

Variations in care quality outcomes of dying people: Latent class analysis of an adult national register population

Running title: Care quality outcomes of dying people

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## **Abstract**

**Context.** Symptom relief is a key goal of palliative care. There is a need to consider complexities in symptom relief patterns for groups of people in order to understand and evaluate symptom relief as an indicator of quality of care at end of life.

**Objectives.** The aims of this study were to distinguish classes of patients who have different symptom relief patterns during the last week of life and to identify predictors of these classes in an adult register population.

**Methods.** In a cross-sectional retrospective design, data was used from 87,026 decedents with expected deaths registered in the Swedish Register of Palliative Care in 2011 and 2012. Study variables were structured into patient characteristics, and processes and outcomes of quality of care. A latent class analysis was used to identify symptom relief patterns. Multivariate multinomial regression analyses were used to identify predictors of class membership.

**Results.** Five latent classes were generated: “relieved pain”, “relieved pain and rattles”, “relieved pain and anxiety”, “partly relieved shortness of breath, rattles and anxiety” and “partly relieved pain, anxiety and confusion”. Important predictors of class membership were age, sex, cause of death, and having someone present at death, individual PRN prescriptions and expert consultations.

**Conclusion.** Inter-individual variability and complexity in symptom relief patterns may inform quality of care and its evaluation for dying people across care settings.

**Keywords:** dying; end of life; palliative care; public health; quality of health care; symptom clusters

## **Introduction**

During the last week of life, a variety of symptoms (e.g. pain, fatigue, dyspnoea, rattles, anxiety, nausea, confusion) are known to be distressing to those who are dying [1,2]. Relieving such symptoms is a fundamental goal of palliative care [3,4].

However, symptom relief presents several challenges: many patients have multiple symptoms that often interact and appear in clusters [5-7], with new symptoms developing and previously relieved symptoms changing character. For example, pain may induce anxiety or vice versa. The distress caused by each symptom may also largely fluctuate between days or even hours.

Moreover, patterns of symptoms may not appear in the same way for all people. For example, anxiety could be associated with pain for some and with shortness of breath for others. Rather than examining differences in patterns of symptoms and how these are relieved [8], most research has instead focused on averages of ratings of symptom prevalence, burden and severity. However, these approaches do not distinguish relief of symptoms from the absence of symptoms or reveal differences in patterns of symptom relief that people at end of life may experience. Consequently, there is a lack of knowledge concerning how symptom presence and relief may differ between groups of patients; there may be heterogeneity or classes of patients who are characterized by different *patterns of symptom relief*.

Symptom relief belongs to the most commonly used outcome measures for quality of palliative care [9]. Accordingly, to understand palliative care quality, it is of importance to examine quality of care indicator variables targeting care structures and processes that are associated with symptom relief as an outcome [9]. Furthermore, to inform tailored interventions to reduce symptom distress and thereby promote wellbeing, we need to know how the relief of symptoms occurs differently between

groups of patients.

Symptom prevalence and symptom relief have also shown to vary depending on the place of care at the end of life and death [10], which may be related to the quality of care being provided. For example, studies suggest that pain is better relieved in inpatient hospice care than in hospital settings [11,12]. Research also indicates better relief of, for example, anxiety in home care, provided that the home is the preferred place of care during the final week of life [13]. In nursing homes, barriers related to structures, competence and resources within the organization have been emphasised as challenging the provision of high quality of care at end of life [14,15]. However, while palliative care global policy claim the right to high quality of care at the end-of-life for all [16], there is a scarcity of studies investigating this across care places and medical diagnoses.

The aims of this study were (a) to distinguish classes of patients who have different symptom relief patterns during the last week of life and (b) to identify predictors of these classes in an adult register population.

## **Methods**

### ***Design and sample***

This study had a cross-sectional retrospective design. Data were obtained from the Swedish Register of Palliative Care (<http://palliativ.se>); a population based quality register reflecting care being provided during the last week of life for all types of deaths [17] covering 53% of all deaths in Sweden in 2011 and 62% in 2012. In addition, the Swedish Causes of Death Certificate Register, covering all deaths, was used to identify the underlying cause of death classified according to the International

Statistical Classification of Diseases and Related Health Problems (reported by physicians).

The Swedish Register of Palliative Care includes data from patient-level and service unit-level questionnaires that are completed by health care providers. The patient-level questionnaire is completed retrospectively to collect information about individual patients' care episodes during the last week of life, including symptom presence and relief. The service unit-level questionnaire collects information about the health service units reporting to the register (updated annually) [17].

Inclusion criteria for this study were adults ( $\geq 18$  yrs.) with expected deaths based on the disease history (as reported in the register) and occurring between January 1<sup>st</sup> 2011 and December 31<sup>st</sup> 2012 ( $n = 87,883$ ) and with data in the register for at least one of the outcome variables ( $n = 87,026$  from 4,295 service units included in the register). Ethical approval for the study was granted by the Regional Ethical Review Board in Stockholm (approval: 2013/1576-31/3).

### ***Study variables***

Selected variables from the patient- and unit-level questionnaires were organized (and in some cases restructured) into five patient characteristics, 20 process and 24 quality of care variables (see Table 1), and 6 symptom relief variables. Patient characteristic variables were age, sex, underlying cause of death, place of death and type of care setting, and number of days enrolled to the service. Processes of care were assessed using patient-level questionnaire variables, including presence of pressure sores, feeding tubes or intravenous fluids, end-of-life discussions, symptom assessment, PRN prescriptions, consultations and someone present at death. Unit-level structure variables included access to consultations, ability for family to stay overnight,

existence of service provider protocols, access to injected drugs for symptom relief and time for staff to reflect following deaths.

Symptom relief variables (pain, nausea, shortness of breath, rattles, anxiety, and confusion) were treated as quality of care outcomes. For each symptom, health care providers reported “yes”, “no”, or “don’t know” to indicate whether the symptom was present during the last week of life. If “yes”, they additionally reported the extent of symptom relief as “totally”, “partially” or “not at all”. For each symptom, these responses were combined to create a variable measuring symptom presence and relief with the following categories: 1= symptom not present, 2= symptom present and totally relieved, 3= symptom present and partially relieved, 4= symptom present and not at all relieved. “Do not know” responses were treated as missing data.

### ***Data analysis***

The first aim was addressed using latent class analysis [18] to identify groups of patients (latent classes) with different patterns of symptom presence and relief using the Latent GOLD (version 5.0) software [19,20]. Service unit clustered data and the symptom variables were specified as nominal with “symptom not present” as the referent. In addition, a single within-class latent factor was specified to account for residual correlations among the symptoms that were observed during preliminary analyses.

The number of classes was determined by sequentially comparing models with k and k-1 classes. The preferred model was identified based on the following recommendations: the lowest Bayesian Information Criterion (BIC), a non-statistically significant difference in the bootstrap log-likelihood ratio test comparing k and k-1 classes [21], and interpretable classes. In addition, residual dependencies among the

latent class indicators that were not fully accounted for by the model were examined based on the bivariate residuals produced by Latent Gold [20]. The results of the preferred latent class model were used to calculate the proportions, based on posterior probability of each characteristic conditional on latent class membership, for each nominal response category of the symptom variables and thereby characterize the latent classes in terms of differences in symptom relief patterns.

Predictors of latent class membership were identified by first conducting multinomial regression analyses with one predictor at a time to determine which variables were significantly associated with latent class membership (Wald test significant at  $p < 0.05$ ). These variables were subsequently included in a multivariate multinomial regression analysis to obtain odd ratios that are adjusted for all other independent variables in the model and to thereby account for potential confounding. The class with the lowest prevalence and the highest relief of symptoms was chosen as the reference for all analyses (i.e., Class 1). The Step3 module in the Latent GOLD software [19] was used to correct for underestimates of the associations resulting from uncertainty in latent class membership by applying a maximum-likelihood-based adjustment based on the estimated number of classification errors in the modal assignment of cases to classes [22]. A hierarchical approach was used to evaluate relative increases in the R-squared by first entering the patient characteristics variables, then the quality of care process variables, and finally the quality of care structure variables into the regression.

Missing data for the latent class indicators (i.e. the symptom presence and relief variables) were accommodated within Latent GOLD using full information maximum likelihood. In the subsequent regression analysis, five variables with more than 10% missing data (see Table 1) were excluded (as indicated in Tables 3a-c). Mean

imputation within Latent Gold (using sample mean replacement based on the unweighted averages of the parameter estimates for each variable) was applied to accommodate the small amount of missing data on the remaining predictor variables (1.2% overall missingness).

## **Results**

### ***Sample description***

The sample (n = 87,026) consisted of 56.0% women. The mean age was 81.6 years (SD = 11.5, range = 18-110). Relatively few patients died in hospices or specialized palliative in-patient care units (11.6%); most patients died in long-term care facilities (39.9%) or in general hospitals (27.4%). The predominant underlying causes of death were neoplasms (36.8%), circulatory diseases (31.0%) and dementia (12.5%). Distributions of other patient characteristics and quality of care process and structure variables are provided in Table 1.

### ***Classes of symptom relief patterns***

The latent class analysis identified 5 latent classes representing different symptom relief patterns (see Figure 1). The 5-class model had the lowest BIC and a non-significant bootstrap log-likelihood test of the comparison with a model that had 6 classes. The entropy was quite low for all models and 0.47 for the 5-class model (see Table 2 for results of the log-likelihood tests, and table note for average posterior classification probabilities [23] and bivariate residuals for the 5-class model).

Class 1 constituted the largest latent class (31% of the sample) and had a pattern characterized as overall low symptom presence and “relieved pain”. This class had the lowest overall prevalence of symptoms, with pain as the most common symptom (50%



of class members). Total symptom relief among those who had symptom(s) was generally high (90% for pain and 93% for anxiety), except for shortness of breath, which was predominantly partially relieved (62%) but also had a low prevalence (9%). Class 2 (25% of the sample) was characterized as “relieved pain and rattles” and had higher prevalence of pain (79%) and rattles (67%) compared to Class 1, which were predominantly totally relieved (76% and 53% of those who had the symptom). A minority had anxiety (16%) and shortness of breath (12%), which were also predominantly totally relieved (82% and 65% of those who had the symptom). In both Classes 1 and 2 there was a low prevalence of confusion (16% and 19% respectively) with various degrees of relief. Class 3 (20% of the sample) was characterized as “relieved pain and anxiety”, with the highest prevalence of pain (91%) and anxiety (99%), which were predominantly totally relieved (79% and 75%). Rattles and confusion were also prevalent (61% and 47% respectively) with various degrees of relief. Class 4 (14% of the sample) was characterized as “partly relieved shortness of breath, rattles and anxiety”. The most prevalent symptoms were shortness of breath (86%), rattles (76%), and anxiety (72%), which were partially relieved (72%, 69% and 53%). Pain was also prevalent (67%), but predominantly totally relieved (65%). Confusion (reported in 35%) was predominantly partially relieved (55%). Class 5 constituted the smallest latent class (9% of the sample) and was characterized as “partly relieved pain, anxiety and confusion”. This class had a high prevalence of pain (83%) and anxiety (82%), which were partially relieved for most people (68% and 90%), and the highest prevalence of confusion (57%), which was partially (78%) or not at all relieved (21%).

Confusion is the symptom with the highest proportions (based on posterior probabilities) of no symptom relief across the five classes (18% to 40%). Nausea is the

symptom with the lowest prevalence across the five classes (12% to 22%), with varying levels of total relief (22% to 63%) and small variations in the proportions of people who were not at all relieved (2% to 5%).

### ***Predictors of latent class membership***

The relative frequencies for each variable within each of the latent classes and parameter estimates for the *overall* (3 step) model are shown in Table 3 a-c.

Step 1 of the hierarchical regression model (Table 3a), including only the patient characteristics, revealed that class membership is significantly predicted by age, sex, location of death and underlying cause of death (*pseudo-R*<sup>2</sup> = .06). There were small but statistically significant differences in age between the classes; the average age ranged from 79 years in Classes 3 and 4 to 85 years in Class 1. Patients in Class 1 were also more likely to be female (63%) than in the other classes (ranging from 46% in Class 4 to 56% in Class 3). Statistically significant differences were observed for underlying causes of death. Although neoplasm was most prevalent in Classes 2 (40%), 3 (52%) and 5 (45%) and least prevalent in Class 1 (24%), the adjusted odds ratios reflect a different pattern; patients in Class 2 are predicted to be relatively most likely to die of neoplasm when controlling for all other variables in the multivariate model (adjusted odds ratio of 1.5, 95% confidence interval (CI): 1.3-1.7). Patients in Classes 3, 4 and 5 were predicted to be least likely to die of a circulatory condition (adjusted odds ratio of 0.5, 95% CIs: 0.4-0.5 and 0.4-0.6). Class 1 had the highest percentage of patients who had died of dementia (19%), versus only 1% in Class 4. The corresponding adjusted odds ratio was 0.1 (95% CI: 0.1-0.2). Patients in Class 4 had 1.8 (95% CI: 1.5-2.2) times higher odds of having died of respiratory conditions (5% in Class 1 versus 19% in Class 4). With respect to places of death, 0% of patients in Class

1 and 63% in Class 4 had died in a hospital. This difference, however, was not found to be statistically significant in the multivariate model. Relative to Class 1, patients in Class 4 were predicted to be less likely to die at home, in a short-term care facility or in a long-term care facility.

Step 2 (Table 3b), which includes the quality of care process variables, resulted in further improved prediction and a corresponding  $pseudo-R^2 = .12$ . All process variables were statistically significant predictors of class membership. The most prominent predictors included having someone present at death, PRN prescriptions and consultations with specialized services. Patients in Classes 2, 3 and 4 were predicted to be more likely than those in Class 1 (adjusted odds ratios ranging from 1.5 to 2.4, 95% CIs from 1.3-1.7 to 2.1-2.8) to have someone (family member, staff or both) present at death compared with having no one present at death (ranging from 7% in class 3 to 22% in class 1). Relative to Class 1, patients in Classes 2 and 3 had 8.8 (95% CI: 6.1-12.26) and 6.6 (95% CI: 3.4-12.8) times the odds of receiving PRN prescriptions for pain, which were provided for all patients in these classes and for 80% of patients in Class 1. The odds of having a PRN prescription for rattles in Classes 2 (97%) and 4 (85%) were 4.8 (95% CI: 4.1-5.6) and 3.9 (95% CI: 3.4-4.5) times the odds in Class 1 (68%). Having a PRN prescription for anxiety was by far most likely in Class 3 (100%). Patients in Class 1 were the least likely to have any consultations with specialized services.

Step 3 (Table 3c), which includes the addition of the quality of care structure variables, resulted in a smaller relative improvement in model fit ( $pseudo-R^2 = .15$ ). There were only a few statistically significant predictors. When controlling for all other variables in the model, patients in Classes 4 and 5 had 1.8 (95% CI: 1.0-3.1) and 2.1 (95% CI: 1.2-3.8) times the odds of having immediate access to a registered nurse, and

patients in Classes 3 and 4 were most likely to have ability for family members to stay overnight at the service. Although immediate access to physicians during office hours was most frequent in Class 4 (90% versus 72% in Class 1), this was not a significant predictor in the multivariate analysis.

## **Discussion**

Pain, rattles, and anxiety were the predominant symptoms during the last week of life for patients included in the national palliative care register data, and only between 45% (rattles) and 75% (pain) were totally relieved. Our analysis, however, revealed substantial heterogeneity with respect to patterns of symptom relief. In particular, the results suggest five classes representing patients with different symptom relief patterns. The five classes varied from presenting predominantly few symptoms that were partly or totally relieved (Classes 1-3) to multiple symptoms that were partly or not at all relieved (Classes 4-5).

Several variables were identified that predict the five classes. Patient characteristics that were predictive include age, sex and underlying cause of death. In addition, several quality of care process indicators were predictive, including presence of someone at death, PRN prescriptions and consultations with specialized services. Few quality of care structure indicators were predictive. Thus, our analyses suggest that although underlying cause of death is predictive, a comprehensive understanding of symptom relief requires consideration of several other important patient characteristics and quality indicators. The following predictive quality of care process variables would be possible to influence in clinical practice and are therefore of particular relevance: presence of someone at death, PRN prescriptions and consultations with specialized palliative care services.

Our results are consistent with previous research indicating that symptom relief varies in relation to the place of care at the end of life and death [10], and that symptom relief could be especially challenging in hospitals [11,12]. However, studies to date have focused on prevalence and severity of individual symptoms or overall symptom burden. Our analyses contribute additional knowledge pertaining to variability in different patterns of symptom relief. Thus, latent class approaches are an alternative to the conventional approach of counting symptoms and symptom relief with potential to provide a representation of the complexity of how symptoms may co-occur; the utility of doing so is an area for further study.

With respect to the two classes with the least symptom relief (Classes 4 & 5; 23% of the sample), most of the patients died in hospitals or long-term care facilities. The class with patients that most often received end-of-life care at specialist in-patient palliative care services (Class III) includes patients who had predominantly totally relieved challenging symptoms, although 73% of patients in this class were still cared for in non-specialized palliative care settings.

Despite these observed differences, the results of the multivariate model revealed other underlying factors that predict different patterns of symptom relief, irrespective of place of death. Appropriate quality of care for patients who are dying with complex unrelieved symptoms (e.g. as in Classes 4 and 5) is known to present special challenges, indicating poor quality of care for patients at old age [24]. Our results confirm that, across all setting where patients are cared for at the end of life, there is a need for appropriate palliative care interventions that target the most challenging symptom relief patterns [25-27]. Attention to different patterns of symptom relief is imperative given the globally recognized right to high quality of care at the end-of-life for all [16].

### ***Limitations***

In the studied years, data in the Swedish Register of Palliative Care covered 53% and 62% respectively of the total death population in the country, which delimits generalization of the results. Compared to national population-level data from 2012 [28], our sample is underrepresented by men and people 69 years and younger and deaths caused by circulatory diseases, and overrepresented by people 80 years and older and deaths caused by neoplasms. However, it is known that service unit participation in the register is associated with care quality improvements [29]. As specialist palliative care services report [30], healthcare professionals are provided with feedback and are becoming aware of and acting according to care quality outcomes. For generalization outside the Swedish health care system, notice should be given to the high proportion of institutional deaths and in particular nursing home deaths [28]. Further, validity of the data in the register depends on retrospectively collected patient record data; we would do well to remember the inherent limitations on professionals' reporting of patients' symptoms. Symptoms are experiential [5] and patient-reported data would always be preferred, but as is well known, obtaining data from patients during the last week of life is highly challenging.

The low entropy value (below .8) [31] and average posterior classification probabilities below .7 [32] for all but Class 1 indicate that patients could not always be uniquely assigned to one class. Nonetheless, the features of the five classes with different symptom relief patterns suggested are clinically recognizable. The latent class analysis was thus an informative approach for the identification and classification of patients according to different patterns of symptom relief. These results are consistent with previous promising latent class research for the understanding of inter-individual

variability in end-of-life care [33-35] and symptom clusters [5,36]. Nonetheless, the symptom relief patterns disclosed in this study need to be validated and refined in future research, including to what extent the patterns make sense for professionals and how understanding of patterns could facilitate symptom relief for the dying.

### ***Conclusions and implications***

The identification of symptom relief patterns is novel, to our knowledge. The results confirmed assumptions about heterogeneity in patients who are dying and variations across health care settings and underlying causes of death. Accordingly, policy and care quality at end of life for patients who are dying should take into account inter-individual variability; different symptom relief patterns may exist for different groups of patients. The patient characteristics, specifically age, sex, cause of death, and all the process variables included in this study were found to predict symptom relief patterns, while quality structure variables were not as predictive. The comparatively less predictive value of quality of care structure indicators is surprising. One hypothesis is that the skills and wisdom of the individual professional provider [37] or team might be comparatively more important than the existence of local practice protocols.

The inter-individual variability observed suggests that clinicians in any type of service need to consider symptom relief in complex ways by focusing on individual symptoms but even more so on patterns of symptoms. In particular, the results suggest focusing on groups of patients having patterns of symptoms, with poor symptom relief outcome not necessarily determined by medical diagnoses. This study thus offers a different way of considering symptom relief at the end of life and at death by drawing

attention to the significance, and possibly benefit, of recognizing groups of patients with certain symptom patterns not uniquely tied to medical diagnoses.

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Table 1. Variable distributions in total sample.

| <b>Variables (% missing)</b>                        |          |
|---|----------|
| <b>Patient characteristics <sup>a</sup></b>         | <b>%</b> |
| Age (mean (SD)) (0.0%)                              | 81.6     |
|   | (11.5)   |
| <b>Age (years)</b>                                  |          |
| 18-29   | 0.1      |
| 30-39   | 0.3      |
| 40-49   | 1.1      |
| 50-59   | 3.2      |
| 60-69   | 10.2     |
| 70-79   | 19.0     |
| 80-89   | 39.6     |
| 90-110  | 26.4     |
| Sex: % male (0.0%)                                  | 44.0     |
| <b>Underlying cause of death (0.0%)</b>             |          |
| Neoplasms   | 36.8     |
| Circulatory   | 31.0     |
| Dementia  | 12.5     |
| Respiratory   | 5.7      |
| Other   | 13.9     |
| <b>Place of death and type of care setting (0%)</b> |          |
| Home; general homecare                              | 5.0      |

|  |      |
|--|------|
| Short-term care facility for old people                | 8.8  |
| Hospital ward/department                               | 27.4 |
| Specialized palliative home care                       | 6.9  |
| Hospice or palliative care unit (inpatient)            | 11.6 |
| Long-term care facility for old people                 | 39.9 |
| Other  | 0.4  |
| <hr/>  |      |
| Number of days enrolled to the service (18.6%)         |      |
| 1-14 days  | 39.7 |
| >14 days   | 60.3 |
| <hr/>  |      |
| <b>Quality of care process variables <sup>a</sup></b>  |      |
| Pressure sores   |      |
| at admittance (4.0%)                                   | 10.8 |
| at death (2.4%)  | 20.3 |
| <hr/>  |      |
| Feeding tube or intravenous fluids <sup>c</sup> (0.9%) | 14.2 |
| <hr/>  |      |
| End-of-life discussions                                |      |
| with patient (14.8%)                                   | 47.1 |
| with family (8.7%)                                     | 76.4 |
| <hr/>  |      |
| Pain assessment <sup>d</sup> (6.7%)                    | 19.2 |
| <hr/>  |      |
| Someone present at death (1.6%)                        |      |
| No one   | 15.0 |
| Staff  | 28.0 |
| Relatives  | 34.9 |
| Relatives and staff                                    | 21.2 |
| <hr/>  |      |

|  |      |
|--|------|
| Other symptom assessment <sup>d</sup> (9.3%)   | 11.3 |
| PRN <sup>e</sup> prescription for:   |      |
| pain (0.5%)  | 91.3 |
| rattles (0.9%)   | 83.4 |
| nausea (2.1%)  | 57.4 |
| anxiety (1.4%)   | 79.9 |
| Consultation with:   |      |
| Pain unit (0.0%)   | 1.4  |
| Palliative team (0.0%)   | 7.7  |
| Other hospital unit (0.0%)   | 6.6  |
| Other health professionals (0.0%)  | 3.3  |
| Chaplin/deacon (0.0%)  | 1.0  |
| <b>Quality of care structure variables <sup>b</sup></b>                              |      |
| Access to immediate consultation (within 2 hours) <i>during</i> office hours with:   |      |
| Physician (3.4%)   | 75.5 |
| Registered nurse (0.6%)  | 99.7 |
| Chaplin/deacon (15.7%)   | 28.5 |
| Social worker (45.8%)  | 37.4 |
| Physiotherapist (3.8%)   | 51.3 |
| Occupational therapist (3.5%)  | 52.0 |
| Access to immediate consultation (within 2 hours) <i>outside</i> of office hours by: |      |
| Physician (12.6%)  | 68.2 |
| Nurse (0.7%)   | 99.3 |

|   |      |
|---|------|
| Family able to stay overnight                                   |      |
| in patient room (0.6%)  | 95.3 |
| in another room (0.6%)  | 68.9 |
| Service provider protocols for:                                 |      |
| Physician documentation of imminent death (0.6%)                | 53.3 |
| Regular assessment of pain (0.6%)                               | 63.5 |
| Regular assessment of nausea (0.6%)                             | 60.1 |
| Regular assessment of anxiety (0.6%)                            | 60.7 |
| Informing family about imminent death (0.6%)                    | 50.8 |
| Accommodating preferences according to ethnic background (0.6%) | 49.6 |
| Accommodating spiritual/religious needs (0.6%)                  | 51.2 |
| Prescriptions of PRN <sup>f</sup> drugs for the dying (0.6%)    | 70.2 |
| Procedures at time of death (0.6%)                              | 93.1 |
| Access to injected drugs for:                                   |      |
| Pain (opioids) (0.6%)   | 99.5 |
| Nausea (0.6%)   | 87.9 |
| Anxiety (0.6%)  | 94.1 |
| Rattles (0.6%)  | 99.3 |
| Time for staff to reflect following death (0.6%)                | 85.9 |

*Notes.* All values represent % “yes”, unless otherwise indicated in the variables column.

<sup>a</sup> Based on the patient-level questionnaire. All variables refer to the last week of life, unless otherwise indicated.

<sup>b</sup> Based on the unit-level questionnaire

<sup>c</sup> During last day of life

<sup>d</sup> Assessment with validated tool(s).

<sup>e</sup> When necessary determined by patient's need.



Table 2: Fit Statistics and Class Proportions for Models with 1-6 Latent Classes

| Parameters             | LL <sup>b</sup> | SBIC <sup>c</sup> | BIC <sup>d</sup> | Entropy   | Class Proportions |       |       |       |       |       |       |
|------------------------|-----------------|-------------------|------------------|-----------|-------------------|-------|-------|-------|-------|-------|-------|
|                        |                 |                   |                  |           | 1                 | 2     | 3     | 4     | 5     | 6     |       |
| 1 class <sup>a</sup>   | 36              | -417955.95        | 836206.95        | 836321.36 | 1.00              | 1.00  |       |       |       |       |       |
| 2 classes <sup>a</sup> | 73              | -411099.25        | 822796.81        | 823028.81 | 0.42              | 0.617 | 0.383 |       |       |       |       |
| 3 classes <sup>a</sup> | 110             | -409534.69        | 819970.92        | 820320.51 | 0.40              | 0.406 | 0.340 | 0.254 |       |       |       |
| 4 classes <sup>a</sup> | 147             | -408889.40        | 818983.60        | 819450.77 | 0.48              | 0.317 | 0.315 | 0.226 | 0.142 |       |       |
| 5 classes <sup>a</sup> | 184             | -408524.89        | 818557.82        | 819142.58 | 0.47              | 0.310 | 0.253 | 0.200 | 0.144 | 0.093 |       |
| 6 classes <sup>a</sup> | 221             | -408393.37        | 818598.03        | 819296.04 | 0.46              | 0.354 | 0.207 | 0.138 | 0.122 | 0.107 | 0.073 |

Note: Differences in between models were tested for K versus K-1 classes using a conditional bootstrap procedure. The test for

K=6 versus K=5 was not significant; all other tests were significant.

<sup>a</sup> All models have one latent factor

<sup>b</sup> Log likelihood

<sup>c</sup> Sample Adjusted Bayesian Information Criterion

<sup>d</sup> Bayesian Information Criterion

Table 3a. Patient characteristics variable distributions and multinomial regression results.

| Variables <sup>c</sup>               | Variable Distributions <sup>a</sup> |         |             |             |             | Odds Ratios/Adjusted Odds Ratios<br>(reference=Class 1) <sup>b</sup> |                      |                      |                      |                  | Wald<br>(bivariate<br>/multivar<br>iate) |
|--------------------------------------|-------------------------------------|---------|-------------|-------------|-------------|--|----------------------|----------------------|----------------------|------------------|--|
|                                      | Class 1                             | Class 2 | Class 3     | Class 4     | Class 5     | Class 2  | Class 3              | Class 4              | Class 5              |                  |  |
| Age (mean)                           | <b>84.8</b>                         | 81.9    | 79.3        | 78.6        | 80.0        | 0.97*** /<br>1.00***   | 0.95*** /<br>0.98*** | 0.95*** /<br>0.97*** | 0.96*** /<br>0.98*** | 517*** /<br>233  |  |
| Sex: Female (ref <sup>d</sup> =male) | <b>63.3</b>                         | 54.5    | 55.5        | 45.7        | 52.1        | 0.70*** /<br>0.77***   | 0.72*** /<br>0.77*** | 0.49*** /<br>0.69*** | 0.63*** /<br>0.78*** | 524*** /<br>141  |  |
| Underlying cause of death            |                                     |         |             |             |             |  |                      |                      |                      |                  |  |
| Neoplasms                            | 24.4                                | 39.8    | <b>52.3</b> | 31.8        | 45.0        | 2.05*** /<br>1.45***   | 3.40*** /<br>0.73    | 1.44*** /<br>0.37    | 2.54*** /<br>0.80    | 463*** /<br>367  |  |
| Circulatory                          | <b>37.0</b>                         | 28.9    | 23.1        | 34.8        | 28.1        | 0.69*** /<br>1.01  | 0.51*** /<br>0.46    | 0.91**/0.<br>49***   | 0.67*** /<br>0.50    | 202*** /<br>412  |  |
| Dementia                             | <b>18.8</b>                         | 14.0    | 11.1        | 0.7         | 8.6         | 0.71*** /<br>0.94  | 0.54*** /<br>0.35    | 0.03*** /<br>0.14    | 0.41*** /<br>0.34    | 260*** /<br>643  |  |
| Respiratory                          | 4.9                                 | 2.9     | 2.7         | <b>19.0</b> | 1.8         | 0.59*** /<br>1.12  | 0.55*** /<br>0.57*** | 4.53*** /<br>1.81*** | 0.35*** /<br>0.27    | 1460*** /<br>195 |  |
| Other                                | 14.9                                | 14.3    | 10.8        | 13.8        | <b>16.5</b> | 0.95/<br>0.69**  | 0.69** /<br>0.91/0.  | 0.91/0.<br>1.12/     | 1.12/<br>57***       | 57*** /<br>0.0   |  |

| Place of death and type of care setting     |             |            |             |             |      | 1.06            | 0.42            | 33                | 0.56           |                |
|---|-------------|------------|-------------|-------------|------|-----------------|-----------------|-------------------|----------------|----------------|
| Home: general homecare                      | 5.1         | <b>6.3</b> | 4.6         | 2.6         | 5.8  | 1.25** / 0.71   | 0.88/0.47*      | 0.49*** / 0.40**  | 1.15/ 0.59     | 72*** / 14**   |
| Short-term care facility <sup>e</sup>       | 7.8         | 9.1        | 11.6        | 4.4         | 12.2 | 1.19* / 0.67    | 1.56*** / 0.76  | 0.55*** / 0.46*   | 1.65*** / 0.95 | 125*** / 6     |
| Hospital ward/department                    | 19.9        | 21.9       | 17.6        | <b>63.1</b> | 33.4 | 1.12/ 0.65      | 0.86/ 0.67      | 6.86*** / 1.53    | 2.01*** / 1.04 | 1080*** / 11*  |
| Specialized palliative home care            | 6.1         | <b>8.1</b> | 8.0         | 5.1         | 6.6  | 1.36*** / 0.54* | 1.34** / 0.38** | 0.84/ 0.58        | 1.09/ 0.63     | 30*** / 10*    |
| Hospice or palliative care unit (inpatient) | 7.5         | 11.7       | <b>19.3</b> | 11.1        | 9.1  | 1.63* / 0.64    | 2.96*** / 0.74  | 1.55* / 0.94      | 1.24/ 0.71     | 82** / 3       |
| Long-term care facility <sup>e</sup>        | <b>53.0</b> | 42.7       | 38.6        | 13.3        | 32.6 | 0.66*** / 0.63  | 0.66*** / 0.61  | 0.14*** / 0.28*** | 0.43*** / 0.65 | 669*** / 19*** |
| Other                                       | <b>0.6</b>  | 0.3        | 0.3         | 0.4         | 0.4  | 0.46** / 0.54   | 0.57/ 0.50      | 0.71/ 0.66        | 0.62/ 0.57     | 10* / 0.0      |

*Notes.* For variable distributions, all values represent % “yes”, unless otherwise indicated in the “Variables” column. Parameter

estimates for the multinomial model are based on the overall model that includes all variables listed in Tables 3a-c.

\*  $p<0.05$ , \*\*  $p<0.01$ , \*\*\*  $p<0.001$

<sup>a</sup> Percentage (for age: mean) for predicted latent classes. For each variable, the class with the highest value is indicated in bold.

<sup>b</sup> Odds ratios based on bivariate logistic regression. Adjusted odds ratios based on multinomial logistic regression. Odds ratios are relative to the “no” response category unless otherwise indicated in the “Variables” column.

<sup>c</sup> Based on the patient-level questionnaire. All variables refer to the last week of life, unless otherwise indicated.

<sup>d</sup> Ref = Reference response category for odds ratios

<sup>e</sup> for old people

Table 3b. Quality of care process variable distributions and multinomial regression results.

| Variables <sup>c</sup>              | Variable Distributions <sup>a</sup> |         |             |             |             | Odds Ratios/Adjusted Odds Ratios<br>(reference=Class 1) <sup>b</sup> |                |                   |                   |               | Wald<br>(bivariate/<br>multivariate) |
|-------------------------------------|-------------------------------------|---------|-------------|-------------|-------------|--|----------------|-------------------|-------------------|---------------|--------------------------------------|
|                                     | Class 1                             | Class 2 | Class 3     | Class 4     | Class 5     | Class 2  | Class 3        | Class 4           | Class 5           |               |                                      |
| Pressure sores at admittance        | 7.8                                 | 12.3    | 10.9        | 13.0        | <b>13.8</b> | 1.78*** / 1.15   | 1.54*** / 1.03 | 1.78*** / 1.35    | 2.00*** / 1.09    | 168*** / 18   |                                      |
| Pressure sores at death             | 14.2                                | 24.0    | 23.2        | 19.4        | <b>26.0</b> | 1.98*** / 1.53   | 1.87*** / 1.52 | 1.38*** / 1.06    | 2.13*** / 1.67*** | 366*** / 109  |                                      |
| Feeding tube or intravenous fluids  | 9.3                                 | 12.2    | 8.7         | <b>35.3</b> | 15.2        | 1.36*** / 1.33   | 0.92 / 1.13    | 5.30*** / 1.90*** | 1.74*** / 1.04    | 1409*** / 147 |                                      |
| End-of-life discussions with family |                                     |         |             |             |             |  |                |                   |                   |               |                                      |
| Yes                                 | 68.4                                | 80.7    | <b>86.8</b> | 74.5        | 71.0        | 1.97*** / 1.04   | 3.15*** / 1.20 | 1.43*** / 0.66    | 1.18** / 0.84     | 522*** / 143  |                                      |
| Had no family members               | 1.5                                 | 1.2     | 1.0         | 2.4         | <b>2.5</b>  | 1.33 / 1.05  | 1.71*** / 1.10 | 2.14*** / 1.09    | 1.94*** / 1.19    | 1016*** / 416 |                                      |
| Someone present at death            |                                     |         |             |             |             |  |                |                   |                   |               |                                      |
| No one (ref <sup>d</sup> )          | 21.7                                | 9.4     | 6.6         | 17.3        | <b>22.8</b> |  |                |                   |                   |               |                                      |
| Staff                               | <b>33.2</b>                         | 25.0    | 25.2        | 24.3        | 30.0        | 1.74*** / 1.52   | 2.48*** / 1.87 | 0.92 / 1.60       | 0.86** / 1.09     |               |                                      |

|  |      |              |              |             |            |                    |                      |                         |                             |                 |
|--|------|--------------|--------------|-------------|------------|--------------------|----------------------|-------------------------|-----------------------------|-----------------|
| Family member                                  | 28.7 | 42.5         | <b>43.2</b>  | 31.9        | 28.2       | 3.42****/2         | 4.92****/2.33        | 1.40****/1.64****       | 0.93*/0.87*                 |                 |
| Family member and staff                        | 16.4 | 23.1         | 25.0         | <b>26.5</b> | 18.9       | 3.25****/2         | 4.96****/2.44        | 2.02****/2.33****       | 1.09*/1.06                  |                 |
| Pain assessment, valid instrument <sup>f</sup> | 16.3 | 19.7         | <b>26.5</b>  | 17.6        | 14.4       | 1.26*/1.06         | 1.85****/1.14        | 1.10*/0.83*             | 0.86/0.84                   |                 |
| Other symptom assessment <sup>f</sup>          | 10.3 | 9.4          | <b>14.8</b>  | 13.8        | 8.6        | 0.90/0.72          | 1.51****/0.90        | 1.40**/1.19             | 0.82*/0.87                  |                 |
| PRN prescription for:                          |      |              |              |             |            |                    |                      |                         |                             |                 |
| pain   | 80.3 | <b>100.0</b> | <b>100.0</b> | 86.1        | 90.8       | -/8.78****         | -/6.59****           | 1.52 <sup>g</sup> /0.94 | 2.42 <sup>g</sup> /1.54**** | -/189****       |
| rattles  | 67.7 | <b>97.4</b>  | 96.5         | 84.9        | 66.5       | 17.93****/4.79**** | 13.00****/1.47****   | 2.68****/3.93****       | 0.95/0.65                   | 870****/649**** |
| nausea   | 49.4 | 62.4         | <b>75.4</b>  | 45.9        | 49.9       | 1.70****/0.81      | 3.14****/0.67        | 0.87*/0.50              | 1.02/0.63                   | 510****/191**** |
| anxiety  | 67.0 | 78.6         | <b>99.9</b>  | 78.7        | 82.1       | 1.81****/0.58****  | 351.39****/51.15**** | 1.82****/2.19****       | 2.26****/3.53****           | 724****/718**** |
| Consultation with:                             |      |              |              |             |            |                    |                      |                         |                             |                 |
| Pain unit                                      | 0.0  | 1.4          | 2.5          | 1.2         | <b>3.8</b> | 44.41/3.44         | 82.51/4.80****       | 37.92/2.97****          | 126.29*/9.03****            | 85****/83****   |
| Palliative team                                | 3.1  | 8.2          | <b>12.3</b>  | 6.6         | 12.9       | 2.76****/1.57****  | 4.35****/2.09****    | 2.20****/1.77****       | 4.60****/2.59****           | 400****/132**** |
| Other hospital unit                            | 4.3  | 5.0          | 5.4          | <b>13.4</b> | 10.3       | 1.17/1.20          | 1.27*/1.54           | 3.43****/2.50****       | 2.56****/2.25****           | 556****/225**** |
| Other health professionals                     | 2.7  | 3.2          | 3.9          | 3.7         | <b>4.0</b> | 1.21*/1.10         | 1.48****/1.46****    | 1.40**/1.43****         | 1.51****/1.27****           | 24****/20****   |
| Chaplain/deacon                                | 0.4  | 0.9          | <b>1.8</b>   | 1.0         | 1.5        | 2.22****/          | 4.36****/            | 2.37****/               | 3.69****/                   | 82****/         |

- *Notes.* For variable distributions, all values represent % “yes”, unless otherwise indicated in the “Variables” column. Parameter estimates for the multinomial model are based on the overall model that includes all variables listed in Tables 3a-c. The following variables from Table 1 are not included in Table 3c as they were not significant at the bivariate level: Access to consultation with a nurse outside office hours, family able to stay overnight in another room, and access to injected drugs for pain and rattle.

\*  $p < 0.05$ , \*\*  $p < 0.01$ , \*\*\*  $p < 0.001$

<sup>a</sup> Percentage for predicted latent classes. For each variable, the class with the highest value is indicated in bold.

<sup>b</sup> Odds ratios based on bivariate logistic regression. Adjusted odds ratios based on multinomial logistic regression. Odds ratios are relative to the “no” response category unless otherwise indicated in “Variables” column.

<sup>c</sup> Based on the unit-level questionnaire

<sup>d</sup> Ref = Reference response category for odds ratios

<sup>e</sup> During last day of life

<sup>f</sup> Assessment with validated tool(s).

<sup>g</sup> Standard errors and significance not available due to 100% probability of membership in classes 2 and 3

Table 3c. Quality of care structure variable distributions and multinomial regression analysis results.

| Variables <sup>c</sup>  | Variable Distributions <sup>a</sup> |         |             |             |         | Odds Ratios/Adjusted Odds Ratios<br>(reference=Class 1) <sup>b</sup> |                   |                     |                     |                 | Wald<br>(bivariate<br>multivari<br>e) |
|---|-------------------------------------|---------|-------------|-------------|---------|--|-------------------|---------------------|---------------------|-----------------|---------------------------------------|
|   | Class 1                             | Class 2 | Class 3     | Class 4     | Class 5 | Class 2  | Class 3           | Class 4             | Class 5             |                 |                                       |
| Access to immediate consultation (within 2 hours) during office hours with: |                                     |         |             |             |         |  |                   |                     |                     |                 |                                       |
| Physician   | 71.7                                | 73.1    | 74.1        | <b>90.2</b> | 74.7    | 0.94/<br>0.99  | 0.89/<br>1.02     | 0.27***/<br>0.98    | 0.86*/<br>1.02      | 221***/<br>0.4  |                                       |
| Registered nurse  | 99.7                                | 99.7    | <b>99.8</b> | 99.6        | 99.4    | 1.17/<br>1.18  | 0.59/<br>0.82     | 1.31/<br>1.79*      | 2.00*/<br>2.12*     | 16***/<br>13*   |                                       |
| Physio therapist  | 52.2                                | 48.7    | 48.1        | <b>59.1</b> | 50.3    | 1.14*/1.<br>18   | 1.17*/<br>0.93    | 0.75***/<br>0.94    | 1.07/<br>1.00       | 38***/<br>6     |                                       |
| Occupational therapist  | 53.7                                | 50.7    | 48.8        | <b>55.8</b> | 50.5    | 1.13*/0.<br>98   | 1.22**/<br>1.26   | 0.91/<br>1.31*      | 1.13/<br>1.20       | 19***/<br>11*   |                                       |
| Family members able to stay overnight <sup>d</sup>                          | 95.3                                | 94.3    | <b>96.7</b> | 95.5        | 94.9    | 0.83/<br>1.00  | 1.44**/<br>1.53** | 1.06/<br>1.34       | 0.93/<br>1.10       | 29***/<br>22    |                                       |
| Service provider protocols for:   |                                     |         |             |             |         |  |                   |                     |                     |                 |                                       |
| Physician documentation of imminent death                                   | 55.4                                | 53.6    | <b>59.1</b> | 44.5        | 46.4    | 0.93/<br>0.94  | 1.16*/<br>1.02    | 0.64***/<br>1.05    | 0.70***/<br>1.03    | 68***/<br>3     |                                       |
| Regular assessment of pain  | 64.6                                | 65.2    | <b>68.5</b> | 54.8        | 58.0    | 1.03/<br>1.05  | 1.19**/<br>0.80   | 0.66***/<br>1.27    | 0.76***/<br>1.03    | 57***/<br>8     |                                       |
| Regular assessment of nausea  | 61.3                                | 62.0    | <b>65.9</b> | 49.8        | 54.5    | 1.03/<br>1.32  | 1.22**/<br>1.58   | 0.63***/<br>1.29    | 0.76***/<br>1.89    | 73***/<br>5     |                                       |
| Regular assessment of anxiety   | 62.2                                | 62.5    | <b>66.5</b> | 49.8        | 54.7    | 1.01/<br>1.01  | 1.21**/<br>1.21** | 0.60***/<br>0.60*** | 0.74***/<br>0.74*** | 81***/<br>81*** |                                       |



|  |             |      |             |             |      |              |               |                |               |            |
|--|-------------|------|-------------|-------------|------|--------------|---------------|----------------|---------------|------------|
| Informing family about imminent death                    | 55.6        | 52.1 | <b>56.2</b> | 36.7        | 41.8 | 0.81         | 0.87          | 0.64*          | 0.56          | 7          |
| Accommodating preferences according to ethnic background | 53.6        | 48.8 | <b>54.5</b> | 40.3        | 41.9 | 0.87*/0.95   | 1.02/0.91     | 0.46****/0.88  | 0.57***/0.86  | 146***/4   |
| Accommodating spiritual/religious needs                  | 55.2        | 50.5 | <b>55.8</b> | 42.0        | 43.8 | 0.82***/0.92 | 1.04/0.98     | 0.58****/0.74* | 0.63***/0.81  | 86***/7    |
| Prescriptions of PRN drugs for the dying                 | 72.7        | 72.3 | <b>74.3</b> | 59.1        | 64.0 | 0.83***/0.90 | 1.03/0.98     | 0.59****/1.18  | 0.63***/0.96  | 79***/6    |
| Procedures at time of death                              | 94.4        | 93.9 | <b>95.0</b> | 87.9        | 90.8 | 0.98/1.04    | 1.09/0.86*    | 0.54****/0.99  | 0.67***/0.94  | 90***/10*  |
| Access to injected drugs for:                            |             |      |             |             |      | 0.90/0.94    | 1.12/0.94     | 0.43****/0.95  | 0.58***/0.95  | 83***/0.4  |
| Nausea   | 84.9        | 87.5 | 87.4        | <b>96.0</b> | 87.1 | 1.24***/1.06 | 1.23**/0.88   | 4.28****/1.26  | 1.20*/0.98    | 141***/11* |
| Anxiety  | 92.7        | 93.6 | 94.7        | <b>97.6</b> | 93.6 | 1.16/1.03    | 1.39****/1.17 | 3.26****/1.05  | 1.16/0.93     | 66***/3    |
| Time for staff to reflect following death                | <b>87.9</b> | 86.2 | 87.8        | 80.8        | 82.6 | 0.86*/0.90   | 0.99/**/0.83  | 0.58***/0.85*  | 0.66***/0.85* | 58***/9    |

*Notes.* For variable distributions, all values represent % “yes”, unless otherwise indicated in the “Variables” column. Parameter estimates for the multinomial model are based on the overall model that includes all variables listed in Tables 3a-c.

\* $p<0.05$ , \*\* $p<0.01$ , \*\*\* $p<0.001$

<sup>a</sup> Percentage for predicted latent classes. For each variable, the class with the highest value is indicated in bold.

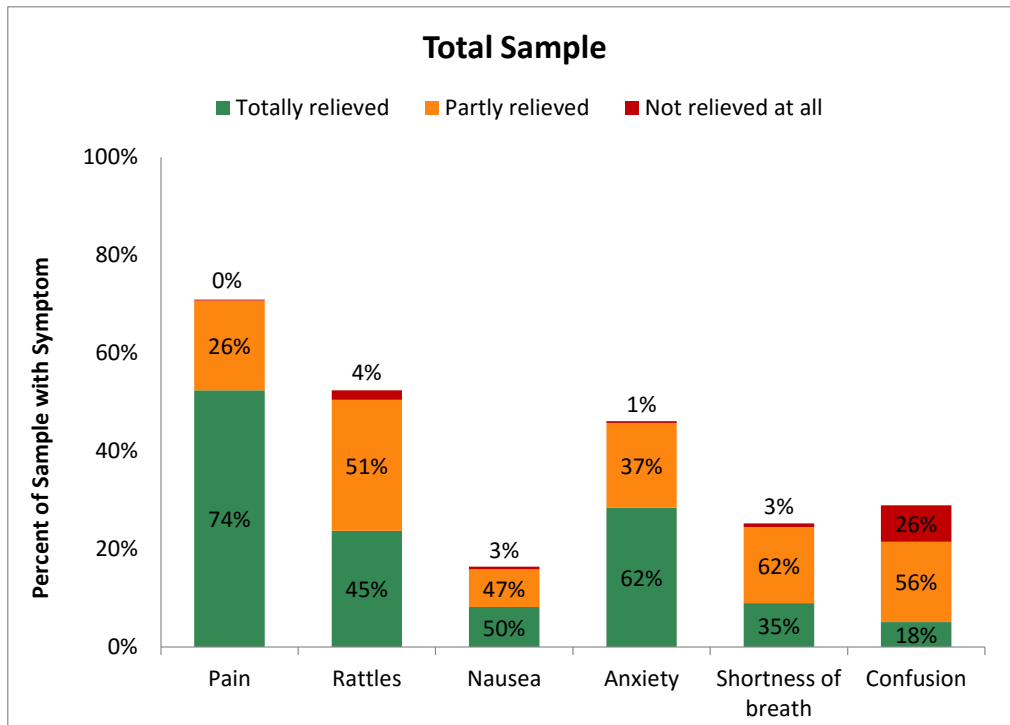
<sup>b</sup> Odds ratios based on bivariate logistic regression. Adjusted odds ratios based on multinomial logistic regression. Odds ratios are relative to the “no” response category.

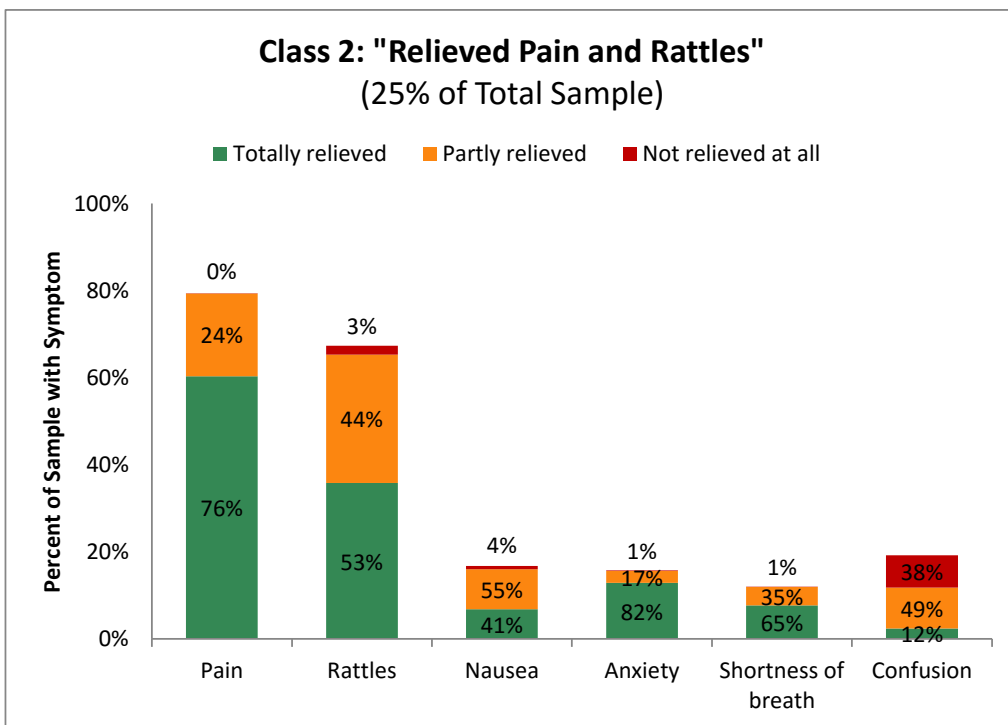
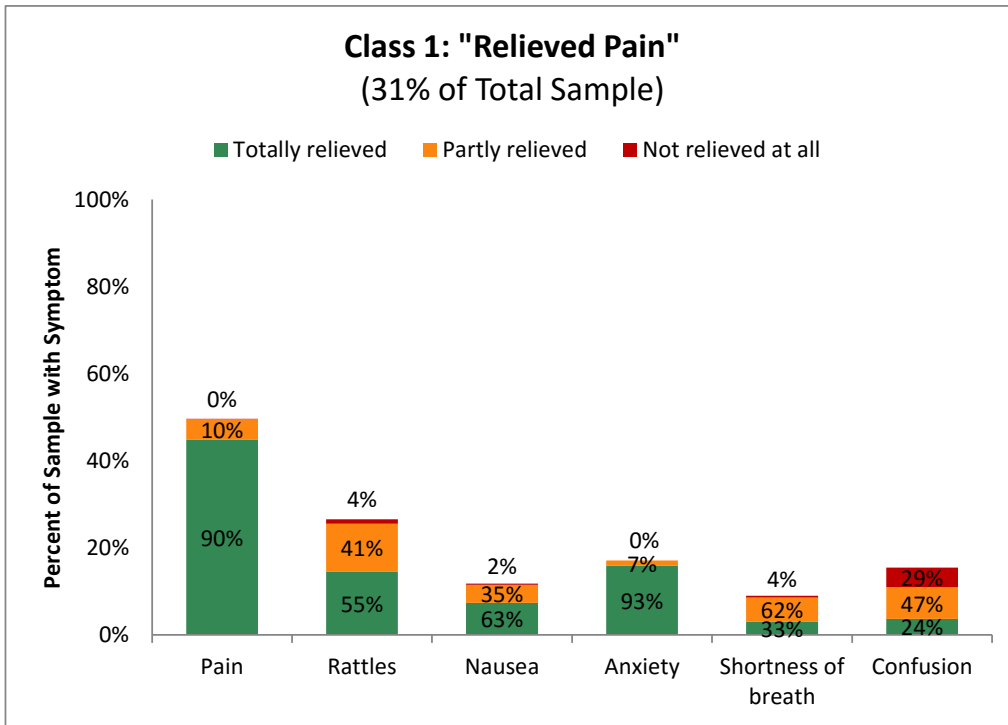
<sup>e</sup> Based on the unit-level questionnaire

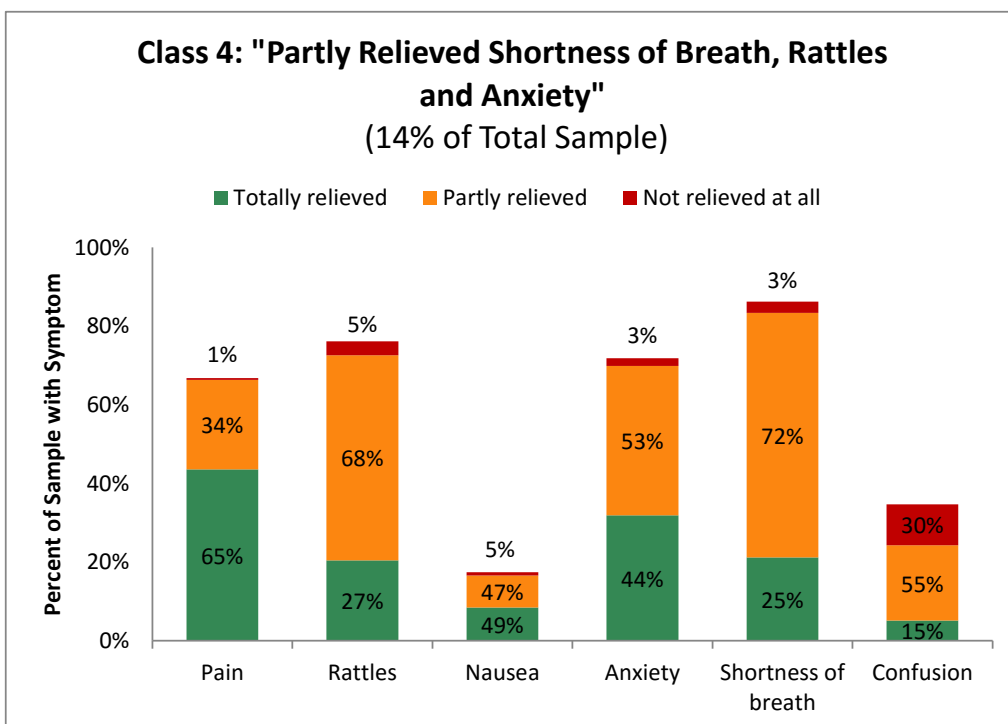
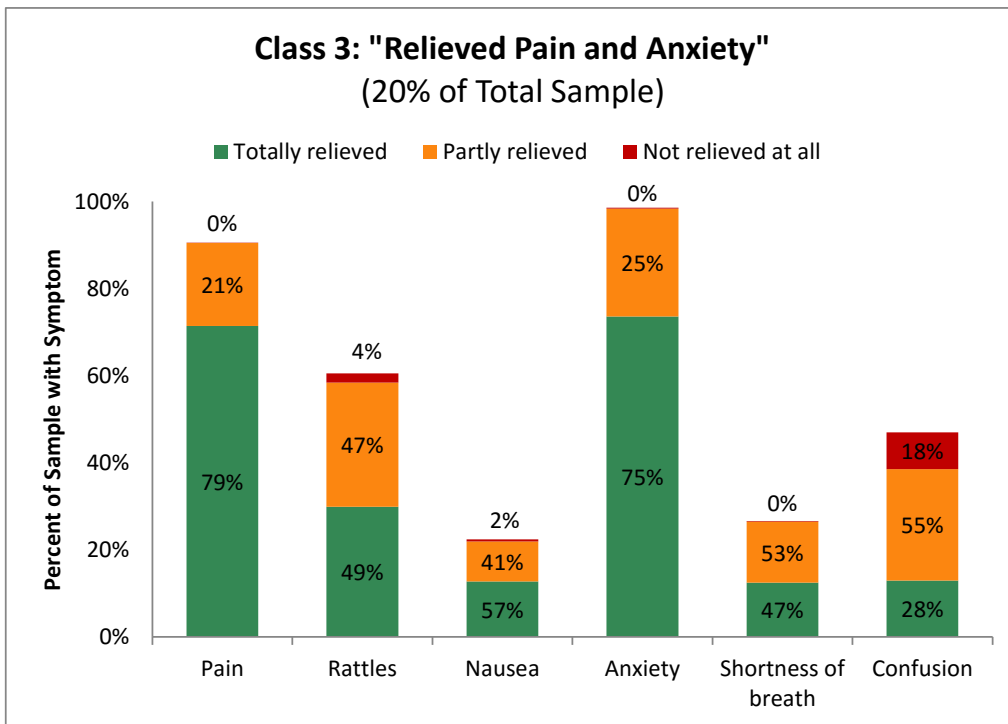
<sup>d</sup> in patient room

Figure 1. Symptom presence and relief profiles in total sample and five latent classes

Note: Percentages in figure bars reflect symptom relief among patients who experienced a symptom. For the total sample, these are observed percentages. For classes 1-5, these are model-based estimated percentages.







**Class 5: "Partly Relieved Pain, Anxiety and Confusion"**  
(9% of Total Sample)

