Registration in a quality register: a method to improve end-of-life care - a cross sectional study

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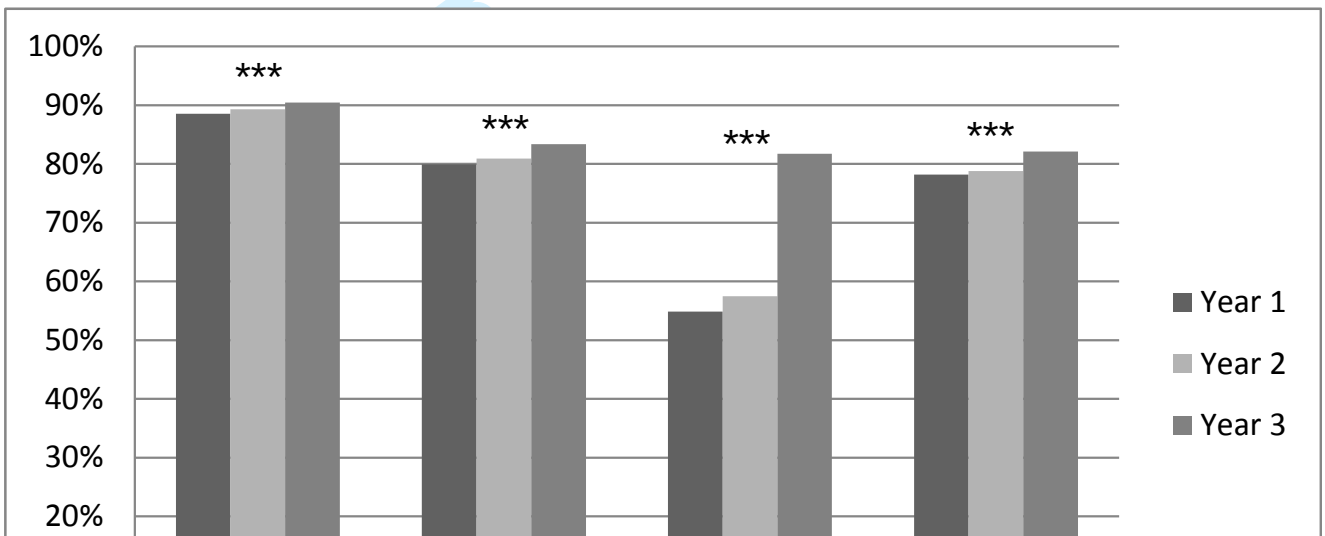
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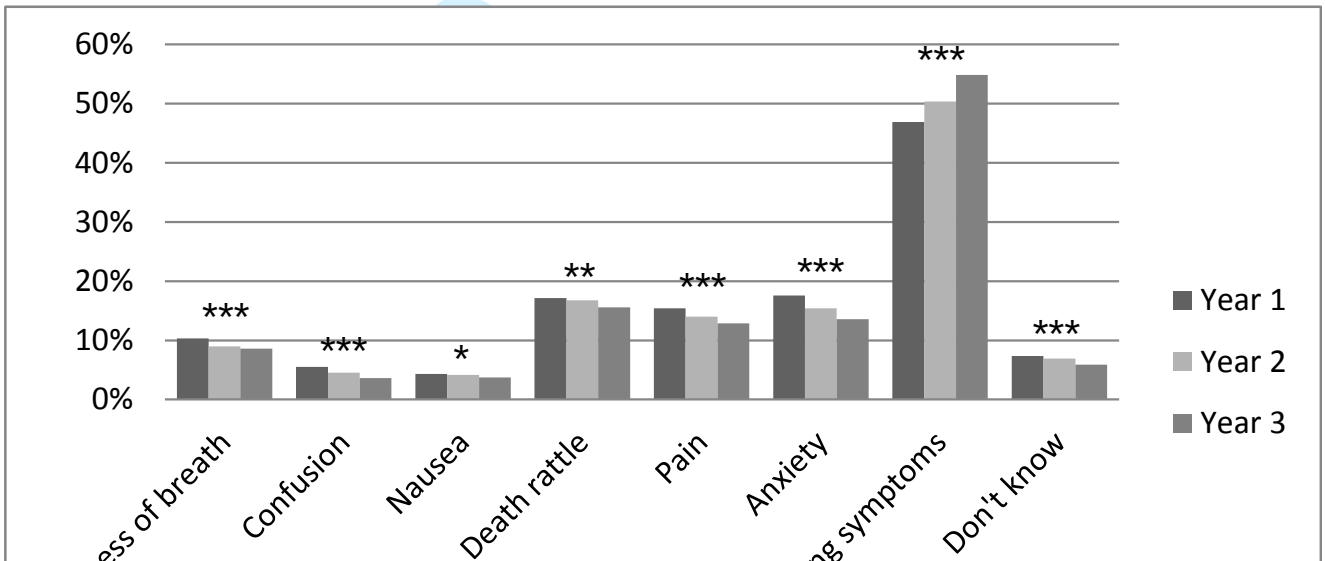
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Shortness of breath
Confusion
Nausea
Death rattle
Pain
Anxiety
No distressing symptoms
Don't know
Year 1
Year 2
Year 3

The end-of-life questionnaire (ELQ) 1 May 2007 – 30 June 2010

The Swedish Palliative Register Form to be filled out in connection with the death of a person.

To be filled in by the responsible doctor or nurse. All reports are to be submitted through www.palliativ.se

1. Unit code _____ (received at registration of participation through the website www.palliativ.se)
2. Social insurance identification number_____
3. Name of the deceased_____ (used first name and surname)
4. Area code_____
5. Sex
   - Male
   - Female
6. Date of admission to the unit where death occurred (for primary care/home care = "active home care")_____
7. Date of death_____
8. The place of death is best described as a:
   - Nursing home
   - Short-term care home
   - Hospital ward – not palliative
   - Hospice/palliative hospital ward
   - Own home, with support from specialized palliative home care
   - Own home, with support from basal home care
   - Other_____
9. Main disease that caused death:
   - Cancer
   - Heart disease
   - Lung disease
   - Dementia
   - Stroke
   - Other neurological disease
   - Infection
   - Diabetes
   - Other, namely_____
10. Will a forensic autopsy be performed?
    - Yes
    - No

If the answer to question 10 is yes, then the questionnaire is completed. If death was caused by disease, please also answer the following questions.

11. According to the deceased's medical history, death was
    - Expected
    - Not expected
    - Don't know
12. Which date, closest before death, did a doctor visit/examine the patient/person receiving care?_____
13. Has an informing conversation with the patient about impending death taken place, during the last period in life?

- No
- Yes, by a doctor
- Yes, by a nurse
- Yes, by both a doctor and a nurse
- Don't know

14. Has an informing conversation with the patient's next of kin about the impending death of the patient/person receiving care taken place, during the last period in life?
    - No
    - Yes, by a doctor
    - Yes, by a nurse
    - Yes, by both a doctor and a nurse
    - Don't know
15. How long before death did the patient/person receiving care loose his/her ability of self-determination?
    - Hours
    - Days
    - Weeks
    - Months
    - Years
    - Don't know
16. Have a VAS or NRS scale (0-10) been used for evaluation of pain during the last week of the patient's life?
    - Yes
    - No
    - The patient cannot participate
    - Don't know
17. Mark the symptom(s) that was/were not fully alleviated during the last week of life.
    - Shortness of breath
    - Confusion
    - Nausea
    - Death rattle
    - Pain
    - Anxiety
    - Other_____
    - No distressing symptoms
    - Don't know
18. Has special competence outside the team/ward been consulted regarding the patient's not completely alleviated symptoms?
    - No
    - Yes, profession/speciality_____
19. Did the person receiving care/patient have pressure ulcers in the last week of life?
    - Grade 1
    - Grade 2
    - Grade 3
    - Grade 4
    - No
    - Don't know
20. Was medication prescribed for use as needed in the form of injections, at least one day before death, for:

- Pain

- Yes
- No

- Death rattle
  - Yes
  - No
- Nausea
  - Yes
  - No
- Anxiety
  - Yes
  - No

21. Who was present at the moment of death?
  - Staff
  - Next of kin
  - Staff and next of kin
  - No one

22. Did the place of death correspond with the person receiving care's/patient's latest spoken wish?
  - Yes
  - No
  - Don't know

23. In how many other places (e.g. home, different wards, nursing home, short-term care home) than the place of death was the person receiving care/patient cared for during the last 2 weeks of life?
  - 0
  - 1
  - 2
  - 3
  - >3
  - Don't know

24. Have the next of kin had or will they be offered a follow-up appointment some time after death?
  - Yes
  - No
  - Don't know

25. Are you content with the end-of- life care provided for the person receiving care/patient?

Not at all
  - 1
  - 2
  - 3
  - 4
  - 5

Completely

26. Date the questions were answered _____

27. Answered by_____ (name)
  - Doctor
  - Nurse

E-mail address_____

STROBE 2007 (v4) Statement—Checklist of items that should be included in reports of *cross-sectional studies*

Section/Topic	Item #	Recommendation	Reported on page #
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract	1, 2
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found	2
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	3, 4
Objectives	3	State specific objectives, including any prespecified hypotheses	4
Methods			
Study design	4	Present key elements of study design early in the paper	4, 5, 6
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	5, 6
Participants	6	(*a*) Give the eligibility criteria, and the sources and methods of selection of participants	5
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	6
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	5, 6
Bias	9	Describe any efforts to address potential sources of bias	see discussion, page 14
Study size	10	Explain how the study size was arrived at	5
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	6
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding	6
		(*b*) Describe any methods used to examine subgroups and interactions	6
		(*c*) Explain how missing data were addressed	No missing data, see page 5
		(*d*) If applicable, describe analytical methods taking account of sampling strategy	-

		(*e*) Describe any sensitivity analyses	-
Results			
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	7-8
		(b) Give reasons for non-participation at each stage	-
		(c) Consider use of a flow diagram	-
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	Table 1, page 7-8
		(b) Indicate number of participants with missing data for each variable of interest	No missing data, see page 5
Outcome data	15*	Report numbers of outcome events or summary measures	7-11
Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	7-11
		(*b*) Report category boundaries when continuous variables were categorized	-
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	-
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	-
Discussion			
Key results	18	Summarise key results with reference to study objectives	11
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	14
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	12-15
Generalisability	21	Discuss the generalisability (external validity) of the study results	15
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	See submission form

*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.

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Addendum 1: End-of-life-questionnaire

ABSTRACT (subheading level A)

Objectives: Structured methods to assess and support improvement in the quality of end-of-life care are lacking and need to be developed. This need is particularly high outside specialized palliative care. This study examines whether participation in a national quality register increased quality of end-of-life care. *Design:* This study is a cross sectional longitudinal register study. *Setting:* The Swedish Register of Palliative Care (SRPC) collects data about end-of-life care for deaths in all types of health care units all over Sweden. Data from all 503 health care units that had reported patients to the register during a three-year period were analysed. *Primary and secondary outcome measures:* Data on provided care during the last weeks of life were compared year-by-year with logistic regression. Subgroup analysis for different places of death was performed. *Participants:* The study included a total 30,283 patients. The gender distribution was 54 % women and 46 % men. 60 % of patients in the study had a cancer diagnosis. *Results:* Provided end-of-life care improved in a number of ways. The prevalence of six examined symptoms decreased. The prescription of p.r.n. medications for pain, nausea, anxiety, and death rattle increased. A higher proportion of patients died in their place of preference. The patient's next of kin was more often offered a follow-up appointment after the patient's death. No changes were seen with respect to providing information to the patient or next of kin. *Conclusions:* Participation in a national quality register appears to contribute to quality improvements in end-of-life care over time.

INTRODUCTION (subheading level A)

Structured methods to assess and support improvement in the quality of end-of-life care are lacking and need to be developed. Approximately 91,000 people die annually in Sweden,[1] which corresponds to about 1% of the Swedish population. About 80% of all deaths are "non-sudden", implying potential need for palliative care.[2] In Sweden, approximately 7-8% of dying patients were cared for in specialized palliative care and approximately 40-50% of dying patients were cared for in nursing homes and short-term care homes.[1] There is still a need to develop end-of-life care in many areas. Data from the Swedish Register of Palliative Care (SRPC) shows that end-of-life care has the potential for further improvement especially in care not provided by specialised palliative care units.[1]

As of 2011, there are 89 national quality registers in Sweden which are financed by Swedish local authorities and regions. Quality registers enable monitoring of care quality, quality care improvement, and clinical research. Sweden has unique opportunities for quality registers because Sweden has comprehensive population registers and unique personal identification numbers. As early as 1975, the first quality register in Sweden – the Swedish Knee Arthroplasty Register – started. Many quality registers focus on specialized care and specific treatments, but in recent years they have also begun to address a broader patient population, including dying people. The Swedish Register of Palliative Care (SRPC) is an example of this type of register. Swedish local authorities and regions invest in quality registers that focus on the elderly with multiple diseases, including SRPC.[3, 4]

Several studies on improvement of quality in palliative care or end-of-life care have been published. Preliminary results using benchmarks to develop palliative care in Catalonia have been presented.[5] In North Carolina (USA), a project for developing a regional database for community-based palliative care has been established.[6]. In addition, the Liverpool Care Pathway for the dying patient (LCP) has been used in several studies and settings to improve end-of-life care. A multi-centre study including hospital wards, palliative nursing homes, regular nursing homes, and home care showed that the use of LCP improved symptom alleviation and increased documentation of end-of-life care issues.[7] Another study showed that the use of LCP in a hospital improved staff knowledge about physical symptom management and increased awareness of problems related to end-of-life care.[8] A method based on LCP was shown to improve end-of-life care in emergency medicine.[9]

Several studies have used register work to improve various areas including stroke, myocardial infarction, cardiac rehabilitation, trauma and in vitro fertilization,[10-14] but no studies reporting nation-wide quality registers with effect on end-of life care quality were found. This study examines whether participation in the SRPC during a three-year period (from May 2007 to April 2010) increased the quality of palliative care regarding eight predetermined quality indicators of good end-of-life care such as symptom alleviation and information provided to patient and next of kin.

METHODS (subheading level A)

Since 2005, the Swedish Register of Palliative Care (SRPC), one of the Swedish national quality registers, has been measuring the quality of end-of-life care.[4]

During 2010, 34.5% of all deaths nationwide were reported to the register.[1] Data is collected through a questionnaire with items based on different essential aspects of end-of-life care as proposed by British Geriatrics Society.[15] Items concern providing information to patients and next of kin, alleviating pain and other distressing symptoms, prescribing necessary drugs, and fulfilling the wish of preferred place of death. The questionnaire is answered by the responsible nurse and/or physician as soon as a patient dies. (See the supplementary material for a translated version of the questionnaire). All questions have to be answered before submission, leading to no missing data. Deaths are reported to the register from all types of health care units. Descriptive data is published continuously on the register website (www.palliativ.se). The individual health care unit has continuous access to its own results online and can use this as a basis for self-improvement.

The version of the questionnaire that was used to collect data was launched in May 2007. Data from May 2007 to April 2010 were used in this study. To examine change over time, only data from the health care units that had reported patients all three years were used. Some units reported patients who eventually died at another type of unit, but since the aim of this study was to examine the effect of using the register on the health care units and the palliative care provided, these patients were not included in the study. Eleven health care units changed their unit type during the study period. These eleven units are characterized as they were defined at the baseline and these are the characteristics used in the results section and in the tables.

Data were compared year-by-year to examine if there was a systematic change in the answers, indicating a possible change in the quality of end-of-life care. The questionnaire contains 27 questions and eight questions about the provided care in the last weeks of life were analysed. The remaining 16 questions (not analysed) cover background information, social demographics, and patient characteristics. The eight items analysed in the study included the following: information provided to the patient about imminent death; information provided to next of kin of the imminent death; whether six symptoms were fully alleviated during the last week of life; whether p.r.n. medications in the form of injections for pain, nausea, anxiety, and death rattle were prescribed at least one day before death; whether the patient had pressure ulcers (graded from 1-4 according to the European Pressure Ulcer Advisory Panel) during the last week of life; whether next of kin and/or staff was present at the moment of death; whether the place of death corresponded to the patient's last spoken wish; and whether next of kin were offered a follow-up appointment after death of the patient. Further details about the questions are presented in the supplementary material.

Data were analysed using logistic regression in the statistic program Stata version 11.0 from StataCorp LP. Subgroup analyses for the five most common places of death were performed. In the analysis of the item concerning information to the patient, only patients without cognitive impairment were included. Cognitive impairment was defined as present when the patient was registered as having lost the ability of self-determination weeks before death or earlier. In the two questions about information, information from the doctor was emphasised because physician

participation was deemed most essential. In question number 19 (pressure ulcers), the ulcers are graded from 1 to 4 according to the European Pressure Ulcer Advisory Panel.[16] P-values below 0.05 were considered significant.

RESULTS (subheading level A)

A total of 30,283 patients reported by 503 health care units were included in this study. Table 1 shows detailed information of the patients regarding the total number of patients, the number patients with of cancer diagnoses, the distribution of women and men, and the number of patients with cognitive impairment. Some aspects of the care in the specialist palliative care were high at baseline. In specialized palliative home care, 94% of the patients died at their preferred place of death, 97% of the patients' next of kin were offered a follow-up appointment, and 93% of the patients had p.r.n. pain medication prescribed. In hospices/palliative hospital wards, 92% of the next of kin were offered a follow-up appointment, 98% of the patients were given p.r.n. medication prescription, 95% of the patients were given anxiety medication, and 92% of the patients were given death rattle medication.

Table 1. Detailed information of the patients in this study.

Place of death		Year 1 (n=)	Year 2 (n=)	Year 3 (n=)	Total (n/%=)
All (503 units)	Patients	7,584	11,409	11,290	30,283
	With cancer	4,814	6,631	6,793	18,238 (60%)
	Cognitively impaired*	1,627	2,527	2,200	6,354 (21%)
	Women	4,073	6,208	6,061	16,342 (54%)
	Men	3,511	5,201	5,229	13,941 (46%)
Hospice/palliative	Patients	2,948	3,739	3,793	10,480

hospital ward (39 units)	With cancer	2,790	3,502	3,540	9,832 (94%)
	Cognitively impaired*	337	312	289	938 (9%)
	Women	1,515	1,979	1,986	5,480 (52%)
	Men	1,433	1,760	1,807	5,000 (48%)
Nursing home (233 units)	Patients	1,628	2,691	2,488	6,807
	With cancer	186	305	287	778 (11%)
	Cognitively impaired*	834	1,444	1,206	3,484 (51%)
	Women	1,050	1,734	1,575	4,359 (64%)
	Men	578	957	913	2,448 (36%)
Specialized palliative home care (60 units)	Patients	1,097	1,532	1,704	4,333
	With cancer	994	1,375	1,518	3,887 (90%)
	Cognitively impaired*	71	119	108	298 (7%)
	Women	519	744	798	2,061 (48%)
	Men	578	788	906	2,272 (52%)
Hospital ward, not palliative (88 units)	Patients	1,333	2,456	2,292	6,081
	With cancer	601	975	931	2,507 (41%)
	Cognitively impaired*	249	501	445	1,195 (20%)
	Women	679	1,258	1,207	3,144 (52%)
	Men	654	1,198	1,085	2,937 (48%)
Short-term care home (56 units)	Patients	508	856	869	2,233
	With cancer	214	407	450	1,071 (48%)
	Cognitively impaired*	120	130	129	479 (21%)
	Women	276	417	424	1,117 (50%)
	Men	232	439	445	1,116 (50%)
Basal home care (27 units)	Patients	70	135	144	349

* Reported to have lost their ability of self-determination weeks before death or earlier.

The prevalence of not fully alleviated symptoms (question number 17) during the study years is presented in Figure 1. During the first study year, the prevalence of distressing symptoms was 10% for shortness of breath, 6% for confusion, 4% for

nausea, 17% for death rattle, 15% for pain, and 17% for anxiety. Reductions in prevalence were seen over time for all symptoms. The use of "Don't know" answers decreased. No decrease in symptoms was seen at nursing homes. Hospital wards (not palliative) showed decrease for pain only, while the other types of care units showed decreases in three or more symptoms.

The item concerning prescription of p.r.n. drugs at least one day before death (question number 20) is presented in Figure 2. Prescriptions against all four symptoms increased. The largest increase was seen for p.r.n. drugs against nausea, from 55% to 82% of the patients. The increase was seen in all types of care units. Nursing homes and hospital wards (not palliative) showed an increase in p.r.n. prescriptions for all registered symptoms.

The item concerning whether the place of death corresponded to the patient's last spoken wish (question number 22) is presented in Table 2. There was a significant trend towards more patients dying in their preferred place of death. A significant trend towards more next of kin being offered follow-up appointments after death of the patient (question number 24) was seen (Table 2).

Table 2. Changes during the study years shown for total and divided into the five subgroups regarding preferred place of death, information to patient and next of kin,

presence at the moment of death, and follow-up appointment offered. Question number from the end-of-life questionnaire is shown.

	Total	Nursing home	Short-term care home	Hospital ward, not palliative	Hospice/ palliative hospital ward	Specialized palliative home care
13. Information from doctor to patient*	N.S.	N.S.	29% → 37% p=0.022	N.S.	75% → 78% p=0.007	76% → 81% p=0.005
14. Information from doctor to next of kin	N.S.	N.S.	53% → 62% p=0.004	N.S.	88%→ 91% p<0.001	N.S.
21. Next of kin and staff present at moment of death	24% → 23% p=0.031	21% → 19% p=0.029	N.S.	N.S.	N.S.	N.S.
21. Next of kin without staff present at moment of death	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.
21. Only staff present at moment of death	21% → 23% p=0.003	N.S.	N.S.	21% → 25% p=0.007	N.S.	N.S.
21. No one present at the moment of death	N.S.	N.S.	N.S.	25% → 22% p=0.007	N.S.	N.S.
22. Place of death corresponded to preference	48% → 50% p=0.001	31% → 35% p=0.020	21% → 33% p<0.001	N.S.	60% → 66% p<0.001	N.S.
24. Next of kin offered follow-up appointment	72% → 74% p=0.001	54% → 63% p<0.001	38% → 70% p<0.001	N.S.	N.S.	N.S.

*Only including patients without cognitive impairment.

The item whether next of kin and/or staff was present at the time of death (question number 21) is presented in Table 2. The proportion of patients dying alone did not change in the whole material. However, a decrease was seen in hospital wards (not palliative). No improvements were seen over time regarding prevalence of pressure ulcers (question number 19). On the contrary, the total number of patients with pressure ulcers grade 1 (graded according to the European Pressure Ulcer Advisory Panel) increased from 9.1% to 10.2%. The number of patients with higher grades of pressure ulcers was unchanged.

No important changes were seen regarding providing information to patients about their imminent death (question number 13) or information to next of kin about the patient's imminent death (question number 14) (Figures 1 and 2 and Table 2). No changes were seen when examining the information given by doctors. The amount of "Don't know" answers decreased regarding providing information to patients.

DISCUSSION (subheading level A)

We have found that structured assessment of end-of-life care using a national quality register can improve care given to dying patients. Large improvements were seen in prevalence of distressing symptoms during the last week of life and prescription of p.r.n. medication for symptom alleviation. The improvements could be demonstrated despite the relatively short study period. The large number of included patients strengthens these findings.

Even if causality cannot be proven, the regular use of SRPC probably contributed to the seen improvements by providing clear lists of important care activities and an opportunity to evaluate each care episode. The principal nurse, or sometimes the principal doctor, via registration of each deceased patient had the opportunity to comprehensively evaluate that patient's end-of-life care. Furthermore, the possibility of immediate web-generated feedback from the SRPC with detailed diagrams illustrating the results over time produced by the reporting care unit compared to similar care units nationwide provides a unique possibility to identify the care activities in most urgent need of improvement. We believe it is likely that these SRPC generated activities over a three-year period have influenced the provided end-of-life care in the desired direction. To a certain extent, the identified improvements could also be due to better documentation and/or staff awareness, both positively contributing to enhanced continuity in care and validity of collected data. The consistency of observed changes in a positive direction and that all involved units were unaware of this study lessen the risk for systematic bias.

The results of this study also confirm that the SRPC as a register is widely applicable in all kinds of care units where end-of-life care is provided and that the potential for improvements are more pronounced outside specialized palliative care. As the coverage of SRPC within specialized palliative units is estimated to be close to 100%, we assume that approximately 7-8% of dying patients nationwide receive end-of-life care at specialized palliative units. Accordingly, the vast majority (about 70%) of the population has to rely on hospital wards, nursing homes, and non-specialized home care for their end-of-life care. If the use of SRPC in these care contexts can

contribute to measurable improvements of end-of life care, the potential impact over time may be immense.

The trend that more patients were prescribed p.r.n. medications for symptom alleviation is encouraging. The level of nausea medication prescription is approaching the prescription levels for the other three symptoms. Only having a prescription for as needed medication does not necessarily mean that the patient suffers less from symptoms, but an adequate prescription is most often a prerequisite for providing immediate relief from symptoms. The trend that lower grade of pressure ulcers increased during the study years does not necessarily mean that pressure ulcers increased. The increase of lesser degree pressure ulcers may be a sign of increased staff awareness.

The widely differing prevalence of cancer (11-94%) and cognitive impairment (7-51%) between different unit types illustrates that they represent different patient populations. These different case-mixes imply different challenges considering end-of-life care and disqualify direct comparisons between different unit types. Hospital wards have probably the most varied patient selections and many of these are resource consuming. Nursing homes and short-term care homes showed marked improvement. The specialized palliative care units performed well in many items leaving limited room for further improvements. For this reason, it is likely that a similar study including only health care units without palliative specialization could have shown greater improvements.

There are some methodological weaknesses with this study. Since the questionnaires are answered retrospectively, recall bias could have affected the results. It is, however, unlikely that recall bias alone could have given systematic positive changes over time. The results could possibly also be affected by a change in interpretation of answering alternatives, the response shift. Although the use of output register data for evaluation at the units is one of the potential mechanisms for the improvement caused by SRPC, this study did not examine to what extent this has been done during the study period. We cannot say how much of the positive changes seen in this study were the result of participating in SRPC. A number of possible factors could have affected the results. The contributions of each are not possible to identify by this study. In addition to the work of the SRPC, the change in society during the study years cannot easily be measured. There has been an increased focus on end-of-life care and the dying process in medicine and in public discourse, but neither of these has been measured in this study. During the studied years, no national health care programs on palliative medicine or palliative care have been launched, but some local areas have started their own palliative programs. This could also have influenced the participating units.

It was not found in the literature how many patients do not want to die alone or who these patients want to be with at the time of their death. According to a Swedish report, many health professionals think that a dignified death means not dying alone.[17] One study found that 87% of terminally ill cancer patients wished to die at home.[18] Another study including patients with congestive heart failure, chronic obstructive pulmonary disease, and pneumonia found that only 43% preferred to

have terminal care at home, while 48% preferred hospitals.[19] The litterature is consistent with the finding in this study that almost all patients in specialized palliative home care (91% cancer patients) died in their preferred place of death. Some patients are not able to communicate their wishes. Almost half of the patients with unknown wishes could represent those who lost their ability of self-determination weeks before death or earlier (Table 1). The other half of those with unknown wishes probably were able to declare their preference if asked. The proportion of patients dying at a place they did not prefer could be close to its possible limit because it is probably inevitable that a small proportion of patients can not have their wishes fulfilled. The proportion of "Don't know" answers was reduced over the studied years, which implies both data quality and health care improvements.

Although the presented data shows that palliative care has improved over the years, there is still potential for further improvement. A regular monitoring of provided end-of-life care enables continuous feedback and constructive discussions for further improvements. Registrations in the SRPC can probably only increase the quality to some extent, as the results suggest. More studies are needed to investigate the possibility of quality improvement in end-of-life care with more extensive actions. It is possible that additional improvements can be achieved with the help of SRPC by combining questionnaire collecting with information to and training for concerned health care professionals and/or prospective use end-of-life care pathways (e.g., Liverpool Care Pathway for the dying patient). Other ways to collect data on patients in end-of-life care should also be reviewed, such as designing a similar questionnaire

to be answered by patients in palliative care or by their next of kin. Methods to promote greater use of evaluation of registry data at the individual units are also options that should be reviewed. Regardless of which means are used to accomplish better end-of-life care, results in SRPC can be an easy and efficient way to monitor improvements and identify areas that need further attention.

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FIGURE LEGENDS

Figure 1. Question number 17 from the end-of-life questionnaire: Mark the symptom(s) that was/were not fully alleviated during the last week of life. *p<0.05, **p<0.01, ***p<0.001, n=7,584 – 11,409 per year.

Figure 2. Question number 20 from the end-of-life questionnaire: Was p.r.n. medication prescribed in the form of injections at least one day before death against pain, anxiety, death rattle, and/or nausea? **p<0.01, ***p<0.001, n=7,584 – 11,409 per year.

Registration in a quality register: a method to improve end-of-life care - a cross sectional study

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Primary Subject Heading:	Palliative care
Secondary Subject Heading:	Palliative care, Geriatric medicine
Keywords:	PALLIATIVE CARE, Adult palliative care < PALLIATIVE CARE, Quality in health care < HEALTH SERVICES ADMINISTRATION & MANAGEMENT

The end-of-life questionnaire (ELQ) 1 May 2007 – 30 June 2010

The Swedish Palliative Register Form to be filled out in connection with the death of a person.

To be filled in by the responsible doctor or nurse. All reports are to be submitted through www.palliativ.se

1. Unit code _____ (received at registration of participation through the website www.palliativ.se)
2. Social insurance identification number_____
3. Name of the deceased_____ (used first name and surname)
4. Area code_____
5. Sex
   - Male
   - Female
6. Date of admission to the unit where death occurred (for primary care/home care = "active home care")_____
7. Date of death_____
8. The place of death is best described as a:
   - Nursing home
   - Short-term care home
   - Hospital ward – not palliative
   - Hospice/palliative hospital ward
   - Own home, with support from specialized palliative home care
   - Own home, with support from basal home care
   - Other_____
9. Main disease that caused death:
   - Cancer
   - Heart disease
   - Lung disease
   - Dementia
   - Stroke
   - Other neurological disease
   - Infection
   - Diabetes
   - Other, namely_____
10. Will a forensic autopsy be performed?
    - Yes
    - No

If the answer to question 10 is yes, then the questionnaire is completed. If death was caused by disease, please also answer the following questions.

11. According to the deceased's medical history, death was
    - Expected
    - Not expected
    - Don't know
12. Which date, closest before death, did a doctor visit/examine the patient/person receiving care?_____
13. Has an informing conversation with the patient about impending death taken place, during the last period in life?

- No
- Yes, by a doctor
- Yes, by a nurse
- Yes, by both a doctor and a nurse
- Don't know

14. Has an informing conversation with the patient's next of kin about the impending death of the patient/person receiving care taken place, during the last period in life?
    - No
    - Yes, by a doctor
    - Yes, by a nurse
    - Yes, by both a doctor and a nurse
    - Don't know
15. How long before death did the patient/person receiving care loose his/her ability of self-determination?
    - Hours
    - Days
    - Weeks
    - Months
    - Years
    - Don't know
16. Have a VAS or NRS scale (0-10) been used for evaluation of pain during the last week of the patient's life?
    - Yes
    - No
    - The patient cannot participate
    - Don't know
17. Mark the symptom(s) that was/were not fully alleviated during the last week of life.
    - Shortness of breath
    - Confusion
    - Nausea
    - Death rattle
    - Pain
    - Anxiety
    - Other_____
    - No distressing symptoms
    - Don't know
18. Has special competence outside the team/ward been consulted regarding the patient's not completely alleviated symptoms?
    - No
    - Yes, profession/speciality_____
19. Did the person receiving care/patient have pressure ulcers in the last week of life?
    - Grade 1
    - Grade 2
    - Grade 3
    - Grade 4
    - No
    - Don't know
20. Was medication prescribed for use as needed in the form of injections, at least one day before death, for:

- Pain

- Yes
- No

- Death rattle
  - Yes
  - No
- Nausea
  - Yes
  - No
- Anxiety
  - Yes
  - No

21. Who was present at the moment of death?
  - Staff
  - Next of kin
  - Staff and next of kin
  - No one

22. Did the place of death correspond with the person receiving care's/patient's latest spoken wish?
  - Yes
  - No
  - Don't know

23. In how many other places (e.g. home, different wards, nursing home, short-term care home) than the place of death was the person receiving care/patient cared for during the last 2 weeks of life?
  - 0
  - 1
  - 2
  - 3
  - >3
  - Don't know

24. Have the next of kin had or will they be offered a follow-up appointment some time after death?
  - Yes
  - No
  - Don't know

25. Are you content with the end-of- life care provided for the person receiving care/patient?

Not at all
  - 1
  - 2
  - 3
  - 4
  - 5

Completely

26. Date the questions were answered _____

27. Answered by_____ (name)
  - Doctor
  - Nurse

E-mail address_____

STROBE 2007 (v4) Statement—Checklist of items that should be included in reports of *cross-sectional studies*

Section/Topic	Item #	Recommendation	Reported on page #
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract	1, 2
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found	2
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	3, 4
Objectives	3	State specific objectives, including any prespecified hypotheses	4
Methods			
Study design	4	Present key elements of study design early in the paper	4, 5, 6
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	5, 6
Participants	6	(*a*) Give the eligibility criteria, and the sources and methods of selection of participants	5
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	6
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	5, 6
Bias	9	Describe any efforts to address potential sources of bias	see discussion, page 14
Study size	10	Explain how the study size was arrived at	5
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	6
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding	6
		(*b*) Describe any methods used to examine subgroups and interactions	6
		(*c*) Explain how missing data were addressed	No missing data, see page 5
		(*d*) If applicable, describe analytical methods taking account of sampling strategy	-

		(*e*) Describe any sensitivity analyses	-
Results			
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	7-8
		(b) Give reasons for non-participation at each stage	-
		(c) Consider use of a flow diagram	-
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	Table 1, page 7-8
		(b) Indicate number of participants with missing data for each variable of interest	No missing data, see page 5
Outcome data	15*	Report numbers of outcome events or summary measures	7-11
Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	7-11
		(*b*) Report category boundaries when continuous variables were categorized	-
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	-
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	-
Discussion			
Key results	18	Summarise key results with reference to study objectives	11
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	14
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	12-15
Generalisability	21	Discuss the generalisability (external validity) of the study results	15
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	See submission form

*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.

Registration in a quality register: a method to improve end-of-life care – a cross sectional study

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Addendum 1: End-of-life-questionnaire

ABSTRACT (subheading level A)

Objectives: Structured methods to assess and support improvement in the quality of end-of-life care are lacking and need to be developed. This need is particularly high outside specialized palliative care. This study examines whether participation in a national quality register increased quality of end-of-life care. *Design:* This study is a cross sectional longitudinal register study. *Setting:* The Swedish Register of Palliative Care (SRPC) collects data about end-of-life care for deaths in all types of health care units all over Sweden. Data from all 503 health care units that had reported patients continuously to the register during a three-year period were analysed. *Primary and secondary outcome measures:* Data on provided care during the last weeks of life were compared year-by-year with logistic regression. *Participants:* The study included a total 30,283 patients. The gender distribution was 54 % women and 46 % men. 60 % of patients in the study had a cancer diagnosis. *Results:* Provided end-of-life care improved in a number of ways. The prevalence of six examined symptoms decreased. The prescription of "as needed" medications for pain, nausea, anxiety, and death rattle increased. A higher proportion of patients died in their place of preference. The patient's next of kin was more often offered a follow-up appointment after the patient's death. No changes were seen with respect to providing information to the patient or next of kin. *Conclusions:* Participation in a national quality register covariates with quality improvements in end-of-life care over time.

INTRODUCTION (subheading level A)

Structured methods to assess and support improvement in the quality of end-of-life care are lacking and need to be developed. Approximately 91,000 people die annually in Sweden,[1] which corresponds to about 1% of the Swedish population. About 80% of all deaths are "non-sudden", implying potential need for palliative care.[2] In Sweden, approximately 7-8% of dying patients were cared for in specialized palliative care and approximately 40-50% of dying patients were cared for in nursing homes and short-term care homes.[1] There is still a need to develop end-of-life care in many areas. Data from the Swedish Register of Palliative Care (SRPC) shows that end-of-life care has the potential for further improvement especially in care not provided by specialised palliative care units.[1]

As of 2011, there are 89 national quality registers in Sweden which are financed by Swedish local authorities and regions. Quality registers enable monitoring of care quality, quality care improvement, and clinical research. Sweden has unique opportunities for quality registers because Sweden has comprehensive population registers and unique personal identification numbers. As early as 1975, the first quality register in Sweden – the Swedish Knee Arthroplasty Register – started. Many quality registers focus on specialized care and specific treatments, but in recent years they have also begun to address a broader patient population, including dying people. The Swedish Register of Palliative Care (SRPC) is an example of this type of register. Swedish local authorities and regions invest in quality registers that focus on the elderly with multiple diseases, including SRPC.[3, 4]

Several studies on improvement of quality in palliative care or end-of-life care have been published. Preliminary results using benchmarks to develop palliative care in Catalonia have been presented.[5] In North Carolina (USA), a project for developing a regional database for community-based palliative care has been established.[6]. In an Australian national project data is collected about cancer patients that have been referred to hospices/palliative care.[7] In addition, the Liverpool Care Pathway for the dying patient (LCP) has been used in several studies and settings to improve end-of-life care. A multi-centre study including hospital wards, palliative nursing homes, regular nursing homes, and home care showed that the use of LCP improved symptom alleviation and increased documentation of end-of-life care issues.[8] Another study showed that the use of LCP in a hospital improved staff knowledge about physical symptom management and increased awareness of problems related to end-of-life care.[9] A method based on LCP was shown to improve end-of-life care in emergency medicine.[10]

Several studies have used register work to improve various areas including stroke, myocardial infarction, cardiac rehabilitation, trauma and in vitro fertilization,[11-15] but no studies reporting nation-wide quality registers with effect on end-of life care quality were found. This study examines whether participation in the SRPC during a three-year period (from May 2007 to April 2010) increased the quality of palliative care regarding eight predetermined quality indicators of good end-of-life care such as symptom alleviation and information provided to patient and next of kin.

METHODS (subheading level A)

Since 2005, the Swedish Register of Palliative Care (SRPC), one of the Swedish national quality registers, has been measuring the quality of end-of-life care.[4] During 2010, 34.5% of all deaths nationwide were reported to the register.[1] Data is collected through a questionnaire with items based on different essential aspects of end-of-life care as proposed by British Geriatrics Society.[16] Items concern providing information to patients and next of kin, alleviating pain and other distressing symptoms, prescribing necessary drugs, and fulfilling the wish of preferred place of death. The online questionnaire is answered by the responsible nurse and/or physician as soon as a patient dies. (See the supplementary material for a translated version of the questionnaire). All questions have to be answered before submission, leading to no missing data. Deaths are reported to the register from all types of health care units. Descriptive data is published continuously on the register website (www.palliativ.se). The individual health care unit has continuous access to its own results online and can use this as a basis for self-improvement.

The version of the questionnaire that was used to collect data was launched in May 2007. Data from May 2007 to April 2010 were used in this study. To examine change over time, only data from the health care units that had reported patients in all three years were used. Some units reported patients who eventually died at another type of unit, but since the aim of this study was to examine the effect of using the register on the health care units and the palliative care provided, these patients were not included in the study. Eleven health care units changed their unit type during the study period. These eleven units are characterized as they were defined at the baseline and these are the characteristics used in the results section and in the tables.

Data were compared year-by-year to examine if there was a systematic change in the answers, indicating a possible change in the quality of end-of-life care. The questionnaire contains 27 questions.Eight of these questions are about the provided care in the last weeks of life and were analysed. The remaining 16 questions (not analysed) cover background information, social demographics, and patient characteristics. Each alternative of the eight questions were analysed separately. Time (the chosen three year period) was the only independent variable. The eight items analysed in the study (dependent variables) included the following: information provided to the patient about imminent death; information provided to next of kin of the imminent death; whether six symptoms were fully alleviated during the last week of life; whether "as needed" medications in the form of injections for pain, nausea, anxiety, and death rattle were prescribed at least one day before death; whether the patient had pressure ulcers (graded from 1-4 according to the European Pressure Ulcer Advisory Panel) during the last week of life; whether next of kin and/or staff was present at the moment of death; whether the place of death corresponded to the patient's last spoken wish; and whether next of kin were offered a follow-up appointment after death of the patient. Further details about the questions are presented in the supplementary material.

Data were analysed using logistic regression in the statistic program Stata version 11.0 from StataCorp LP. Subgroup analyses for the five most common places of death were performed. Statistical analyses of significant differences in effect size between different health care unit types were not performed. In the analysis of the

item concerning information to the patient, only patients without cognitive impairment were included. Cognitive impairment was defined as present when the patient was registered as having lost the ability of self-determination weeks before death or earlier. In the two questions about information, information from the doctor was emphasised because physician participation was deemed most essential. In question number 19 (pressure ulcers), the ulcers are graded from 1 to 4 according to the European Pressure Ulcer Advisory Panel.[17] P-values below 0.05 were considered significant. This study was approved by the ethics committee at Umeå University, Sweden.

RESULTS (subheading level A)

A total of 30,283 patients reported by 503 health care units were included in this study. Table 1 shows detailed information of the total number of patients, the number of patients with cancer diagnoses, the distribution of women and men, and the number of patients with cognitive impairment. Some aspects of the care in specialized palliative units were high at baseline, see Table 2 and Table 3. In specialized palliative home care, 94% of the patients died at their preferred place of death, 97% of the patients' next of kin were offered a follow-up appointment, and 93% of the patients had "as needed" pain medication prescribed. In hospices/palliative hospital wards, 92% of the next of kin were offered a follow-up appointment, 98% of the patients were given "as needed" medication prescription, 95% of the patients were given anxiety medication, and 92% of the patients were given death rattle medication.

Table 1. Detailed information of the patients in this study.

Place of death		Year 1 (n/% of year total)	Year 2 (n/% of year total)	Year 3 (n/% of year total)	Total (n/%=)
All (503 units)	Patients	7,584	11,409	11,290	30,283
	With cancer	63%	58%	60%	18,238 (60%)
	Cognitively impaired*	21%	22%	19%	6,354 (21%)
	Women	54%	54%	54%	16,342 (54%)
	Men	46%	46%	46%	13,941 (46%)
Hospice/palliative hospital ward (39 units)	Patients	2,948	3,739	3,793	10,480
	With cancer	95%	94%	93%	9,832 (94%)
	Cognitively impaired*	11%	8%	8%	938 (9%)
	Women	51%	53%	52%	5,480 (52%)
	Men	49%	47%	48%	5,000 (48%)
Nursing home (233 units)	Patients	1,628	2,691	2,488	6,807
	With cancer	11%	11%	12%	778 (11%)
	Cognitively impaired*	51%	54%	48%	3,484 (51%)
	Women	64%	64%	63%	4,359 (64%)
	Men	36%	36%	37%	2,448 (36%)
Specialized palliative home care (60 units)	Patients	1,097	1,532	1,704	4,333
	With cancer	91%	90%	89%	3,887 (90%)
	Cognitively impaired*	6%	8%	6%	298 (7%)
	Women	47%	49%	47%	2,061 (48%)
	Men	53%	51%	53%	2,272 (52%)
Hospital ward, not palliative (88 units)	Patients	1,333	2,456	2,292	6,081
	With cancer	45%	40%	41%	2,507 (41%)
	Cognitively impaired*	19%	20%	19%	1,195 (20%)
	Women	51%	51%	53%	3,144 (52%)
	Men	49%	49%	47%	2,937 (48%)
Short-term care home (56 units)	Patients	508	856	869	2,233
	With cancer	42%	48%	52%	1,071 (48%)
	Cognitively impaired*	24%	15%	15%	479 (21%)
	Women	54%	49%	49%	1,117 (50%)
	Men	46%	51%	51%	1,116 (50%)
Basal home care (27 units)	Patients	70	135	144	349

* Reported to have lost their ability of self-determination weeks before death or earlier.

The prevalence of not fully alleviated symptoms (question number 17) during the study years is presented in Figure 1. During the first study year, the prevalence of distressing symptoms was 10% for shortness of breath, 6% for confusion, 4% for nausea, 17% for death rattle, 15% for pain, and 17% for anxiety. Reductions in prevalence were seen over time for all symptoms. No decrease in symptoms was seen at nursing homes. Hospital wards (not palliative) showed decrease for pain only, while the other types of care units showed decreases in three or more symptoms.

The item concerning prescription of "as needed" drugs at least one day before death (question number 20) is presented in Figure 2 and Table 2. Prescriptions against all four symptoms increased significantly. The largest increase was seen for "as needed" drugs against nausea, from 55% to 82% of the patients. Prescriptions against nausea increased significantly in all types of care units. Nursing homes and hospital wards (not palliative) showed an increase in "as needed" prescriptions for all registered symptoms.

Table 2. Number of patients with prescriptions for "as needed" medication for pain, death rattle, nausea and anxiety during the last day of life.

	Total	Nursing home	Short-term care home	Hospital ward, not palliative	Hospice/ palliative hospital ward	Specialized palliative home care
Pain medication "as needed" prescribed	89% → 90% p<0.001	78% → 83% p<0.001	83% → 88% p=0.012	79% → 81% p=0.001	98% → 99% N.S.	93% → 94% N.S.
Death rattle medication "as needed" prescribed	80% → 83% p<0.001	72% → 78% p<0.001	76% → 81% N.S.	60% → 69% p<0.001	92% → 94% p=0,008	84% → 89% p<0.001
Nausea medication "as needed" prescribed	55% → 82% p<0.001	24% → 74% p<0.001	30% → 78% p<0.001	28% → 67% p<0.001	83% → 94% p<0.001	71% → 88% p<0.001
Anxiety medication "as needed" prescribed	78% → 82% p<0.001	61% → 69% p<0.001	65% → 76% p<0.001	59% → 69% p<0.001	95% → 96% N.S.	88% → 91% p=0,005

The item whether someone was present at the time of death (question number 21) is presented in Table 3. The proportion of patients dying alone did not change overall. However, a decrease was seen in hospital wards (not palliative). The item concerning whether the place of death corresponded to the patient's last spoken wish (question number 22) is presented in Table 3. There was a significant trend towards more patients dying in their preferred place of death. A significant trend towards more next of kin being offered follow-up appointments after death of the patient (question number 24) was seen (Table 3).

Table 3. Changes during the study years shown for total and divided into the five subgroups regarding preferred place of death, information to patient and next of kin, presence at the moment of death, and follow-up appointment offered. Question number from the end-of-life questionnaire is shown.

	Total	Nursing home	Short-term care home	Hospital ward, not palliative	Hospice/ palliative hospital ward	Specialized palliative home care
13. Information from doctor to patient*	58% → 58% N.S.	16% → 17% N.S.	29% → 37% p=0.022	39% → 39% N.S.	75% → 78% p=0.007	76% → 81% p=0.005
14. Information from doctor to next of kin	70% → 71% N.S.	33% → 31% N.S.	53% → 62% p=0.004	73% → 73% N.S.	88%→ 91% p<0.001	85% → 87% N.S.
21. No one present at the moment of death	15% → 15% N.S.	15% → 14% N.S.	18% → 15% N.S.	25% → 22% p=0.007	14% → 16% N.S.	6% → 6% N.S.
22. Place of death corresponded to preference	48% → 50% p=0.001	32% → 35% p=0.020	21% → 33% p<0.001	13% → 12% N.S.	60% → 66% p<0.001	94% → 94% N.S.
24. Next of kin offered follow-up appointment	72% → 74% p=0.001	54% → 63% p<0.001	38% → 70% p<0.001	42% → 39% N.S.	92% → 94% N.S.	97% → 96% N.S.

*Only including patients without cognitive impairment.

No improvements were seen over time regarding prevalence of pressure ulcers (question number 19), see Table 4. On the contrary, the total number of patients with pressure ulcers grade 1 (graded according to the European Pressure Ulcer Advisory Panel) increased from 9.1% to 10.2%. The number of patients with higher grades of pressure ulcers was unchanged.

Table 4. Presence of pressure ulcers during the last week of life.

	Total
Pressure ulcer grade 1	9% → 10% p=0.016
Pressure ulcer grade 2	5% → 6% N.S.
Pressure ulcer grade 3	3% → 3% N.S.
Pressure ulcer grade 4	2% → 2% N.S.
No pressure ulcer	79% → 77% p=0.006
Don't know if patient had pressure ulcer	3% → 2% N.S.

No important changes were seen regarding providing information to patients about their imminent death (question number 13) or information to next of kin about the patient's imminent death (question number 14) Table 3). No changes were seen when examining the information given by doctors.

DISCUSSION (subheading level A)

We have found by following structured assessment of end-of-life care using a national quality register that palliative care improved in several aspects, implying that the structured assessment itself may have contributed to the improvements. Large improvements were seen in prevalence of distressing symptoms during the last week of life and prescription of "as needed" medication for symptom alleviation. The large number of included patients strengthens these findings.

Even if causality cannot be proven, the regular use of SRPC covariates with the seen improvements. By providing clear lists of important care activities and an opportunity to evaluate each care episode it is not unlikely that the SRPC use has contributed to this improvement.. The principal nurse, or sometimes the principal doctor, via registration of each deceased patient had the opportunity to comprehensively evaluate that patient's end-of-life care. Furthermore, the possibility of immediate web-generated feedback from the SRPC with detailed diagrams illustrating the results over time produced by the reporting care unit compared to similar care units nationwide provides a unique possibility to identify the care

activities in most urgent need of improvement. We believe it is likely that these SRPC generated activities over a three-year period have influenced the provided end-of-life care in the desired direction. To a certain extent, the identified improvements could also be due to better documentation and/or staff awareness, both positively contributing to enhanced continuity in care and validity of collected data. The consistency of observed changes in a positive direction and that all involved units were unaware of this study lessen the risk for systematic bias.

The results of this study also confirm that the SRPC as a register is widely applicable in all kinds of care units where end-of-life care is provided and that the potential for improvements are more pronounced outside specialized palliative care. As the coverage of SRPC within specialized palliative units is estimated to be close to 100%, we assume that approximately 7-8% of dying patients nationwide receive end-of-life care at specialized palliative units. Accordingly, the vast majority (about 70%) of the population has to rely on hospital wards, nursing homes, and non-specialized home care for their end-of-life care. If the use of SRPC in these care contexts can contribute to measurable improvements of end-of life care, the potential impact over time may be immense.

The trend that more patients were prescribed “as needed” medications for symptom alleviation is encouraging. The level of nausea medication prescription is approaching the prescription levels for the other three symptoms. Only having a prescription for “as needed” medication does not necessarily mean that the patient suffers less from symptoms, but an adequate prescription is most often a prerequisite

for providing immediate relief from symptoms. The trend that lower grade of pressure ulcers increased during the study years does not necessarily mean that pressure ulcers increased. The increase of lesser degree pressure ulcers may be a sign of increased staff awareness.

The widely differing prevalence of cancer (11-94%) and cognitive impairment (7-51%) between different unit types illustrates that they represent different patient populations. These different case-mixes imply different challenges considering end-of-life care and disqualify direct comparisons between different unit types. Hospital wards have probably the most varied patient selections and many of these are resource consuming. Nursing homes and short-term care homes showed marked improvement. The specialized palliative care units performed well in many items leaving limited room for further improvements. For this reason, it is likely that a similar study including only health care units without palliative specialization could have shown greater overall improvements.

There are some methodological weaknesses with this study. Since the questionnaires are answered retrospectively, recall bias could have affected the results. It is, however, unlikely that recall bias alone could have given systematic positive changes over time. The results could possibly also be affected by a change in interpretation of answering alternatives, the response shift. Although the use of output register data for evaluation at the units is one of the potential mechanisms for the improvement caused by SRPC, this study did not examine to what extent this has been done during the study period. We cannot say how much of the positive changes seen in this study

were the result of participating in SRPC. A number of possible factors could have affected the results. The contributions of each are not possible to identify by this study. In addition to the work of the SRPC, the change in society during the study years cannot easily be measured. There has been an increased focus on end-of-life care and the dying process in medicine and in public discourse, but neither of these has been measured in this study. During the studied years, no national health care programs on palliative medicine or palliative care have been launched, but some local areas have started their own palliative programs. This could also have influenced the participating units.

It was not found in the literature how many patients do not want to die alone or who these patients want to be with at the time of their death. According to a Swedish report, many health professionals think that a dignified death means not dying alone.[18] One study found that 87% of terminally ill cancer patients wished to die at home.[19] Another study including patients with congestive heart failure, chronic obstructive pulmonary disease, and pneumonia found that only 43% preferred to have terminal care at home, while 48% preferred hospitals.[20] The litterature is consistent with the finding in this study that almost all patients in specialized palliative home care (91% cancer patients) died in their preferred place of death. Some patients are not able to communicate their wishes. Almost half of the patients with unknown wishes could represent those who lost their ability of self-determination weeks before death or earlier (Table 1). The other half of those with unknown wishes were probably able to declare their preference if asked. The proportion of patients dying at a place they did not prefer could be close to its

possible limit because it is probably inevitable that a small proportion of patients can not have their wishes fulfilled.

Although the presented data shows that palliative care has improved over the years, there is still potential for further improvement. A regular monitoring of provided end-of-life care enables continuous feedback and constructive discussions for further improvements. Registrations in the SRPC can probably only increase the quality to some extent, as the results suggest. More studies are needed to investigate the possibility of quality improvement in end-of-life care with more extensive actions. It is possible that additional improvements can be achieved with the help of SRPC by combining questionnaire collecting with information to and training for concerned health care professionals and/or prospective use end-of-life care pathways (e.g. Liverpool Care Pathway for the dying patient). Other ways to collect data on patients in end-of-life care should also be reviewed, such as designing a similar questionnaire to be answered by patients in palliative care or by their next of kin. Methods to promote greater use of evaluation of registry data at the individual units are also options that should be reviewed. Regardless of which means are used to accomplish better end-of-life care, results in SRPC can be an easy and efficient way to monitor improvements and identify areas that need further attention.

Contributorship Statement

Lisa Martinsson - contribution to conception and design, analysis and interpretation of data and drafting the article.

Carl Johan Fürst - contribution to conception and design, analysis and interpretation

of data, critically revising article.

Staffan Lundström - contribution to conception and design, analysis and interpretation of data, critically revising article.

Lena Nathanaelsson - analysis and intrepretation of data, critilally revising article.

Bertil Axelsson - contribution to conception and design, acquisition of data, analysis and interpretation of data, drafting the article.

All authors have given final approval of the version to be published.

Data Sharing Statement

- There is no additional data available.

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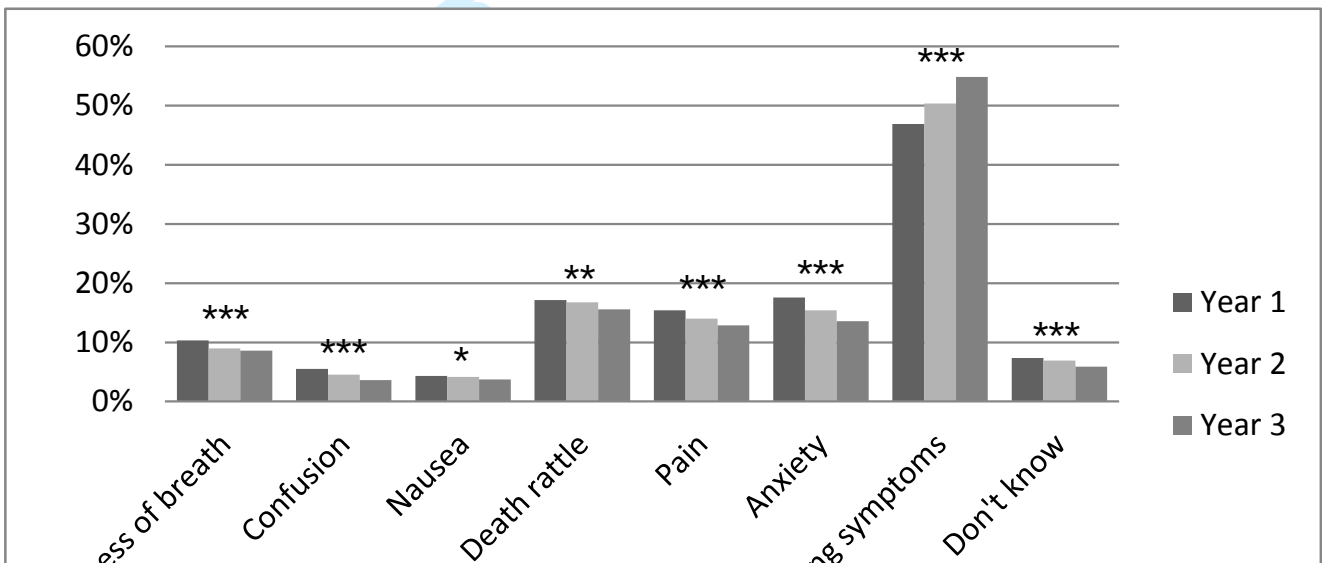
FIGURE LEGENDS

Figure 1. Question number 17 from the end-of-life questionnaire: Mark the symptom(s) that was/were not fully alleviated during the last week of life. *p<0.05, **p<0.01, ***p<0.001, n=7,584 – 11,409 per year.

Figure 2. Question number 20 from the end-of-life questionnaire: Was "as needed" medication prescribed in the form of injections at least one day before death against

pain, anxiety, death rattle, and/or nausea? **p<0.01, ***p<0.001, n=7,584 – 11,409 per year.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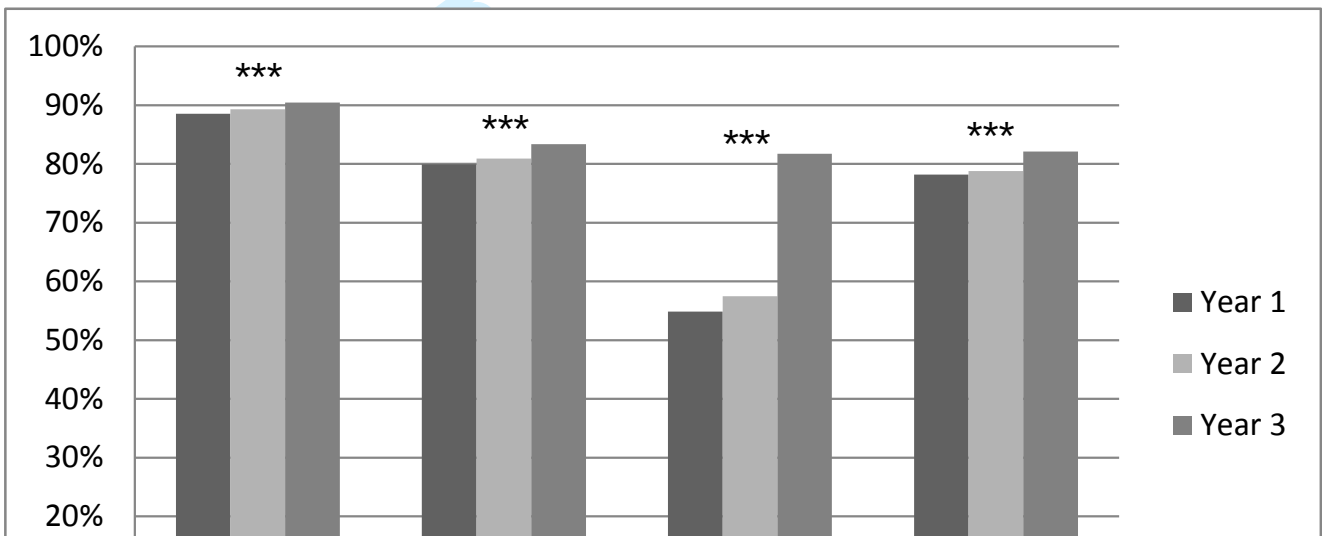
Shortness of breath
Confusion
Nausea
Death rattle
Pain
Anxiety
No distressing symptoms
Don't know
Year 1
Year 2
Year 3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Pain
Death rattle
Nausea
Anxiety
Year 1
Year 2
Year 3