards. On average, the residents were 84 years old and 75% were women. No significant differences were found between the two groups in educational background, burden of comorbidities, proportions of inclusion criteria terminal conditions, mean number of medications, regular pain medications, or MMSE or CDR scores. The intervention group had slightly more symptoms according to ESAS (10.9 vs. 9.1, $P = 0.046$) and pain according to PAINAD (0.58 vs. 0.36, $P = 0.044$) at baseline. In addition, 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% vs. 68%, $P<0.001$) at baseline. According to the CDR, those in the control group were more dependent on assistance (need for help) than those in the intervention group (Table 1).

Symptom score changes according to ESAS showed a significant difference between groups at the 6-month follow-up, favoring the intervention group (-0.82 [95% CI: -2.24 − 0.59] points vs. 2.01 [95% CI 0.71 to 3.31], $P = 0.004$), but this difference disappeared at the 12-month follow-up. A trend of increasing PAINAD scores in the control group was observed, while the scores in the intervention group remained stable, but these differences were not statistically significant (Fig. 2). ESAS and PAINAD measurements were obtained for all living residents at all time points. Statistical models for ESAS and PAINAD were adjusted for the baseline differences in DNR orders and need for help in addition to age and gender.

PWB remained fairly stable in both groups throughout the follow-up, with no observable intervention effects (Fig. 3). Proxies' satisfaction with care measured by SWC-EOLD declined slightly over time, without differences between the groups (Fig. 4). Response rates varied between 80% and 92% for PWB and between 69% and 87% for SWC-EOLD, without significant differences between groups. Statistical models for PWB and SWC-EOLD were adjusted for baseline differences in DNR orders and need for help in addition to age and gender.

Table 1
Baseline Characteristics of Residents

Baseline characteristic	Control (N=173)	Intervention (N=151)	*P* value
Mean age, years (SD)	84 (8)	83 (8)	0.15
Women, n (%)	130 (75)	115 (76)	0.87
Education <8 years, n (%)	91 (53)	73 (49)	0.52
Main terminal condition, n (%)			0.96
Severe dementia	112 (65)	91 (60)	
Cancer	10 (6)	11 (7)	
Heart failure	19 (11)	21 (14)	
COPD	1 (1)	0 (0)	
Renal failure	2 (1)	2 (1)	
Severe disability	23 (13)	21 (14)	
Other terminal condition	6 (3)	5 (3)	
Charlson comorbidity index[31], mean (SD)	2.7 (1.8)	2.9 (1.5)	0.47
CDR[32], n (%)			0.57
0.5−1	35 (20)	38 (25)	
2	44 (25)	33 (22)	
3	94 (54)	80 (53)	
Pain medications[a], n (%)	118 (68)	97 (64)	0.45
Needs assistance in ADL[b], n (%)	157 (91)	125 (83)	0.033
Do-not-resuscitate order in medical records, n (%)	164 (95)	102 (68)	<0.001
ESAS[22], mean (SD), [0 − 110]	9.1 (6.8)	10.9 (8.9)	0.046
PAINAD[24], mean (SD), [0 − 10]	0.36 (0.79)	0.58 (1.11)	0.044
PWB[26], mean (SD), [0 − 1]	0.71 (0.22)	0.72 (0.23)	0.87
SWC-EOLD[24] mean (SD), [10 − 40]	27.8 (5.1)	28.7 (5.2)	0.14

ADL = Activities of Daily Living, CDR = Clinical Dementia Rating, COPD = Chronic obstructive pulmonary disease, ESAS = Edmonton Symptom Assessment Scale, PAINAD = Pain Assessment in Advanced Dementia, PWB = Psychological Well-Being, SWC-EOLD = Satisfaction with Care − End-of-Life in Dementia.
Selective and nonselective nonsteroidal anti-inflammatory drugs (M01A)[33]
[a]Including opioids (N02A), paracetamol (N02BE01),
[b]Personal care ≥ 2 points in CDR.

Discussion

Our randomized trial with a feasible low-complexity training intervention had minor and short-term effects on symptoms and did not produce significant changes in residents' pain and psychological well-being or proxies' satisfaction with care. The change in ESAS score favored the intervention group over the control group at the 6-month follow-up, but this difference was not maintained at the 12-month follow-up.

The strength of this trial was a rigorous cluster randomized design with assessments blinded for group

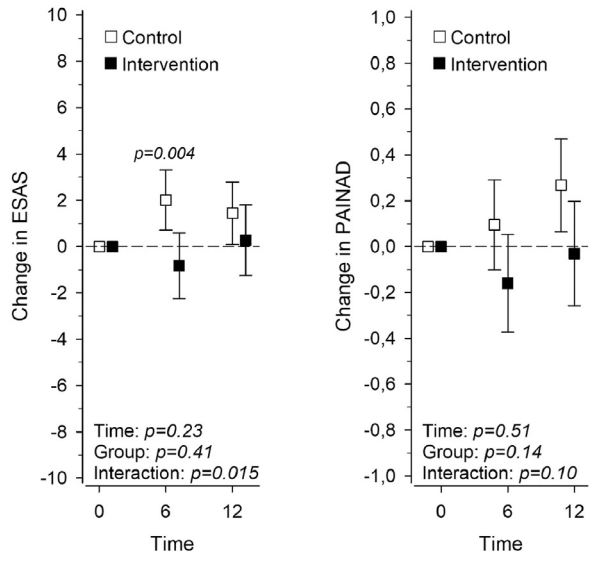

Fig 2. Change in ESAS and PAINAD scores from baseline according to group. Differences from mean baseline scores during follow-up (months), adjusted for age, gender, DNR order, and need for help. ESAS: Edmonton Symptom Assessment Score, PAINAD: Pain Assessment in Advanced Dementia.

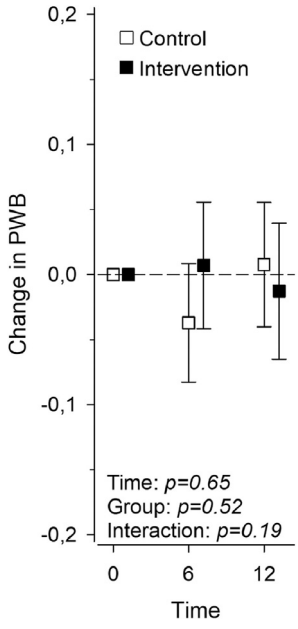

Fig 3. Change in psychological well-being (PWB) from baseline according to group. Differences from mean baseline scores during follow-up (months), adjusted for age, gender, DNR order, and need for help.

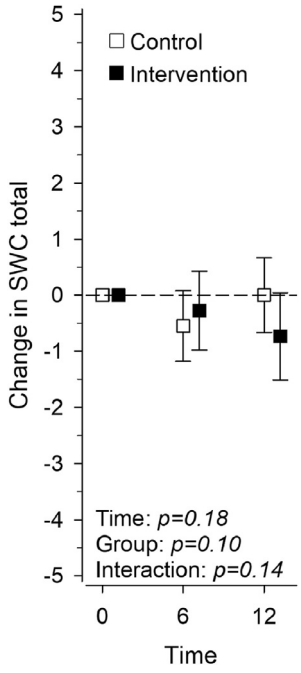

Fig 4. Change in proxies' satisfaction with care (SWC) from baseline according to group. Differences from mean baseline scores during follow-up (months), adjusted for age, gender, DNR order, and need for help.

allocation. Our intervention was designed to be feasible and easy to adapt and scale up. The training themes were informed by a learning needs survey. The workshops were practical, building on a plenitude of resident cases and utilizing modern, proven adult education techniques and methods.[21] Our measures for symptoms, PWB, and proxy satisfaction were valid and appropriate, as they focus on domains considered important by residents and proxies[34] and have been shown to be sensitive to change.[25,29,35,36] The drop-out rate was rather small, and we were able to get two measurement points for 87% of intervention residents and for 91% of control residents.

Due to practical issues, the number of clusters was quite small. Despite pair-matching the wards according to MDS information, considerable differences existed in some baseline characteristics between the groups. This meant that our analyses had to be adjusted for DNR order status and need for help according to CDR at baseline, decreasing our statistical power. Furthermore, some of the wards in our control group had taken part in another palliative care improvement project just before our project started, which might have diluted our effects and produced some of the unbalanced baseline findings. The outcomes presented here are secondary outcomes of the trial, and our initial power calculations and follow-up schedules were not optimized for these measurements. Utilizing a light intervention, we provided no support for implementing changes and developments arising from the workshops, nor were we able to give booster-trainings or re-train new staff. We suspect that participating residents were in a more stable condition than some of the residents refusing participation, as healthier individuals have been previously noted to be overrepresented in trials.[37] Also, proxies with existing conflicts with the facilities could be more prone to decline consent to participate in the trial, introducing additional selection bias.

We did observe a significant difference between groups in ESAS total scores, implying that in the intervention group symptoms decreased compared with the control group. For the ESAS scores, a minimal clinically significant change has been approximated to be 3–5 points for improvement.[35] Our statistically significant difference of around 3 points between groups at 6 months can also be considered clinically significant. The difference disappeared at the 12-month assessment, making it difficult to evaluate the overall significance of the finding.

Pain has been historically undertreated in LTCFs, with an increased likelihood for undertreatment with declining cognition.[38] Systematic evaluation of pain with observational tools, such as PAINAD, has been suggested as a mean of improving pain treatment, but the results of implementation trials remain inconclusive.[39,40] Even interventions with analgesics show mixed results.[41,42] Low baseline scores for PAINAD and ESAS suggest a possibility of a floor effect for these measurements. Satisfaction with care measured by SWC-EOLD is used increasingly as a proxy in determining quality of end-of-life care in LTCFs. Satisfaction with care has been seen to reflect the level of consensus about treatment choices between staff and proxies.[43] However, our recent systematic review did not find any trials that could improve proxy satisfaction.[12] Our difficulties in improving satisfaction with care are also in line with recent research highlighting that Finnish LTCF residents' proxies reported the lowest satisfaction with treatment when six European countries were compared.[44] While our training aimed to improve staff communication skills, we did not sufficiently succeed to reach a better consensus with proxies.

In a study investigating barriers to nurse participation in end-of-life care planning, Sutherland et al[7] found several factors limiting the participation of front-line staff (nurse practitioners and assistant nurses) in EOL decision-making. Of note, organization of daily routines and facility cultures were found to be based on a biomedical model of care that emphasizes diagnoses, vital signs, and eating and elimination, and places less importance on the knowledge gathered through daily conversations with residents and family members. In addition a palliative approach was still commonly associated with the treatment of the very last days and decisions about end-of-life were considered to be made in formal gatherings

with more medically knowledgeable staff members.[7] As these type of barriers to change are structural within caring communities, cultures, and education systems, rather than only based on a lack of knowledge, continuous attention is required to produce change. Even with continuous attention and support, person-centered views and approaches better suiting quality palliative care are likely to be adopted slowly.

Several of the previously known barriers for quality improvement interventions in LTCF also apply to our trial.[13] We managed to train three-quarters of the staff members, including all physicians working in these facilities, and attrition to training was not considerable, in contrast to many larger scale development projects.[13] The participants' feed-back for training sessions was very good.[14] Judging from the small group conversations during the workshops, staff viewed the topics positively but clear differences concerning the types of changes in practices deemed possible were observed, suggesting possibly conflicting attitudes in some of the facilities. Support from facility management was generally good, and staff was encouraged to take part in the training. However, we have no information on how much support for development efforts was received from management after the initial training. High staff and management turnover is a common issue in many LTCFs and was also noted in our follow-up. High turnover is likely to dilute most developmental activities over time. Scarce monetary resources and tight staffing ratios also make it challenging to keep the focus on long-term development in addition to coping with day-to-day work.

Conclusion

Our rigorous RCT on a palliative care training intervention demonstrated mild effects on residents' symptoms, but no robust effects on psychological well-being or on proxies' satisfaction with care. Unsupported short-term educational interventions might be insufficient to change care practices. Future studies should strive to find the most effective aspects from both feasible real-life interventions and more complex quality improvement projects to ensure good end-of-life care for the growing population of LTCF residents.

Author Contributions

Study concept and design: PJL, HFS, MLL, JVL, KHP; analysis and interpretation of data: PJL, KHP, HK; preparation of manuscript: PJL, HFS, HK, MLL, JVL, KHP

Disclosures and Acknowledgments

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The authors declare no conflicts of interest relevant to this report and no financial conflicts related to the topic.

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