Severe pain at the end of life: a population-level observational study

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Abstract

Background: Pain is a prevalent symptom at the end of life and negatively impacts quality of life. Despite this, little population level data exist that describe pain frequency and associated factors at the end of life. The purpose of this study was to explore the prevalence of clinically significant pain at the end of life and identify predictors of increased pain.

Methods: Retrospective population-level cohort study of all decedents in Ontario, Canada, from April 1, 2011 to March 31, 2015 who received a home care assessment in the last 30 days of life (n = 20,349). Severe daily pain in the last 30 days of life using linked Ontario health administrative databases. Severe pain is defined using a validated pain scale combining pain frequency and intensity: daily pain of severe intensity.

Results: Severe daily pain was reported in 17.2% of 20,349 decedents. Increased risk of severe daily pain was observed in decedents who were female, younger and functionally impaired. Those who were cognitively impaired had a lower risk of reporting pain. Disease trajectory impacted pain; those who died of a terminal illness (i.e. cancer) were more likely to experience pain than those with frailty (odds ratio 1.66).

Conclusion: Pain is a common fear of those contemplating end of life, but severe pain is reported in less than 1 in 5 of our population in the last month of life. Certain subpopulations may be more likely to report severe pain at the end of life and may benefit from earlier palliative care referral and intervention.

Keywords: Pain, End-of-life, Palliative care, Palliative medicine, Palliative homecare

Background

Uncontrolled pain is consistently listed by patients as a primary source of fear for end-of-life care [1–3]. Palliative care aims to provide relief of pain and other physical symptoms in addition to supportive care for patients and their families at the end of life [4, 5]. Pain is often considered one of the more treatable symptoms in palliative care [6] and a request for assistance with pain management is a common reason for referral to palliative care physician specialists and palliative care teams. Uncontrolled pain is a common reason for palliative patients to present to acute care. Nearly one in ten emergency department visits from oncology patients in the last months of life cited pain as reason for visit [7]. Additionally, nearly 20% of patients who die in hospital experience some degree of pain [8]. Identification of those patients at risk for increased pain near the end of life is important for prompt initiation of a palliative approach and consideration of specialist palliative care referral [6, 9] as there is evidence that pain may be mitigated by palliative care intervention and home visits [10].

The bulk of the current data on the prevalence of pain is limited to specific populations. A systematic review examining studies between 1965 and 2006 demonstrated the pooled prevalence of pain in patients with advanced cancer was 64% [11]. Additionally, increased pain has been reported in advanced cancer patients with mental health illnesses, including depression and anxiety [12–14].
Estimates of the prevalence of pain in various late stage non-malignant populations (i.e., congestive heart failure (CHF), end-stage renal disease, chronic obstructive pulmonary disease (COPD)) range from 47 to 93% [15–17]. Studies of pain in persons with dementia have consistently demonstrated lower rates of reported pain [18, 19]. These studies, however, do not provide a sense of the prevalence of pain across the general population at end of life nor between disease trajectories (frailty, terminal illness, organ failure, sudden death). This is important as current evidence demonstrates disparities between disease trajectory and access to palliative care services [20]. An American retrospective observational study (N = 4703) demonstrated clinically significant pain in 47% of the population in the last month of life (as reported using non-validated 2 question measurement: participant “often troubled by moderate to severe pain”) [21]. The authors found pain was associated with proximity to death, arthritis and certain demographic factors such as sex, age, race and income. To our knowledge, no studies to date have captured in detail how pain varies across end-of-life trajectories, a wide variety of comorbid chronic diseases, home-based palliative care services, living arrangement (e.g., presence of a family caregiver) and other important patient characteristics such as impairment in function and cognition.

Our goal was to explore pain at the end of life across a wide variety of patient characteristics at a population level. To address the deficit in knowledge, we used multiple health linked databases providing access to detailed covariates in order to observe the frequency and severity of pain in the last month of life. We aimed to identify predictive or protective factors for pain at the end of life as well as potential risk factors that could be targeted for screening and prompt initiation of pain management strategies and palliative care referral.

Methods
We conducted a population-based retrospective observational study using linked health administrative databases held at ICES. Our population included all decedents in Ontario, Canada from April 1, 2011 to March 31, 2015 (most recent, complete data available at time of analysis) who received a Resident Assessment Instrument–Home Care (RAI-HC) [22] assessment in the last 30 days of life. The RAI-HC database contains RAI-HC assessments which are conducted for all Ontarians seeking to receive long-stay home care (i.e., anticipated greater than 60 days). These assessments are conducted by trained assessors with input from the clinic team, the patient’s chart, the patient, and caregivers. Demographics, symptomatology, and detailed covariates were collected from each assessment. These covariates include: cognitive functioning, caregiver and living arrangements, activities of daily living (ADLs) on a 0–6 point performance scale (describing the discrete stages of loss in personal hygiene, toileting, locomotion and eating), instrumental activities of daily living (IADLs) (ordinary housework, meal preparation and phone use) [23]. Ethics approval was obtained from the Sunnybrook Health Sciences Centre Research Ethics Board in Toronto, Canada and from the Ottawa Health Science Network Research Ethics Board in Ottawa, Canada.

Data sources
Encrypted health card numbers were used as unique identifiers and linked across several administrative databases held at ICES (Additional file 1). All data were de-identified and anonymized. Deaths and demographics including age and sex were captured from the Registered Persons Database (RPDB). Postal codes of residence were used to derive neighborhood income and rurality at the time of death through the Postal Code Conversion Files which are derived from the Statistics Canada 2011 census. The presence of chronic conditions at death was captured using previously developed—and in some cases validated—chronic disease databases held at ICES [24]. A total of 17 chronic diseases were examined and the number of diseases identified was totaled for each individual [25–31]. End-of-life trajectories (i.e., frailty, terminal illness, sudden death, organ failure, other) were captured using cause of death information from the Ontario Registrar General Database (ORGD) – deaths. The International Classification of Diseases (ICD-10) codes used to group deaths into these four categories, including validation in the Canadian population, are described elsewhere [20, 32–34].

Designated palliative homecare (e.g., from nurses, nurse practitioners, and personal support workers) and physician home visits were captured between 30 days to 6 months prior to death. Palliative home care was captured when a patient was given an end-of-life designation by home care services, which allows them to access additional and often specialized palliative care services. Physician home visits were identified using physician billing claims for services delivered at home, captured in the Ontario Health Insurance Plan (OHIP) database (Additional file 2). The subset of home visits delivered by palliative care physician specialists were identified using a validated definition of greater than 10% of all billings in the previous 2 years classified as palliative care [35]. Palliative home visits and services delivered by non-physician specialties (e.g. nurse practitioners, spiritual care, personal support workers, social workers, etc.) that occurred outside of designated publicly-funded palliative home care (i.e. out-of-pocket expenses or private insurance) is not captured in available health administrative databases and were therefore not included in our analyses.

Pain at end of life
Reported pain was captured using the RAI-HC database. Data was captured from those who received a RAI-HC
assessment in the last month of life, the period associated with the highest pain scores [21]. A validated pain scale that combines pain intensity and frequency from the RAI-HC was applied to generate a four-point pain scale from no pain to severe pain occurring daily [36]. In this scale, severe daily pain was equivalent to an average of 5/10 on a visual analog scale. As pain beyond 4/10 has been shown to be associated with decreased functional status and quality of life [37, 38], we elected to compare decedents with severe daily pain to those without severe daily pain.

Analysis
A logistic regression model was run for the primary outcome of severe daily pain in the last 30 days of life. Decedents with severe daily pain were compared to those without severe daily pain. Covariates of interest included demographics, comorbidities, functional status, and physician home visits in the 6 months to 1 month prior to death. Additionally, we examined the effect of a palliative care specialist being involved in at least one of the visits. The multivariable model examined the independent effect of potential predictors of pain that are available in health administrative databases: age, sex, neighborhood income quintile, rurality, functional status (i.e. ADLs and IADLs), Cognitive Performance Scale (CPS) [39] score, number of comorbidities, and end-of-life trajectories. All analyses were conducted using SAS 9.3 (SAS Institute Inc., Cary, NC).

Results
In Ontario, between April 1, 2011 to March 31, 2015, there were 370,524 deaths. We captured data from 20,349 decedents who received a RAI-HC assessment in the last month of life (5.5% of total decedent population). The average age of our cohort was 81.4 years. The majority were female (51.6%) and lived in an urban setting. 42.8% had 5 or more chronic conditions. Less than 1 in 5 people (17.2%) reported severe daily pain using the validated pain scale (Table 1), with 30.3% of decedents reporting no pain. The majority (73.8%) felt they had adequate pain control at baseline or with medications, however 42.4% described pain that disrupted usual activities.

Factors associated with severe daily pain
Demographics
The proportion of severe daily pain was higher in those who died at a younger age (Fig. 1a).

Among female decedents, 18.4% reported severe daily pain compared to 15.9% of male decedents (Fig. 1b; Table 2). Younger decedents had a higher risk severe daily pain; 34.0% of 0–49-year-olds compared to only 13.3% of those aged 90+. Rurality and income were not found to significantly impact risk of severe daily pain. Those with 5+ chronic conditions reported more severe daily pain (17.8%) than those with 0–2 or 3–4 (17.5 and 16.3% respectively).

Reported severe daily pain varied with living arrangements (Table 3): decedents who lived in a private community home with or without homecare reported higher severe daily pain (17.5, 18.2%) than those who lived in an assisted living or residential care facility (15.9, 14.5%). Those who lived with relatives were more likely to report severe daily pain (with spouse:18.4%, with spouse and others:19.0%, with child:18.7%) compared to those who lived alone (17.1%) or with non-relatives (15.3%). Decedents with reported caregiver stress had increased pain compared to those with no caregiver stress (18.3% vs. 16.4%).

Functional status
In examining ADLs (Table 3), reported severe daily pain was highest in those who were dependent (19.5%) and

### Table 1 Reported pain in decedents with a RAI-HC assessment in the last 30 days of life

| Pain Frequency                  | N   | COL% |
|---------------------------------|-----|------|
| No pain                         | 6181| 30.28|
| Less than daily                 | 2036| 9.97 |
| Daily-one period                | 1262| 6.18 |
| Daily-multiple periods (e.g. morning and evening) | 10,936 | 53.57 |

| Pain Intensity                  | N   | COL% |
|---------------------------------|-----|------|
| No pain                         | 6188| 30.31|
| Mild                            | 3211| 15.73|
| Moderate                        | 7419| 36.34|
| Severe or excruciating          | 2776| 13.6 |
| Times when pain is horrible     | 821 | 4.02 |

Pain disrupts usual activities

| Yes/No pain                     | N   | COL% |
|---------------------------------|-----|------|
| Yes                             | 15,072| 73.83|
| Medications do not adequately control pain | 3407 | 16.69 |
| Pain present, medication not taken | 1936 | 9.48 |

Pain Scale

| No pain                         | 6184| 30.29|
| Less than daily                 | 2036| 9.97 |
| Daily pain but not severe       | 8680| 42.52|
| Severe daily pain               | 3515| 17.22|

*Resident Assessment Instrument–Home Care
lowest in those who were totally dependent (15.8%). Similarly, pain severity generally trended up with increasing impairment in IADLs to a maximum of great difficulty in 2 out of 3 IADLs as collected on the RAI-HC (20.1%). Those decedents with great difficulty carrying out all three IADLs reported lower than average severe daily pain (14.7%).

**Clinical factors**
Reported severe daily pain decreased with worsening cognitive impairment, with 20.3% of cognitively intact persons reporting severe daily pain compared to 12.8% with very severe cognitive impairment. Pain scores varied with end-of-life trajectory. Those with frailty (e.g., dementia), organ failure (e.g., COPD or
| Table 2 | Cohort characteristics by pain severity in the last 30 days of life |
|---|---|---|---|---|
| | No severe daily pain | (%) | Severe daily pain | (%) | All |
| | N | | N | | N |
| **Age** | | | | | |
| 0–49 | 161 | 66.0% | 83 | 34.0% | 244 |
| 50–59 | 559 | 70.4% | 235 | 29.6% | 794 |
| 60–69 | 1452 | 75.4% | 474 | 24.6% | 1926 |
| 70–79 | 3285 | 81.0% | 773 | 19.0% | 4058 |
| 80–89 | 7181 | 84.7% | 1297 | 15.3% | 8478 |
| 90+ | 4206 | 86.7% | 643 | 13.3% | 4849 |
| **Sex** | | | | | |
| Male | 8281 | 84.1% | 1569 | 15.9% | 9850 |
| Female | 8563 | 81.6% | 1936 | 18.4% | 10,499 |
| **Income Quintile** | | | | | |
| Highest | 2990 | 83.8% | 576 | 16.2% | 3566 |
| High | 3141 | 82.4% | 673 | 17.6% | 3814 |
| Middle | 3307 | 82.6% | 695 | 17.4% | 4002 |
| Low | 3679 | 83.2% | 744 | 16.8% | 4423 |
| Lowest | 3727 | 82.0% | 817 | 18.0% | 4544 |
| **Rurality** | | | | | |
| Urban | 13,807 | 82.9% | 2850 | 17.1% | 16,657 |
| Rural | 3037 | 82.3% | 655 | 17.7% | 3692 |
| **Palliative Home Care** | | | | | |
| No | 13,205 | 84.1% | 2488 | 15.9% | 15,693 |
| Yes | 3639 | 78.2% | 1017 | 21.8% | 4656 |
| **Physician Home Visit** | | | | | |
| No | 14,711 | 83.0% | 3008 | 17.0% | 17,719 |
| Yes - Non-PC specialist | 1817 | 81.8% | 405 | 18.2% | 2222 |
| Yes - PC specialist | 372 | 78.5% | 102 | 21.5% | 474 |
| **Number of Chronic Conditions** | | | | | |
| 0–2 | 3744 | 82.5% | 795 | 17.5% | 4539 |
| 3–4 | 5938 | 83.7% | 1157 | 16.3% | 7095 |
| 5+ | 7162 | 82.2% | 1553 | 17.8% | 8715 |
| **Cancer (any)** | | | | | |
| No | 11,968 | 83.6% | 2341 | 16.4% | 14,309 |
| Yes | 4876 | 80.7% | 1164 | 19.3% | 6040 |
| **Dementia** | | | | | |
| No | 13,355 | 81.2% | 3092 | 18.8% | 16,447 |
| Yes | 3489 | 89.4% | 413 | 10.6% | 3902 |
| **Diabetes Mellitus** | | | | | |
| No | 10,571 | 83.1% | 2145 | 16.9% | 12,716 |
| Yes | 6273 | 82.2% | 1360 | 17.8% | 7633 |
| **Mental Health (other)** | | | | | |
| No | 15,816 | 82.9% | 3268 | 17.1% | 19,084 |
| Yes | 1028 | 81.3% | 237 | 18.7% | 1265 |
and sudden death had a lower proportion reporting severe daily pain than those with terminal illness (e.g., cancer) (Table 3). The following chronic conditions were associated with increased risk of severe daily pain (Table 2): rheumatoid arthritis (23.9%), mood and anxiety disorders (19.5%), renal failure (19.4%), cancer (19.3%), osteoarthritis (19.1%) and other mental health illness (18.7%). Many cardiac conditions (acute myocardial infarction, congestive heart failure, hypertension) as well as chronic neurological conditions [history of stroke (16.0%) and dementia (10.6%)] were associated with lower than average reports of severe daily pain.

Physical symptoms as reported on the RAI-HC associated with higher severe daily pain include dyspnea (19.2%), anorexia (22.2%), emesis (29.5%), constipation (31.4%) and edema (20.2%) (Table 4). Increasing severity of pressure ulcers were also associated with higher rates of pain. Additionally, psychological symptoms such as loneliness and sad mood were associated with increased reports of severe daily pain.

### System factors
A minority of decedents received designated palliative home care or a physician home visit between 30 days to 6 months prior to death, at 22.9 and 13.2% respectively. Decedents who received designated palliative home care had higher severe daily pain in the last 30 days of life than those without (21.8% vs 15.9%). A trend was also demonstrated toward increased pain in those who received a physician home visit. Pain tended upward with time since self-reported admission to hospital with 14.8% of those in hospital versus 19.9% in those who had not reported a hospitalization in the previous 180 days.

### Logistic regression models for odds of severe daily pain
Adjusting for multiple covariates as listed in our methods, females had greater odds of having severe daily pain \[ OR = 1.25; 95\% CI: 1.16 \text{ to } 1.35 \] (Table 5). The odds ratio of severe daily pain was 0.31 in the decedents aged 90+ compared to 0–49 (95% CI: 0.23 to 0.42). Those with severe or very severe cognitive impairment had an OR of 0.68 and 0.52, respectively, compared to those who were cognitively intact. When examining disease trajectory, compared to frailty, those with terminal illness were more likely to report severe daily pain (OR 1.66, (95% CI: 1.46 to 1.88). Decedents with designated palliative home care had greater odds of increased pain compared to those without [OR 1.13 (95% CI: 1.03 to 1.24)]. Conversely, the trend seen with physician home visits was no longer statistically significant for specialist or non-specialist home visits when all covariates were accounted for [OR 1.12 (95% CI: 0.99 to 1.26) and 1.14 (95% CI: 0.91 to 1.44)].

### Discussion
We examined the proportion of severe daily pain reported in the last 30 days of life using population-based administrative databases. We observed that less than 1 in 5 decedents (17.2%) report severe daily pain.
| ADLS | No severe daily pain (%) | Severe daily pain (%) | All N |
|------|--------------------------|-----------------------|-------|
| Independent | 83.2% | 16.8% | 3821 |
| Supervision required | 82.4% | 17.6% | 1791 |
| Limited impairment | 83.1% | 16.9% | 3746 |
| Extensive assistance required (I) | 83.2% | 16.8% | 2283 |
| Extensive assistance required (II) | 83.4% | 16.6% | 3619 |
| Dependent | 80.5% | 19.5% | 3427 |
| Total dependence | 84.2% | 15.8% | 1662 |
| IADLS | No difficulty in any of three IADLs | Some difficulty in one IADL but no difficulty in the other two | Some difficulty in two IADLs but no difficulty in the other one | Some difficulty in all three IADLs |
| | 97 | 158 | 144 | 94 |
| | 9.3% | 88.3% | 85.3% | 89.5% |
| | 7 | 21 | 82 | 11 |
| | 0.7% | 1.7% | 14.7% | 10.5% |
| Cognitive Performance Scale (CPS) | Intact | Borderline intact | Mild impairment | Moderate impairment |
| | 3230 | 2260 | 5853 | 2395 |
| | 79.7% | 79.2% | 82.1% | 86.3% |
| | 824 | 595 | 1275 | 381 |
| | 20.3% | 20.8% | 17.9% | 13.7% |
| Caregiver Stress | Yes | No |
| | 7383 | 9461 |
| | 81.7% | 83.6% |
| | 1652 | 1853 |
| | 18.3% | 16.4% |
| | 9035 | 11,314 |
| Where Lived at Time of Referral | Missing | Private home/apt. With no home care services | Private home/apt. With home care services | Board and care/assisted living/group home |
| | 8659 | 5184 | 1803 | 768 |
| | 83.2% | 81.8% | 82.5% | 84.1% |
| | 1747 | 1156 | 383 | 145 |
| | 16.8% | 18.2% | 17.5% | 15.9% |
| | 10,406 | 6340 | 2186 | 913 |
| Who Lived with at Time of Referral | Missing | Lived alone | Lived with spouse only | Lived with spouse and other(s) |
| | 8659 | 2300 | 2795 | 666 |
| | 83.2% | 82.9% | 81.6% | 81.0% |
| | 1747 | 476 | 633 | 156 |
| | 16.8% | 17.1% | 18.4% | 19.0% |
| | 10,406 | 2776 | 3431 | 822 |
| | Lived with child (not spouse) | Lived with other(s) (not spouse or children) | Lived in group setting with non-relative(s) |
| | 1105 | 572 | 744 |
| | 81.3% | 84.5% | 84.7% |
| | 254.0 | 105 | 134 |
| | 18.7% | 15.5% | 15.3% |
pain. This level of pain is considered inadequately treated and would likely be associated with lower quality of life and functional impairment [37, 38]. We identified multiple demographic, clinical and system factors associated with increased end-of-life pain, many of which have not been previously described. Notably, disease trajectory impacted reported severe daily pain at the end of life. Those with terminal illness (i.e. cancer) and other had higher odds of reporting pain than those with frailty, sudden death or organ failure (cardiac or pulmonary). Interestingly, renal failure is categorized into the other disease trajectory and was associated with increased reported pain. Although this is a condition that is not typically considered inherently painful, it is possible that pain in this population may be undertreated, possibly due to fear of using analgesic medications that may worsen renal function or are renally cleared. Additionally, increased pain reported by females and younger decedents could be hypothesized to be related to the specific illness or trajectory related to these populations; however, this trend is persistent when disease trajectory was accounted for. The increased reported pain in those receiving palliative services may have been related to referral bias where those with increased pain are more likely to receive a palliative care referral. However, only a small minority received a palliative home care designation or physician home visit despite being close to death. This is consistent with other jurisdictions signaling large room for improvement in access to palliative care services [35, 40].

Our study addresses a gap in the previous literature by examining end-of-life pain in a large sample, using a validated pain scale and conducting analyses adjusting for multiple potential confounders. The proportion of pain reported in this study is lower than previously reported by other population research [21]. This may be attributed to our study examining those with daily severe pain compared to previous research including intensity (moderate-severe) but not considering frequency when determining clinical significance. Previous studies [11–13, 21] have demonstrated an association between pain and select comorbidities: arthritis, cancers and mental health conditions, which was again shown in our population. We demonstrated lower reported pain in persons with neurological impairment (dementia and post-stroke). Decreased reported pain in those with reduced cognitive functioning was maintained with confounders such as age, frailty and gender accounted for. This is consistent with previous studies demonstrating that pain may be underreported in those with cognitive impairment [18, 19]. It is difficult to infer if perceived pain levels are in fact lower or if those with cognitive impairment are unable to vocalize pain.

Strengths and limitations
We examined a wide array of health care services at the end of life for a large, population-based decedent cohort. This is possible in Ontario, comprising of approximately 40% of the Canadian population, where well-developed health administrative databases are linked at an individual level for a range of publicly-funded health services. Previous studies have focused on specific populations or had limited access to other health care services utilized by decedents. We recognize the data used for this study is relatively old, although there were no significant policy or practice changes since 2015 that would reasonably be expected to influence the relevance of our findings to current
While used widely as a clinical assessment tool in many settings, we also acknowledge that the validation for the RAI-HC pain scale was completed in elderly patients in nursing homes, potentially limiting the generalizability of this scale. Additionally, one of our primary limitations is that our data is collected from those who have received a RAI-HC assessment in the last month of life. This may limit the generalizability to those in long-term care home (nursing home), community, or hospital settings who have not been assessed for publicly funded home services (about 40% of decedent population) [41]. This approach also does not capture palliative home care received through private (out-of-pocket) expenses or nurse practitioner palliative home visits. Nevertheless, the RAI-HC provided us with a rare large population-based cohort that contained detailed information about patient-centered variables and outcomes beyond what has previously been presented in literature.

### Conclusion

We observed multiple demographic, clinical and system factors associated with increased pain at the end of life. Clinicians should recognize severe daily pain is common but perhaps not proportional to the fear of suffering in pain that many experience when contemplating end of life [2]. Regardless this is still a

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#### Table 4 Symptomology self-reported in RAI-HC by pain severity in the last 30 days of life

| Symptom                  | Severe Daily Pain | All |
|--------------------------|-------------------|-----|
|                          | No                | Yes | N  | %  | N  | %  | N  |
| Shortness of Breath     |                   |     | N  | %  | N  | %  | N  |
| No                       | 9029              | 84.6| 1643 | 15.4| 10,672 |
| Yes                      | 7815              | 80.8| 1862 | 19.2| 9677  |
| Loss of Appetite         |                   |     | N  | %  | N  | %  | N  |
| No                       | 11,202            | 86.0| 1825 | 14.0| 13,027 |
| Yes                      | 5642              | 77.1| 1680 | 22.9| 7322  |
| Vomiting                 |                   |     | N  | %  | N  | %  | N  |
| No                       | 16,126            | 83.5| 3197 | 16.5| 19,323 |
| Yes                      | 718               | 70.5| 301  | 29.5| 1019  |
| Constipation             |                   |     | N  | %  | N  | %  | N  |
| No                       | 16,271            | 83.4| 3243 | 16.6| 19,514 |
| Yes                      | 573               | 68.6| 262  | 31.4| 835   |
| Delusions                |                   |     | N  | %  | N  | %  | N  |
| No                       | 16,359            | 82.8| 3400 | 17.2| 19,759 |
| Yes                      | 485               | 82.2| 105  | 17.8| 590   |
| Hallucinations           |                   |     | N  | %  | N  | %  | N  |
| No                       | 15,925            | 82.9| 3282 | 17.1| 19,207 |
| Yes                      | 919               | 80.5| 223  | 19.5| 1142  |
| Sad Mood^b               |                   |     | N  | %  | N  | %  | N  |
| 0                        | 12,052            | 85.9| 1981 | 14.1| 14,033 |
| 1                        | 2692              | 79.6| 691  | 20.4| 3383  |
| 2                        | 2100              | 71.6| 833  | 28.4| 2933  |
| Pressure Ulcer^c         |                   |     | N  | %  | N  | %  | N  |
| 0                        | 13,824            | 83.6| 2718 | 16.4| 16,542 |
| 1                        | 1595              | 81.7| 357  | 18.3| 1952  |
| 2                        | 1066              | 79.1| 282  | 20.9| 1348  |
| 3                        | 254               | 73.8| 90   | 26.2| 344   |
| 4                        | 105               | 64.4| 58   | 35.6| 163   |
| Edema                    |                   |     | N  | %  | N  | %  | N  |
| No                       | 16,689            | 84.6| 1943 | 15.4| 12,632 |
| Yes                      | 6155              | 79.8| 1562 | 20.2| 7717  |
| Loneliness               |                   |     | N  | %  | N  | %  | N  |
| Unknown                  | 4879              | 85.2| 845  | 14.8| 5724  |
| No                       | 10,826            | 82.5| 2303 | 17.5| 13,129 |
| Yes                      | 1139              | 76.1| 357  | 23.9| 1496  |
| Client Felt/Advised to Reduce Drinking | | | | | |
| No                       | 16,573            | 82.8| 3446 | 17.2| 20,019 |
| Yes                      | 271               | 82.1| 59   | 17.9| 330   |
| Compliance/Adherence With Medications | | | | | |
| Always Compliant         | 14,905            | 83.0| 3059 | 17.0| 17,964 |
| Compliant > 80%          | 1427              | 79.7| 364  | 20.3| 1791  |

^aResident Assessment Instrument–Home Care
^bSad Mood- 0. Indicator not exhibited in last 3 days, 1. Exhibited 1–2 of last 3 days. 2. Exhibited on each of last 3 days
^cPresence of an ulcer anywhere on the body. Ulcers include any area of persistent skin redness (Stage 1); partial loss of skin layers (Stage 2); deep craters in the skin (Stage 3); breaks in skin exposing muscle or bone (Stage 4). [Code 0 if no ulcer, otherwise record the highest ulcer stage (Stage 1–4)]
### Table 5 Multivariate logistic regression for factors associated with severe daily pain among the last 30 days of life

| Effect                      | Odds Ratio Estimate | Lower 95% Confidence Limit for Odds Ratio | Upper 95% Confidence Limit for Odds Ratio |
|-----------------------------|---------------------|------------------------------------------|------------------------------------------|
| **Age**                     |                     |                                          |                                          |
| 0–49 ref                    | ref                 | ref                                      | ref                                      |
| 50–59                       | 0.79                | 0.58                                     | 1.08                                     |
| 60–69                       | 0.60                | 0.45                                     | 0.80                                     |
| 70–79                       | 0.44                | 0.33                                     | 0.59                                     |
| 80–89                       | 0.36                | 0.27                                     | 0.47                                     |
| 90+                         | 0.31                | 0.23                                     | 0.42                                     |
| **Sex**                     |                     |                                          |                                          |
| Male ref                    | ref                 | ref                                      | ref                                      |
| Female                      | 1.25                | 1.16                                     | 1.35                                     |
| **Income Quintile**         |                     |                                          |                                          |
| Highest ref                 | ref                 | ref                                      | ref                                      |
| High                        | 1.10                | 0.97                                     | 1.24                                     |
| Middle                      | 1.07                | 0.94                                     | 1.21                                     |
| Low                         | 1.03                | 0.92                                     | 1.17                                     |
| Lowest                      | 1.08                | 0.95                                     | 1.21                                     |
| **Rurality**                |                     |                                          |                                          |
| Urban ref                   | ref                 | ref                                      | ref                                      |
| Rural                       | 0.98                | 0.89                                     | 1.08                                     |
| **ADLs<sup>a</sup>**        |                     |                                          |                                          |
| Independent ref             | ref                 | ref                                      | ref                                      |
| Limited impairment          | 1.12                | 0.98                                     | 1.28                                     |
| Supervision required        | 1.10                | 0.94                                     | 1.29                                     |
| Extensive assistance required (I) | 1.26          | 1.08                                     | 1.46                                     |
| Extensive assistance required (II) | 1.31         | 1.13                                     | 1.51                                     |
| Dependent                   | 1.76                | 1.53                                     | 2.04                                     |
| Total dependence            | 2.05                | 1.63                                     | 2.59                                     |
| **IADLs<sup>b</sup>**       |                     |                                          |                                          |
| No difficulty in any of three IADLs ref | ref | ref                                      | ref                                      |
| Some difficulty in one IADL only | 2.04         | 0.83                                     | 5.03                                     |
| Some difficulty in two IADLs only | 2.69         | 1.20                                     | 6.04                                     |
| Some difficulty in all three IADLs | 2.16        | 0.80                                     | 5.87                                     |
| Great difficulty in one IADL but less than great difficulty in the other two | 3.57 | 1.63                                     | 7.83                                     |
| Great difficulty in two IADLs but less than great difficulty in the other one | 3.90 | 1.79                                     | 8.51                                     |
| Great difficulty in all three IADLs | 3.09 | 1.41                                     | 6.77                                     |
| **Palliative Home Care**    |                     |                                          |                                          |
| No ref                      | ref                 | ref                                      | ref                                      |
| Yes                         | 1.13                | 1.03                                     | 1.24                                     |
| **Physician Home Visit**    |                     |                                          |                                          |
| No Physician Home Visit ref | ref                 | ref                                      | ref                                      |
| Physician Home Visit Non Specialist | 1.12      | 0.99                                     | 1.26                                     |
significant number of people who report severe pain, and prompt screening and management of pain should be considered, particularly for those with increased risk factors. Improvements in access and quality of care likely would reduce the prevalence of severe pain at the end of life, given previous studies showing large gaps in palliative care provision [41].

Supplementary information
Supplementary information accompanies this paper at https://doi.org/10.1186/s12904-020-00569-2.

Supplementary file 1. Databases held at ICES used in this study. Includes database name and a description of the type of data (variables) obtained from each database.

Supplementary file 2. Definitions of Palliative Home Care and Palliative Physician Home Visits. Includes a list and description of billing (physician) and service (home care) codes used to determine if a patient received either service.

Abbreviations
CHF: Congestive heart failure; COPD: Chronic obstructive pulmonary disease; RAI-HC: Resident assessment instrument – home care; ADLs: Activities of daily living; IADLs: Instrumental activities of daily living; RPDB: Registered Persons Database; ORGD: Ontario Registrar General Database; ICD-10: International classification of diseases; OHIP: Ontario health insurance plan; CPS: Cognitive performance scale; OR: Odds ratio; CI: Confidence interval

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Not applicable.

Authors’ contributions
All authors had access to all of the data in the study and take responsibility for the integrity of the data and the accuracy of the data analysis. MH, SB, and PT conceived and designed the study. RT acquired the data and conducted statistical analysis. MH, SB, RT, JL, and PT interpreted the data. MH drafted the manuscript. All authors provided revisions for important intellectual content and approved the final version for publication.

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Availability of data and materials
The data that support the findings of this study are available from ICES, but restrictions apply to the availability of these data according to ICES policies and provincial and federal privacy laws to protect individual patient data, and so are not publicly available. As the data custodian, all requests for data

Table 5  Multivariate logistic regression for factors associated with severe daily pain among the last 30 days of life (Continued)

| Effect                                      | Odds Ratio Estimate | Lower 95% Confidence Limit for Odds Ratio | Upper 95% Confidence Limit for Odds Ratio |
|---------------------------------------------|---------------------|------------------------------------------|------------------------------------------|
| Palliative Care Specialist                  | 1.14                | 0.91                                     | 1.44                                     |
| Cognitive Performance Scale (CPS)           | ref                 | ref                                      | ref                                      |
| Intact                                      | 1.10                | 0.97                                     | 1.24                                     |
| Borderline intact                           | 0.97                | 0.88                                     | 1.08                                     |
| Mild impairment                             | 0.75                | 0.65                                     | 0.87                                     |
| Moderate impairment                         | 0.61                | 0.48                                     | 0.78                                     |
| Moderate/severe impairment                  | 0.68                | 0.56                                     | 0.82                                     |
| Severe impairment                           | 0.52                | 0.40                                     | 0.68                                     |
| Number of Chronic Conditions                | ref                 | ref                                      | ref                                      |
| 0–2                                         | 1.09                | 0.98                                     | 1.21                                     |
| 3–4                                         | 1.34                | 1.21                                     | 1.49                                     |
| Trajectory                                  | ref                 | ref                                      | ref                                      |
| Frailty                                     | 1.06                | 0.94                                     | 1.19                                     |
| Organ Failure                               | 1.28                | 1.04                                     | 1.58                                     |
| Sudden Death                                | 1.26                | 0.95                                     | 1.68                                     |
| Undetermined                                | 1.59                | 1.28                                     | 1.97                                     |
| Terminal Illness                            | 1.66                | 1.46                                     | 1.88                                     |

*Activities of daily living
bInstrumental activities of daily living
should go through ICES. Please contact the corresponding author (PT) should you have questions about accessing study data.

Ethics approval and consent to participate
Ethics approval was obtained from the Sunnybrook Health Sciences Centre Research Ethics Board in Toronto, Canada and from the Ottawa Health Science Network Research Ethics Board in Ottawa, Canada.

Consent for publication
Not applicable.

Competing interests
The authors declare they have no competing interests.

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