Original Article

Factors Associated With Symptom Relief in End-of-Life Care in Residential Care Homes: A National Register-Based Study



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Abstract

Context. Residential care homes (RCHs) are a common place of death. Previous studies have reported a high prevalence of symptoms such as pain and shortness of breath among residents in the last week of life.

Objectives. The aim of the study was to explore the presence of symptoms and symptom relief and identify factors associated with symptom relief of pain, nausea, anxiety, and shortness of breath among RCH residents in end-of-life care.

Methods. The data consisted of all expected deaths at RCHs registered in the Swedish Register of Palliative Care (N = 22,855). Univariate and multiple logistic regression analyses were conducted.

Results. Pain was reported as the most frequent symptom of the four symptoms (68.8%) and the one that most often had been totally relieved (84.7%) by care professionals. Factors associated with relief from at least one symptom were gender; age; time in the RCH; use of a validated pain or symptom assessment scale; documented end-of-life discussions with physicians for both the residents and family members; consultations with other units; diseases other than cancer as cause of death; presence of ulcers; assessment of oral health; and prescribed pro re nata injections for pain, nausea, and anxiety.

Conclusion. Our results indicate that use of a validated pain assessment scale, assessment of oral health, and prescribed pro re nata injections for pain, nausea, and anxiety might offer a way to improve symptom relief. These clinical tools and medications should be implemented in the care of the dying in RCHs, and controlled trials should be undertaken to prove the effect. J Pain Symptom Manage 2018;55:1304—1312. © 2017 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.

Key Words

Nursing homes, older persons, palliative care, quality of care, register study, symptom relief

Background

In Sweden and most other western countries, the number of older persons is increasing.¹ A recent cross-national study indicated that higher age increased the odds of being in need for palliative care.² The British Geriatrics Society³ has highlighted several important components in palliative care for

the dying person, irrespective of diagnosis: symptom control, retaining control, deciding who should be present at the time of death, and preparing for an imminent death through end-of-life (EOL) discussions for both the dying person and their family members. According to the World Health Organization, older persons lack access to palliative care

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0885-3924/\$ - see front matter https://doi.org/10.1016/j.jpainsymman.2017.12.489 and have often been left with their symptoms unassessed and untreated, thus increasing the risk of unnecessary suffering. In Sweden, older age is a risk factor for poor EOL care quality. Poor EOL care quality was related to likelihood of dying in the presence of a family member or caregiver, information and bereavement support, prescriptions of injectable drugs for symptom relief, systematic assessment of pain or other symptoms, and use of palliative consultation services.

Residential care homes (RCHs) are replacing hospitals as a common place of death for older persons.^{6–8} The highest prevalence for palliative care needs has been reported when death occurs in RCHs or at home. Palliative care needs is based on causes of death and chronic conditions, identified as conditions eligible on palliative care needs.² RCHs therefore play a significant role in EOL care.⁹ In 2012, the proportion of older persons who died in RCHs in Sweden varied from 45% among those aged 80-89 years to 62% among those aged 90 years and older. Older persons who live in RCHs also usually die there. 10,11 Family members have reported a lower quality of EOL care regarding psychosocial and spiritual well-being in RCHs and hospitals compared to at home or in hospices. 12

The goal of palliative care is to include every dying person, wherever they are cared for, irrespective of diagnosis. 13 The most common causes of death for older residents in RCHs in Sweden are diseases of the circulatory system^{14,15} and dementia.¹⁴ The majority of persons with life-threatening diseases, regardless of setting, have pain, shortness of breath, and other symptoms. 16,17 Earlier studies have reported differences in symptom prevalence and symptom relief between persons with cancer and those with other diagnoses. Persons with stroke had significantly lower prevalence of pain (42.7% vs. 78.0%), shortness of breath (16.3% vs. 23.3%), and anxiety (18.9% vs. 42.3%) than persons with cancer. 18 Persons with advanced fibrosing interstitial lung disease had more shortness of breath (75.0% vs. 42.0%) than patients with cancer, in different settings. 19 Persons with heart disease had more shortness of breath (10.5% vs. 6.9%) than persons with cancer, as well as significantly more unrelieved nausea (2.7% vs. 4.1%), anxiety (12.6% vs. 15.2%), and pain (9.8% vs. 14.9%). 20 Studies focusing on symptom and symptom relief during the last week of life in RCHs have shown a high prevalence of pain^{14,15} and shortness of breath.¹⁴

In summary, most studies of symptoms and symptom relief in EOL care have focused on persons with different diagnoses and not on the context of care. There is a lack of evidence regarding symptom relief and factors associated with symptom relief in EOL care in RCHs. Hospital care for older people in

Europe is being replaced by other care facilities such as RCHs. RCHs play an increasing and important role in EOL care.

Objective

The aim was to explore the presence of symptoms and symptom relief and identify factors associated with symptom relief of pain, nausea, anxiety, and shortness of breath among residents in EOL care in RCHs.

Method

Design

This was a retrospective register-based study.

Setting

In Sweden, older people living in RCHs often had dementia diseases and multiple diseases. In the municipality, the care professionals are primarily assistant nurses and registered nurses who work on a consultation basis. The physicians work as consultants at RCHs. ²¹

Data Collection

This register study was based on the Swedish Register of Palliative Care (SRPC). The SRPC is a national quality register of EOL for all deaths, independent of diagnosis, and focuses on care during the last week of life. Its goal is to improve the quality of EOL care, wherever the individuals are cared for.²² The register includes variables related to key components of palliative care. After the resident's death, physicians or registered nurses complete a questionnaire regarding relevant indicators for quality of EOL care based on data and documentation in the patients' record and also report whether the death was expected. In 2016, two-thirds (64.3%) of all deaths were registered in the SRPC from all municipalities in Sweden.²³ The inclusion criteria for this study were that the resident should have died as an expected death in an RCH at the age of ≥65 years between 1 October, 2015, and 31 December, 2016. A total of 22,855 questionnaires were included.

Variables

All data were taken from the SRPC. The background variables included age, gender, cancer vs. other diagnoses as cause of death, and time in the RCH (divided into four categories: 0–100 days, 101–365 days, 366 days to five years, and five years or more). The variable cancer vs. other diagnoses were included because earlier studies have reported differences in symptom prevalence and symptom relief between persons with cancer and those with other diagnoses. ^{18–20}

The prevalence of symptom and symptom relief of pain, nausea, anxiety, and shortness of breath in the last week of life were included because these are common symptoms in palliative care. 17,21,24 Additional variables were presence of symptom and symptom relief of pain, nausea, anxiety, and shortness of breath; use of pain assessments with validated patient-reported scales (e.g., Visual Analogue Scale, Numeric Rating Scale, Abbey Pain Scale); use of other validated symptom assessment scales; documented EOL discussions with a physician for the resident and family members; consultation with other health care specialists; having been examined by a physician during the last week; presence of pressure ulcers; assessment of oral health; and prescription of individual injections as needed (pro re nata [PRN]) for symptom relief of pain, nausea, and anxiety.

The variables covering symptom relief were dichotomized into totally relieved vs. partly relieved or not relieved at all. This choice assumed the goal of total symptom relief during dying.¹³ The variables covering circumstances around death were coded "yes" or "no"; answers of "unknown" were excluded from the analysis.

Statistics

Descriptive statistics were used to describe the EOL care, including mean, median, numbers, and percentages for the presence of the four symptoms. Univariate and multiple logistic regression analyses were conducted to identify explanatory variables associated with the outcome variables (symptom relief of pain, nausea, anxiety, and shortness of breath). The explanatory variables were age, gender, number of days enrolled in the RCH, diagnosis, use of validated pain and symptom assessment scales, documented EOL discussion with a physician for residents and/or family members, consulting another health care specialist, examination by a physician during the last week, pressure ulcers, assessment of oral health, and individually prescribed injections to be taken when required (PRN).

Univariate logistic regressions were conducted with one explanatory variable at a time to identify factors associated with symptom relief. A multiple logistic regression was conducted with all explanatory variables included to identify the independent effect of each variable (one model for each symptom relief). No problems with multicollinearity were detected across the explanatory variables according to the variance inflation factor. The Hosmer and Lemeshow test was used to evaluate the goodness of fit of the logistic regression models, with a nonsignificant test supporting model fit. Overall, a 5% significance level was used (i.e., P < 0.05).

Version 23.0 of IBM SPSS Statistics for Windows (IBM Corp., Armonk, NY) was used for all statistical computations.

Results

The mean age of the residents was 87.9 years (SD = 7.1), and the majority were female (65.2%). Cause of death was cancer diagnosis (13.7%) or other diagnoses (86.3%) (Table 1). Most of those with symptoms had been prescribed PRN injections for symptom relief (pain 97.4%, nausea 90.4%, and anxiety 97.0%).

Symptom Prevalence and Relief

The most commonly reported symptoms were pain (68.8%) and anxiety (44.0%). Shortness of breath (14.1%) and nausea (10.2%) were less common (Table 2). However, pain was the symptom that most often had been totally relieved (84.7%), followed by anxiety (77.0%), nausea (58.0%), and shortness of breath (47.7%) (Table 2).

Factors Associated With Pain Relief

Twelve explanatory variables were significantly associated with pain relief in the univariate models (Table 3). Higher age, female gender, a longer time at the RCH, use of validated pain and symptom assessment scales, documented EOL discussions with a physician for both residents and family members, assessment of oral health, and PRN injections for pain were associated with higher probability of pain relief. Conversely, consultation with other health care specialists, diseases other than cancer as cause of death, and the presence of pressure ulcers were associated with lower probability of pain relief. These associations remained in the full model including all 12 explanatory variables, except for age, gender, and documented EOL discussions with residents (Table 3).

Table 1

Background Characteristics, Age, Gender, Cause of Death and Time Living at Unit

Characteristics		
	2.5	
Age	Mean	SD
	87.9	7.1
Gender	n	%
Female	14,893	65.2
Male	7962	34.8
Cause of death	n	%
Cancer	3125	13.7
Heart disease	7832	34.3
Dementia disease	11,354	49.7
Diabetes mellitus	1666	7.3
Stroke	2836	12.4
Other neuro disease than stroke	1010	4.4
Lung disease	1857	8.1
Post-fracture	943	4.1
Other disease	2261	9.9
Time living in unit (days)	Median	q1-q3
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Table 2
Presence of Symptom (N = 22,855), and Symptom Totally Relieved, Partly Relieved, or Not at all Relieved

	n	%
Presence of pain		
No	6666	29.2
Don't know	466	2.0
Yes	15,723	68.8
Yes, totally relieved	13,318	84.7
Yes, partly relieved	2373	15.1
Yes, not relieved at all	32	0.2
Presence of nausea		
No	18,962	83.0
Don't know	1567	6.8
Yes	2326	10.2
Yes, totally relieved	1349	58.0
Yes, partly relieved	888	38.2
Yes, not relieved at all	89	3.8
Presence of anxiety		
No	11,271	49.3
Don't know	1524	6.7
Yes	10,060	44.0
Yes, totally relieved	7747	77.0
Yes, partly relieved	2264	22.5
Yes, not relieved at all	49	0.5
Presence of shortness of breath		
No	18,944	82.9
Don't know	688	3.0
Yes	3223	14.1
Yes, totally relieved	1537	47.7
Yes, partly relieved	1605	49.8
Yes, not relieved at all	81	2.5

Factors Associated With Nausea Relief

Seven explanatory variables were significantly associated with nausea relief in the univariate models (Table 4). A longer time at the RCH, use of validated pain and symptom assessment scales, documented EOL discussions with physician for both residents and family members, assessment of oral health, and PRN injections for nausea were associated with higher probability of nausea relief (Table 4).

These associations all remained in the full model, except for longer time at the RCH, use of validated symptom assessment scales, and documented EOL discussions with a physician for family members. In the full model, the presence of pressure ulcers became significantly associated with lower probability of nausea relief (Table 4).

Factors Associated With Anxiety Relief

Twelve explanatory variables were significantly associated with anxiety relief in the univariate models (Table 5). Higher age, female gender, longer time at the RCH, use of validated pain and symptom assessment scales, documented EOL discussions with a physician for both residents and family members, assessment of oral health, and PRN injections for anxiety were associated with higher probability of anxiety

 Table 3

 Factors Associated With Symptom Relief in Pain

Relieved Pain		Univariate Model				
Factors	OR	95% CI for OR	<i>P</i> -value	OR	95% CI for OR	<i>P</i> -value
Age at time of death	1.01	1.00-1.01	0.048	1.00	1.00-1.01	0.315
Gender						
Male (ref.)	Ref.			Ref.		
Female	1.20	1.10 - 1.31	< 0.001	1.07	0.95 - 1.21	0.261
Time at RCHs						
0-100 days (ref.)	Ref.			Ref.		
100-365 days	1.16	1.00 - 1.34	0.048	1.05	0.87 - 1.26	0.626
366 days to five yrs	1.59	1.40 - 1.80	< 0.001	1.39	1.18 - 1.64	< 0.001
More than five yrs	1.47	1.26 - 1.72	< 0.001	1.18	0.96 - 1.46	0.120
Use of validated pain assessment scale	1.70	1.55-1.87	<0.001	1.34	1.17-1.54	< 0.001
Use of validated symptom assessment scale	1.70	1.52-1.90	<0.001	1.27	1.08-1.49	0.003
Documented EOL discussions with the residents	1.20	1.09-1.31	<0.001	1.04	0.92 - 1.18	0.528
Documented EOL discussions with the family members	1.44	1.30-1.60	<0.001	1.24	1.06-1.45	0.006
Consultation from other health care specialists	0.64	0.57 - 0.73	<0.001	0.64	0.55 - 0.75	< 0.001
Examination by a physician last week	1.00	0.91-1.10	0.950	0.96	0.85 - 1.07	0.428
Cancer diagnosis or other diagnoses as cause of death	0.72	0.64 - 0.80	<0.001	0.74	0.64 - 0.87	< 0.001
Presence of pressure ulcers	0.64	0.58 - 0.71	< 0.001	0.66	0.58 - 0.75	< 0.001
Assessment of oral health	1.71	1.54 - 1.90	< 0.001	1.36	1.18 - 1.56	< 0.001
PRN injection pain	5.49	4.46 - 6.75	< 0.001	4.17	3.12 - 5.57	< 0.001

OR = odds ratio; RCHs = residential care homes; EOL = end-of-life; PRN = pro re nata. Bold text indicates *P*-value <0.05. Nagelkerke R^2 0.065. Hosmer & Lemeshow *P*-value 0.787.

 Table 4

 Factors Associated With Symptom Relief in Nausea

Relieved Nausea		Univariate Model		Full Model		
Factors	OR	95% CI for OR	<i>P</i> -value	OR	95% CI for OR	<i>P</i> -value
Age at time of death	1.01	0.99 - 1.02	0.369	1.01	0.99-1.02	0.373
Gender						
Male	Ref.			Ref.		
Female	1.01	0.84 - 1.22	0.896	0.94	0.73 - 1.20	0.590
Time at RCHs						
<100 days	Ref.			Ref.		
100-365 days	1.06	0.81 - 1.38	0.667	1.44	1.02 - 2.04	0.039
366 days to five yrs	1.27	1.01 - 1.59	0.044	1.34	0.99 - 1.83	0.061
More than five yrs	1.42	1.04 - 1.93	0.026	1.37	0.91 - 2.06	0.137
Use of validated pain assessment scale	2.04	1.72-2.42	<0.001	1.85	1.42-2.40	< 0.001
Use of validated symptom assessment scale	1.69	1.39-2.07	<0.001	0.85	0.64 - 1.14	0.286
Documented EOL discussions with the residents	1.55	1.30-1.85	<0.001	1.30	1.02-1.66	0.038
Documented EOL discussions with the family members	1.44	1.17-1.78	<0.001	0.79	0.58-1.08	0.133
Consultation from other health care specialists	0.95	0.75 - 1.20	0.662	0.92	0.68 - 1.23	0.559
Examination by a physician last week	1.17	0.98 - 1.41	0.092	1.16	0.93-1.44	0.184
Cancer diagnosis or other diagnoses as cause of death	1.10	0.91 - 1.34	0.310	1.08	0.83 - 1.40	0.571
Presence of pressure ulcers	0.87	0.71 - 1.06	0.159	0.72	0.55 - 0.93	0.012
Assessment of oral health	1.99	1.62 - 2.43	< 0.001	1.60	1.23-2.09	< 0.001
PRN injection nausea	3.64	2.69 - 4.93	< 0.001	2.92	1.91 - 4.49	< 0.001

OR = odds ratio; RCHs = residential care homes; EOL = end-of-life; PRN = pro re nata. Bold text indicates *P*-value <0.05. Nagelkerke R^2 0.092. Hosmer & Lemeshow *P*-value 0.466.

relief. Conversely, consultation with other health care specialists, diseases other than cancer as cause of death, and the presence of pressure ulcers were associated with lower probability of symptom relief (Table 5).

In the full model, use of a validated pain assessment scale, documented EOL discussions with a physician for family members, assessment of oral health, and PRN injections for anxiety were significantly associated with higher probability of anxiety relief, while consultation with other health care specialists was associated with lower probability of symptom relief (Table 5).

Factors Associated With Relief From Shortness of Breath

Seven explanatory variables were significantly associated with relief from shortness of breath in the univariate models (Table 6). A longer time at the RCH, use of validated pain and symptom assessment scales, documented EOL discussions with a physician for both residents and family members, and assessment of oral health were associated with higher probability of relief from shortness of breath (Table 6). Conversely, consultation with other care specialists was associated with lower probability of relief from shortness of breath.

In the full model, use of a validated pain assessment scale, documented EOL discussions with a physician for family members, and assessment of oral health were associated with higher probability of relief from shortness of breath (Table 6).

Summary of Factors Associated With Relief From Pain, Nausea, Anxiety, or Shortness of Breath

Use of a validated pain assessment scale, assessment of oral health, and prescribed PRN injections for pain, nausea, and anxiety were significantly associated with a higher probability of relief from pain, nausea, and anxiety in the multiple logistic regression analyses (Tables 3–5). Use of a validated pain assessment scale and assessment of oral health were significantly associated with a higher probability of relief from shortness of breath (Table 6).

Discussion

The result of this study showed a high prevalence of pain and anxiety among RCH residents in EOL care. However, our results indicate that use of a validated pain assessment scale, assessment of oral health, and prescribed PRN injections for pain, nausea, and anxiety might offer a way to improve EOL care in RCHs. The use of a validated pain assessment scale and assessment of oral health could also help relieve shortness of breath. We cannot say whether prescribed PRN injections for shortness of breath would help

 Table 5

 Factors Associated With Symptom Relief in Anxiety

Relieved Anxiety		Univariate Model		Full Mode			
Factors	OR	95% CI for OR	<i>P</i> -value	OR	95% CI for OR	<i>P</i> -value	
Age at time of death	1.01	1.01-1.02	< 0.001	1.01	1.00-1.02	0.003	
Gender							
Male	Ref.			Ref.			
Female	1.16	1.05 - 1.27	0.003	1.05	0.93 - 1.19	0.488	
Time at RCHs							
<100 days	Ref.			Ref.			
100-365 days	0.95	0.81 - 1.12	0.569	0.89	0.73 - 1.09	0.252	
366 days to five yrs	1.26	1.10 - 1.45	< 0.001	1.17	0.97 - 1.40	0.093	
More than five yrs	1.34	1.12 - 1.60	< 0.001	1.16	0.92 - 1.47	0.205	
Use of validated pain assessment scale	1.66	1.51-1.83	< 0.001	1.42	1.23-1.65	< 0.001	
Use of validated symptom assessment scale	1.56	1.40 - 1.75	<0.001	1.17	0.99-1.38	0.067	
Documented EOL discussions with the residents	1.14	1.03-1.25	0.010	1.02	0.89-1.16	0.817	
Documented EOL discussions with the family members	1.45	1.30-1.62	<0.001	1.23	1.05-1.45	0.012	
Consultation from other health care specialists	0.65	0.57 - 0.74	<0.001	0.69	0.59-0.82	< 0.001	
Examination by a physician last week	0.97	0.88-1.08	0.594	1.03	0.91-1.16	0.636	
Cancer diagnosis or other diagnoses as cause of death	0.80	0.71 - 0.91	<0.001	0.85	0.72 - 1.00	0.051	
Presence of pressure ulcers	0.87	0.77 - 0.98	0.020	0.87	0.75 - 1.01	0.071	
Assessment of oral health	1.65	1.47 - 1.85	< 0.001	1.39	1.20 - 1.60	< 0.001	
PRN injection anxiety	3.93	3.12 - 4.96	< 0.001	3.27	2.37 - 4.50	< 0.001	

OR = odds ratio; RCHs = residential care homes; EOL = end-of-life; PRN = pro re nata. Bold text indicates P-value <0.05. Nagelkerke R^2 0.057. Hosmer & Lemeshow P-value 0.818.

because information on this type of injection is not included in the SRPC.

In line with our results, earlier studies also reported a high prevalence of symptoms at EOL. A Swedish study using data from the SRPC reported that 58.7% of RCH residents had pain during the last week of life, 15 as did 46.5% of those in our earlier study of RCHs from one municipality. ¹⁴ A study from different settings (long- and short-term RCHs, hospitals, and specialist and general palliative home care) reported that pain was most frequent in specialist palliative care inpatient units (83.6%) and least frequent in hospitals (68.2%); RCHs were in-between, with 70.8% of residents experiencing pain.²⁵ One barrier to symptom relief could be that persons at EOL are unable to report or communicate pain.²⁶ Our results are congruent with an earlier study that found that a high degree of RCH residents had dementia disease¹⁴ and many were unconscious some or all of the time at EOL.¹⁴ A metasynthesis found that another barrier to pain management could be that pain has been normalized in RCHs. The older persons had a perception that pain was a natural part of aging, which was confirmed by care professionals and family members.²⁷

To our knowledge, this is the first study identifying factors associated with symptom relief in EOL care in RCHs. In both the univariate and

multiple logistic regressions, the use of a validated pain symptom assessment scale was significantly associated with relief of pain, nausea, anxiety, and shortness of breath. Despite this, recent studies have shown that symptom assessment scales are seldom used in dying patients with end-stage kidney disease²⁸ and heart failure.²⁹ One explanation could be that persons at EOL may have restricted verbal communication, making it hard for them to express their needs. Symptom assessment of persons with dementia disease is highly complex. It is not easy to capture nuanced and detailed observation of muscle tone, facial expressions, and gesstandardized assessment However, proxy ratings using behavioral or observational symptom scales²⁶ could be a complement. A study exploring differences between patients' and nurses' assessments regarding presence of symptoms among hospice patients found that there was a good concordance, but the nurses underestimated the intensity of the symptoms.³¹ An intervention study conducted among nursing homes in a Swedish municipality found that nurses were not only initially positive about the use of pain assessment scales but that this positive attitude seemed to be strengthened by continued assessment and the nurses' perceptions of improved pain relief. However, there were no significant differences in

 Table 6

 Factors Associated With Symptom Relief in Shortness of Breath

Relieved Shortness of Breath		Univariate Model	Univariate Model			Full Model	
Factors	OR	95% CI for OR	<i>P</i> -Value	OR	95% CI for OR	<i>P</i> -Value	
Age at time of death	1.00	0.99 - 1.01	0.499	1.00	0.99 - 1.02	0.709	
Gender							
Male	Ref.			Ref.			
Female	1.11	0.97 - 1.28	0.144	1.13	0.94 - 1.35	0.182	
Time at RCHs							
<100 days	Ref.			Ref.			
100-365 days	1.10	0.87 - 1.39	0.444	0.95	0.70 - 1.27	0.717	
366 days to five yrs	1.33	1.08 - 1.63	0.007	1.22	0.94 - 1.58	0.142	
More than five yrs	1.43	1.11 - 1.85	0.006	1.26	0.91 - 1.76	0.168	
Use of validated pain assessment scale	1.57	1.36-1.82	< 0.001	1.49	1.19-1.85	< 0.001	
Use of validated symptom assessment scale	1.55	1.31-1.82	<0.001	1.12	0.88 - 1.42	0.369	
Documented EOL discussions with the residents	1.21	1.05-1.40	0.010	1.02	0.84 - 1.24	0.820	
Documented EOL discussions with the family members	1.52	1.28-1.81	<0.001	1.33	1.05-1.70	0.019	
Consultation from other health care specialists	0.78	0.64 - 0.96	0.019	0.85	0.66-1.09	0.201	
Examination by a physician last week	1.02	0.87-1.19	0.828	1.07	0.89 - 1.28	0.491	
Cancer diagnosis or other diagnoses as cause of death	0.96	0.78 - 1.17	0.655	0.99	0.76 - 1.29	0.926	
Presence of pressure ulcers	1.00	0.84 - 1.20	0.994	0.96	0.77 - 1.20	0.701	
Assessment of oral health	1.63	1.38 - 1.93	< 0.001	1.28	1.03 - 1.58	0.028	

OR = odds ratio; RCHs = residential care homes; EOL = end-of-life.

Bold text indicates P-value <0.05. Nagelkerke R^2 0.042. Hosmer & Lemeshow P-value 0.222

either pain or well-being between the intervention group and the control group.³²

In our study, prescribed PRN injections were significantly associated with symptom relief for pain, nausea, and anxiety. Earlier studies from different settings (general care, specialist palliative home care, RCHs long/short term, hospital, hospice) found that PRN injections were often prescribed but care professionals still reported insufficient symptom relief. ^{27,29} This is congruent with our results; although most of the residents had been prescribed PRN injections for pain (97.4%), nausea (90.4%), and anxiety (97.0%), the proportions reporting total relief were lower (pain 84.7%, nausea 58%, anxiety 77.0%).

A noteworthy result in our study is that assessment of oral health was associated with symptom relief from pain, nausea, anxiety, and shortness of breath. A recent registry study showed that among patients who died of stroke or cancer, just over 60% underwent assessment of oral health during the last week of life, whereas in 16% of cases, it was not known whether this took place. Is In an international qualitative study, staff were asked to list the nonpharmacological caregiving activities they performed in the last days of a patient's life; the results showed that mouth care was usually integrated with other caregiving activities. In light of the present study, this could indicate that more attention to oral care might be associated with higher quality of EOL care. The results also indicated

that consultation with other health care specialists, cancer diagnosis as cause of death, and pressure of ulcers were associated with lower probability of relief from pain and anxiety. It is reasonable that these factors are related to those who experience high symptom burden. Residents who had received hospice care in RCHs had more often pain than those who did not receive hospice care. Furthermore, older people who received hospice care more often received pain management. An earlier study had reported that consultation with palliative care specialists, compared with no consultations, had reduced hospitalization in the last 30 days of life. However, further research is needed.

Methodological Considerations

The data in the SRPC were reported by care professionals rather than the residents themselves or their family members; this could be a limitation. There is also a risk of recall bias because the SRPC questionnaire is completed retrospectively. Given the cross-sectional nature of the data, the results do not allow for a causal relation to be inferred between factors associated with symptom relief. Older age could have an unpredictable trajectory; therefore, there is a risk that these patients may have been misclassified as an expected or unexpected death. Another selection bias could be that participating units in SRPC were

the most positive to palliative care. However, the strengths of the study are that the SRPC covers the majority (64.3%) of all deaths in Sweden and the register is continually validated. ^{22,36}

Conclusions and Clinical Implications

We found a high prevalence of pain and anxiety and inadequate symptom management among RCH residents in EOL care. The results indicate that use of a validated pain assessment scale, assessment of oral health, and prescribed pro re nata injections for pain, nausea, and anxiety might offer a way to improve symptom relief. These clinical tools and medications should be implemented in the care of the dying in RCHs, and controlled trials should be undertaken to prove the effect.

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References

- 1. WHO. World Report on Ageing and Health, 2015. Available from http://apps.who.int/iris/bitstream/10665/186463/1/9789240694811_eng.pdf?ua=1. Accessed October 1, 2017.
- 2. Morin L, Aubry R, Frova L, et al. Estimating the need for palliative care at the population level: a cross-national study in 12 countries. Palliat Med 2017;31:526–536.
- 3. British Geriatrics Society BGS. Palliative and end of life care for older people. London: British Geriatrics Society, 2010. Available from http://www.bgs.org.uk/good-practice-guides/resources/goodpractice/palliativecare. Accessed October 1, 2017.
- 4. WHO. Palliative care for older people: better practices. Copenhagen: World Health Organization, Regional Office for Europe, 2011.
- 5. Lindskog M, Tavelin B, Lundström S. Old age as risk indicator for poor end-of-life care quality—a population-based study of cancer deaths from the Swedish Register of Palliative Care. Eur J Cancer 2015;51:1331—1339.
- **6.** Evans CJ, Ho Y, Daveson BA, et al. Place and cause of death in centenarians: a population-based observational study in England, 2001 to 2010. PLoS Med 2014;11:e1001653.
- 7. Reyniers T, Deliens L, Pasman HR, et al. International variation in place of death of older people who died from dementia in 14 European and non-European countries. J Am Med Dir Assoc 2015;16:165–171.
- 8. Håkanson C, Ohlén J, Morin L, Cohen J. A population-level study of place of death and associated factors in Sweden. Scand J Public Health 2015;43:744–751.

- 9. Davies EH, Higginson IJ. Better palliative care for older people. World Health Organization. Copenhagen: WHO Regional Office for Europe, 2004.
- 10. Davis J, Shute J, Morgans A. Supporting a good life and death in residential aged care: an exploration of service use towards end of life. Int J Palliat Nurs 2016;22:424–429.
- 11. Penders YW, Van den Block L, Donker GA, et al. Comparison of end-of-life care for older people living at home and in residential homes: a mortality follow-back study among GPs in The Netherlands. Br J Gen Pract 2015;65: e724–730.
- 12. de Boer D, Hofstede JM, de Veer AJE, Raijmakers NJH, Francke AL. Relatives' perceived quality of palliative care: comparisons between care settings in which patients die. BMC Palliat Care 2017;16:41.
- 13. WHO. WHO definition of palliative care, 2002. Available from http://www.who.int/cancer/palliative/definition/en/. Accessed October 10, 2017.
- 14. Andersson S, Lindqvist O, Fürst CJ, Brännström M. Endof-life care in residential care homes: a retrospective study of the perspectives of family members using the VOICES questionnaire. Scand J Caring Sci 2016;31:72–84.
- 15. Smedbäck J, Öhlén J, Årestedt K, et al. Palliative care during the final week of life of older people in nursing homes: a register-based study. Palliat Support Care 2017; 15:417–424.
- **16.** Radbruch L, de Lima L, Lohmann D, Gwyther E, Payne S. The Prague Charter: urging governments to relieve suffering and ensure the right to palliative care. Palliat Med 2013;27:101–102.
- 17. Van Lancker A, Velghe A, Van Hecke A, et al. Prevalence of symptoms in older cancer patients receiving palliative care: a systematic review and meta-analysis. J Pain Symptom Manage 2014;47:90—104.
- 18. Eriksson H, Milberg A, Hjelm K, Friedrichsen M. End of life care for patients dying of stroke: a comparative registry study of stroke and cancer. PLoS One 2016;11:e0147694.
- **19**. Ahmadi Z, Wysham NG, Lundström S, et al. End-of-life care in oxygen-dependent ILD compared with lung cancer: a national population-based study. Thorax 2016;71:510—516.
- **20.** Brännström M, Hägglund L, Fürst CJ, Boman K. Unequal care for dying patients in Sweden: a comparative registry study of deaths from heart disease and cancer. Eur J Cardiovasc Nurs 2012;11:454–459.
- 21. Brännström M, Fürst CJ, Tishelman C, Petzold M, Lindqvist O. Effectiveness of the Liverpool care pathway for the dying in residential care homes: an exploratory, controlled before-and-after study. Palliat Med 2015;30: 54–63.
- 22. Lundström S, Axelsson B, Heedman PA, Fransson G, Fürst CJ. Developing a national quality register in end-of-life care: the Swedish experience. Palliat Med 2012;26: 313–321.
- 23. SRPC. Årsrapport för Svenska palliativregistret verksamhetsåret 2016, 2017. Available from http://media.palliativ.se/2017/03/Svenska-palliativregistret-%C3%85rsrapport-2017.pdf. Accessed October 15, 2017.
- 24. Moens K, Higginson IJ, Harding R, EURO IMPACT. Are there differences in the prevalence of palliative care-related problems in people living with advanced cancer and eight

- non-cancer conditions? A systematic review. J Pain Symptom Manage 2014;48:660–677.
- 25. Carlsson ME, Gunningberg L. Predictors for development of pressure ulcer in end-of-life care: a national quality register study. J Palliat Med 2017;20:53–58.
- **26.** Herr K, Coyne PJ, McCaffery M, Manworren R, Merkel S. Pain assessment in the patient unable to self-report: position statement with clinical practice recommendations. Pain Manag Nurs 2011;12:230–250.
- **27.** Vaismoradi M, Skär L, Söderberg S, Bondas TE. Normalizing suffering: a meta-synthesis of experiences of and perspectives on pain and pain management in nursing homes. Int J Qual Stud Health Well-being 2016;11:31203.
- 28. Axelsson L, Alvariza A, Lindberg J, et al. Unmet palliative care needs among patients with end-stage kidney disease: a national registry study about the last week of life. J Pain Symptom Manage 2018;55:236—244.
- 29. Årestedt K, Alvariza A, Boman K, et al. Symptom relief and palliative care during the last week of life among patients with heart failure: a national register study. J Palliat Med 2017, https://doi.org/10.1089/jpm.2017.0125. [Epub ahead of print].
- **30.** Koppitz A, Bosshard G, Kipfer S, Imhof L. Decision-making in caring for people with dementia at the end of life in nursing homes. Int J Palliat Nurs 2016;22:68—75.

- 31. de Graaf E, Zweers D, de Graeff A, Stellato RK, Teunissen S. Symptom intensity of hospice patients: a longitudinal analysis of concordance between patients' and nurses' outcomes. J Pain Symptom Manage 2018;55: 272–281.
- 32. Mamhidir AG, Sjölund BM, Fläckman B, et al. Systematic pain assessment in nursing homes: a cluster-randomized trial using mixed-methods approach. BMC Geriatr 2017;17:61.
- **33.** Lindqvist O, Tishelman C, Hagelin CL, et al. on behalf of OPCARE9. Complexity in non-pharmacological caregiving activities at the end of life: an international qualitative study. PLoS Med 2012;9:e1001173.
- 34. Hunnicutt J, Tjia J, Lapane K. Hospice use and pain management in elderly nursing home residents with cancer. J Pain Symptom Manage 2017;53:561–570.
- 35. Miller S, Dahal R, Lima J, et al. Palliative care consultations in nursing homes and end-of-life hospitalizations. J Pain Symptom Manage 2017;52:878–883.
- **36.** Martinsson L, Heedman PA, Lundström S, Fransson G, Axelsson B. Validation study of an end-of-life questionnaire from the Swedish Register of Palliative Care. Acta Oncol 2011;50:642–647.