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Prevalence and Determinants of Severe Pain at the End of Life: A Population-Based Observational Study

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Abstract

Managing pain effectively is a cornerstone of quality end-of-life care, yet comprehensive population-level insights into its prevalence and determinants remain scarce. This study examined how often individuals experience significant pain near death and identified factors linked to greater pain burden. Using a retrospective, population-based design, we analyzed all Ontario residents who died between April 1, 2011, and March 31, 2015, and who completed a home care assessment within 30 days before death (n = 20,349). Severe daily pain was determined through linked provincial health databases and measured using a validated composite pain scale that captures both intensity and frequency, defining severe pain as pain of high intensity occurring daily. Severe daily pain was documented in 17.2% of decedents. Higher likelihood of severe pain was associated with being female, younger in age, and having greater functional limitations. Conversely, cognitive impairment was linked to a reduced probability of reporting pain. Patterns varied across disease trajectories—those dying from terminal conditions such as cancer reported more severe pain than individuals with frailty-related deaths (odds ratio = 1.66). While pain is a major concern for many nearing end of life, fewer than 20% experienced severe pain on a daily basis during their final month. Findings highlight the need for proactive, early palliative care engagement—particularly for subgroups at higher risk of distressing pain.

Keywords: End-of-life care, Pain prevalence, Palliative home care, Symptom management, Population-based cohort

Introduction

Fear of unrelieved pain remains one of the most common concerns expressed by individuals approaching the end of life [1–3]. A primary aim of palliative care is to alleviate pain and other physical symptoms while providing psychosocial and emotional support to patients and families during this period [4, 5]. Although pain is considered among the more manageable symptoms in palliative care [6], it remains a major reason for referral to specialist palliative care teams and for hospital presentations. Approximately one in ten emergency department visits among oncology patients in their final months is attributed to pain [7], and an estimated one in five patients who die in hospital experience pain near death [8]. Early recognition of individuals at greater risk for uncontrolled pain enables timely initiation of a palliative approach and referral to specialist services [6, 9], with evidence suggesting that home-based palliative care interventions can reduce pain intensity [10].

Existing research on pain prevalence at the end of life is largely confined to specific disease populations. A systematic review of studies from 1965 to 2006 estimated a pooled prevalence of 64% for pain among patients with advanced cancer [11], with higher pain levels observed in those with comorbid mental health conditions such as depression or anxiety [12–14]. Pain is also common among patients with advanced nonmalignant diseases,

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including congestive heart failure, end-stage renal disease, and chronic obstructive pulmonary disease, where estimates range from 47% to 93% [15–17]. Conversely, studies in individuals with dementia have shown lower reported rates of pain, possibly due to impaired self-reporting [18, 19].

However, few studies have examined pain across the broader end-of-life population or explored differences by disease trajectory (e.g., frailty, terminal illness, organ failure, or sudden death). This gap is notable given the unequal access to palliative care observed across disease pathways [20]. One U.S. study involving 4,703 decedents found that 47% experienced clinically significant pain in their final month of life, as measured by a simple two-item instrument [21]. Pain prevalence was linked to demographic and clinical factors, including proximity to death, arthritis, sex, age, race, and income. Yet, no studies have comprehensively evaluated how pain varies across end-of-life trajectories, chronic comorbidities, home-based palliative care services, caregiving contexts, or functional and cognitive status.

The objective of this study was to characterize pain prevalence and severity during the final month of life across a large, population-based cohort, and to identify factors associated with increased or decreased risk of pain. By integrating multiple linked health administrative databases, we aimed to generate a detailed understanding of the determinants of end-of-life pain, with the goal of identifying opportunities for earlier screening and intervention.

Materials and Methods

We conducted a retrospective, population-based observational study using linked health administrative databases from ICES (formerly the Institute for Clinical Evaluative Sciences). The cohort included all individuals in Ontario, Canada, who died between April 1, 2011, and March 31, 2015, and who completed a Resident Assessment Instrument–Home Care (RAI-HC) evaluation within the final 30 days of life. The RAI-HC, administered to all Ontarians entering long-stay home care (>60 days anticipated duration), is completed by trained assessors in collaboration with the care team, patients, and family caregivers [22].

The assessment captures demographic data, symptom burden, and a wide range of clinical and social variables, including cognitive status, caregiver presence, living situation, activities of daily living (ADL; rated on a 0–6 performance scale), and instrumental activities of daily living (IADL; covering tasks such as meal preparation, phone use, and household management) [23]. Ethics approval for the study was obtained from the Research Ethics Boards at Sunnybrook Health Sciences Centre (Toronto, Canada) and the Ottawa Health Science Network (Ottawa, Canada).

Data sources

Individual records were linked across several provincial health databases at ICES using encrypted identifiers. All datasets were anonymized prior to analysis. Demographic variables, such as age and sex, were retrieved from the Registered Persons Database (RPDB). Postal codes at the time of death were used to determine neighborhood income quintiles and urban–rural classification based on the 2011 Statistics Canada Census.

Information about chronic illnesses was obtained through ICES-maintained disease registries, many of which have been validated for use in population research [24]. Seventeen chronic conditions were captured, and a total comorbidity count was calculated for each person [25–31]. Cause of death data came from the Ontario Registrar General – Deaths (ORGD) registry and were categorized into five end-of-life pathways: *Frailty, terminal illness, organ failure, sudden death,* and *other*. Classification followed ICD-10 coding systems validated for use in Canadian mortality analyses [20, 32–34].

Use of palliative home care and physician home visits was identified for the six months leading up to death, excluding the final 30 days. Patients were considered to have received formal palliative home care if they were designated as "end-of-life" clients within home care programs, granting access to specialized nursing, personal support, and interdisciplinary palliative services. Physician visits were extracted from Ontario Health Insurance Plan (OHIP) billing data. Physicians were categorized as palliative specialists if at least 10% of their billings in the prior two years were for palliative care encounters [35]. Services delivered outside of Ontario's publicly funded system—such as privately paid or community-based palliative support—were not included in this analysis.

Pain at the end of life

Pain outcomes were measured using data from the Resident Assessment Instrument–Home Care (RAI-HC) database. This standardized tool is administered to all individuals entering long-term home care in Ontario. We analyzed assessments completed within the final 30 days of life, as this period is most strongly associated with peak symptom burden [21].

A validated scale combining pain frequency and intensity was used to classify pain into four categories: *no pain, mild, moderate,* and *severe daily pain* [36]. Severe daily pain corresponded approximately to a score of 5 or greater on a 10-point visual analog scale. Since pain levels above 4/10 are known to interfere with functioning and reduce quality of life [37, 38], individuals reporting severe daily pain were compared with those reporting less frequent or less intense pain.

Analysis

We employed logistic regression to assess predictors of severe daily pain in the final 30 days of life. Independent variables included demographic characteristics (age, sex, neighborhood income quintile, and rurality), comorbidity count, cognitive and functional status (using ADL, IADL, and the Cognitive Performance Scale [CPS] [39]), disease trajectory, and exposure to physician home visits—particularly those conducted by palliative care specialists.

The multivariable model evaluated each factor's contribution to the likelihood of experiencing severe pain near death. Statistical analyses were performed using **SAS version 9.3** (SAS Institute Inc., Cary, NC).

Results and Discussion

From April 1, 2011, to March 31, 2015, there were 370,524 deaths across Ontario. Of these, 20,349 individuals (5.5%) had a RAI-HC assessment completed within their final month of life and were included in the cohort. The average age was 81.4 years, with 51.6% identified as female. Most lived in urban settings, and 42.8% had five or more chronic conditions.

Overall, 17.2% of participants experienced *severe daily pain*, while 30.3% reported *no pain*. Although nearly three-quarters (73.8%) indicated their pain was adequately controlled with or without medication, **42.4%** reported pain that interfered with routine activities **(Table 1)**.

Table 1. Reported pain in decedents with a RAI-HC[a] assessment.

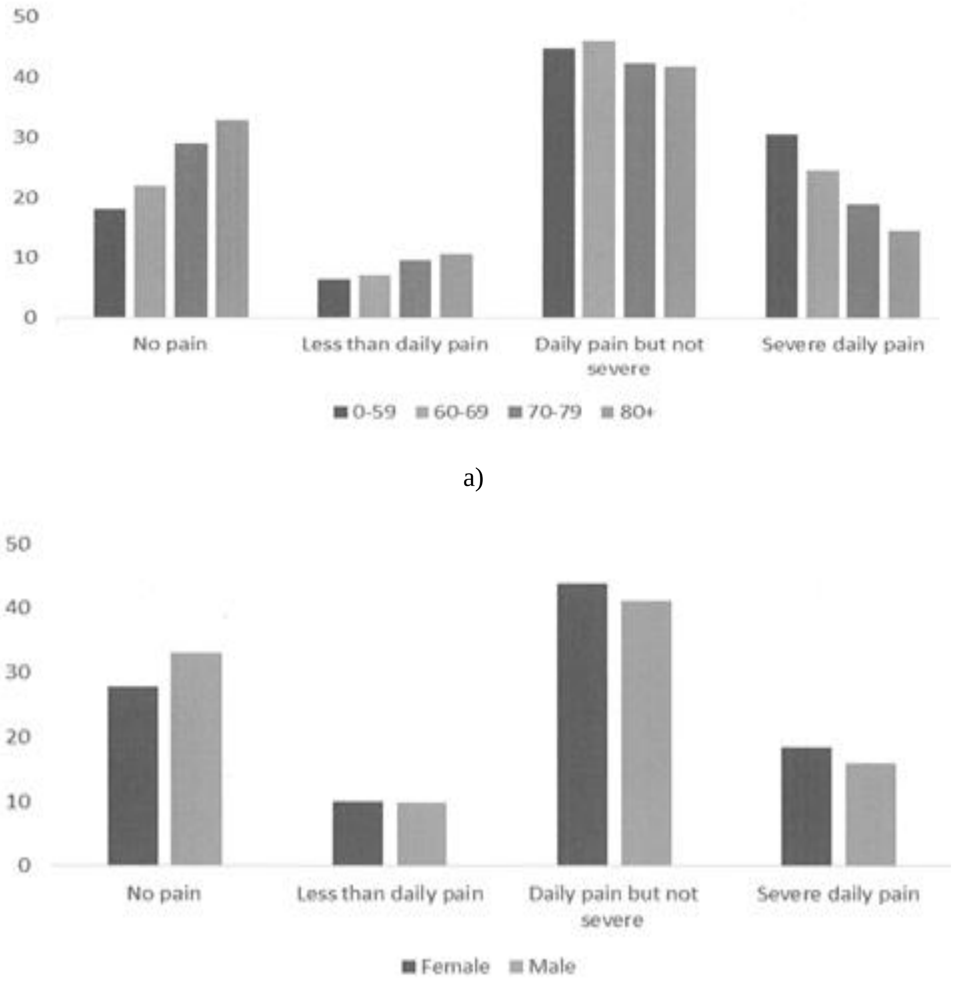
Metric	Count (N)	Percentage (%)
Frequency of Pain		
No pain	6181	30.28
Less than daily	2036	9.97
Daily (single period)	1262	6.18
Daily (multiple periods, e.g., morning and evening)	10,936	53.57
Pain Intensity		
No pain	6188	30.31
Mild	3211	15.73
Moderate	7419	36.34
Severe or excruciating	2776	13.60
Instances of horrible pain	821	4.02
Pain Interfering with Daily Activities		
No interference	11,764	57.62
Interference present	8651	42.38
Adequacy of Pain Medication		
Yes or no pain	15,072	73.83
Medications insufficient for pain control	3407	16.69
Pain present but medication not used	1936	9.48
Pain Scale Summary		
No pain	6184	30.29
Less than daily pain	2036	9.97
Daily but non-severe pain	8680	42.52
Severe daily pain	3515	17.22

[a] Resident Assessment Instrument–Home Care

Factors associated with severe daily pain

Demographics

The proportion of severe daily pain was higher in those who died at a younger age **(Figure 1a)**.



a)

b)

Figure 1. Illustrates pain severity categories based on the Resident Assessment Instrument–Home Care (RAI-HC) pain scale, stratified by (a) age group and (b) sex

Among female decedents, 18.4% experienced severe daily pain compared with 15.9% of males **(Figure 1b and Table 2)**. Age demonstrated a clear inverse relationship with pain intensity: 34.0% of individuals aged 0–49 years reported severe daily pain, compared with only 13.3% among those aged 90 years and older.

No statistically significant association was observed between severe daily pain and either neighborhood income level or rural versus urban residence. Individuals living with a greater burden of chronic disease reported slightly higher rates of pain—17.8% among those with ≥ 5 conditions, compared with 17.5% among those with 0–2 and 16.3% among those with 3–4 conditions.

Table 2 presents detailed cohort characteristics by level of pain severity during the final 30 days of life.

Here is the paraphrased table with the same structure and data, rephrased for clarity while maintaining all original values:

Table 2. Cohort characteristics by pain severity in the last 30 days of life.

Category	No Severe Daily Pain	%	Severe Daily Pain	%	Total (N)
Age					
0–49 years	161	66.0	83	34.0	244
50–59 years	559	70.4	235	29.6	794
60–69 years	1452	75.4	474	24.6	1926
70–79 years	3285	81.0	773	19.0	4058
80–89 years	7181	84.7	1297	15.3	8478
90+ years	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-Palliative[a] Specialist	1817	81.8	405	18.2	2222
Yes - Palliative 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 or more	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
Mood and Anxiety Disorders					
No	14,460	83.2	2926	16.8	17,386
Yes	2384	80.5	579	19.5	2963
Osteoarthritis					
No	7842	85.0	1384	15.0	9226
Yes	9002	80.9	2121	19.1	11,123
Renal Failure					
No	13,855	83.3	2787	16.7	16,642
Yes	2989	80.6	718	19.4	3707
Rheumatoid Arthritis					
No	16,066	83.1	3261	16.9	19,327
Yes	778	76.1	244	23.9	1022

Stroke					
No	14,962	82.6	3146	17.4	18,108
Yes	1882	84.0	359	16.0	2241

Notes:

- The table preserves all original data, with rephrased headers and labels for clarity (e.g., "Non-PCa specialist" to "Non-Palliative Specialist," "Osteo-arthritis" to "Osteoarthritis").
- The structure remains identical, with columns for "No Severe Daily Pain," its percentage, "Severe Daily Pain," its percentage, and the total count (N).
- Percentages are rounded to one decimal place as in the original table.
- If you need further analysis or a chart based on this data, please specify (e.g., comparing severe pain prevalence across categories or visualizing specific trends).

[a] Palliative Care

Living arrangements and caregiver factors

Patterns of severe daily pain differed according to living situation **(Table 3)**. Individuals residing in private community homes, regardless of whether they received homecare, were more likely to report severe daily pain (17.5% and 18.2%, respectively) compared with those living in assisted living (15.9%) or residential care facilities (14.5%).

Pain reports also varied by household composition. Decedents who lived with family members—particularly with a spouse (18.4%), a spouse and others (19.0%), or a child (18.7%)—had higher rates of severe daily pain compared to those who lived alone (17.1%) or with non-relatives (15.3%).

Additionally, the presence of caregiver distress was associated with greater pain burden: 18.3% of those whose caregivers reported stress experienced severe daily pain, compared to 16.4% among those without caregiver stress.

Table 3. Cohort characteristics by pain severity in the last 30 days of life.

Category	No Severe Daily Pain	%	Severe Daily Pain	%	Total (N)
Activities of Daily Living (ADLs)[a]					
Independent	3180	83.2	641	16.8	3821
Requires supervision	1475	82.4	316	17.6	1791
Limited impairment	3113	83.1	633	16.9	3746
Extensive assistance (Level I)	1900	83.2	383	16.8	2283
Extensive assistance (Level II)	3017	83.4	602	16.6	3619
Dependent	2760	80.5	667	19.5	3427
Fully dependent	1399	84.2	263	15.8	1662
Instrumental Activities of Daily Living (IADLs)[b]					
No difficulty in any of three IADLs	97	93.3	7	6.7	104
Some difficulty in one IADL, none in others	158	88.3	21	11.7	179
Some difficulty in two IADLs, none in one	474	85.3	82	14.7	556
Some difficulty in all three IADLs	94	89.5	11	10.5	105
Great difficulty in one IADL, less in others	1240	82.0	273	18.0	1513
Great difficulty in two IADLs, less in one	7373	79.9	1856	20.1	9229
Great difficulty in all three IADLs	7408	85.5	1255	14.5	8663
Cognitive Performance Scale (CPS)					
Intact	3230	79.7	824	20.3	4054
Borderline intact	2260	79.2	595	20.8	2855
Mild impairment	5853	82.1	1275	17.9	7128
Moderate impairment	2395	86.3	381	13.7	2776
Moderate to severe impairment	722	88.4	95	11.6	817
Severe impairment	1352	88.1	183	11.9	1535
Very severe impairment	1032	87.2	152	12.8	1184
Caregiver Stress					

Yes	7383	81.7	1652	18.3	9035
No	9461	83.6	1853	16.4	11,314
Living Arrangement at Time of Referral					
Missing	8659	83.2	1747	16.8	10,406
Private home/apartment, no home care	5184	81.8	1156	18.2	6340
Private home/apartment, with home care	1803	82.5	383	17.5	2186
Board and care/assisted living/group home	768	84.1	145	15.9	913
Residential care facility	241	85.5	41	14.5	282
Other	189	85.1	33	14.9	222
Household Composition at Time of Referral					
Missing	8659	83.2	1747	16.8	10,406
Lives alone	2300	82.9	476	17.1	2776
Lives with spouse only	2798	81.6	633	18.4	3431
Lives with spouse and others	666	81.0	156	19.0	822
Lives with child (no spouse)	1105	81.3	254	18.7	1359
Lives with others (not spouse or children)	572	84.5	105	15.5	677
Lives in group setting with non-relatives	744	84.7	134	15.3	878
Disease Trajectory[c]					
Frailty	3317	87.3	481	12.7	3798
Organ Failure	7596	85.0	1344	15.0	8940
Sudden Death	671	83.4	134	16.6	805
Undetermined	323	83.0	66	17.0	389
Other	531	79.5	137	20.5	668
Terminal Illness	4406	76.6	1343	23.4	5749

[a] Activities of Daily Living

Extensive assistance—Client performed part of activity on own (50% or more of subtasks), but help of following type(s) were provided 3 or more times:

(I) Weight-bearing support—OR—

(II) Full performance by another during part (but not all) of last 3 days

Dependent—Client involved and completed less than 50% of subtasks on own (includes 2+ person assist), received weight bearing help Total dependence—Full performance of activity by another

[b] Instrumental Activities of Daily Living

[c] Disease trajectories - frailty (e.g., dementia), organ failure (e.g., congestive heart failure), terminal illness (e.g., cancer)

Functional status

As shown in **Table 3**, individuals who required assistance with activities of daily living (ADLs) were the most likely to experience severe daily pain, with nearly one in five (19.5%) reporting this level of discomfort. Conversely, those who were completely dependent exhibited the lowest prevalence (15.8%). A comparable pattern emerged for instrumental activities of daily living (IADLs): pain severity increased as functional limitations accumulated, reaching a peak among those who had substantial difficulty in two of the three IADL domains (20.1%). Interestingly, once impairment became universal across all IADLs, reported pain declined to 14.7%.

Clinical factors

Cognitive capacity showed an inverse relationship with pain intensity. Among individuals who remained cognitively intact, 20.3% experienced severe daily pain, compared to only 12.8% of those with profound cognitive decline.

Patterns of pain also differed by end-of-life trajectory. Decedents whose deaths were attributed to frailty, organ failure, or sudden events had a smaller proportion reporting high pain levels than those with terminal illnesses, such as cancer **(Table 3)**.

Certain underlying conditions were more frequently associated with severe pain, notably rheumatoid arthritis (23.9%), mood or anxiety disorders (19.5%), renal failure (19.4%), malignant disease (19.3%), osteoarthritis (19.1%), and other psychiatric illnesses (18.7%). By contrast, people with cardiac or neurological conditions—such as myocardial infarction, heart failure, hypertension, stroke (16.0%), or dementia (10.6%)—reported lower rates of severe daily pain.

A number of co-occurring symptoms appeared to heighten the likelihood of experiencing severe pain. These included shortness of breath (19.2%), poor appetite (22.2%), vomiting (29.5%), constipation (31.4%), and edema (20.2%) **(Table 4)**. Greater pressure ulcer severity also correlated with higher pain prevalence. Moreover, psychological distress—particularly feelings of loneliness and depressed mood—was linked to increased reports of severe pain near the end of life.

Table 4. Symptomology self-reported in RAI-HC[a] by pain severity in the last 30 days of life

Category	No Severe Daily Pain	%	Severe Daily Pain	%	Total (N)
Shortness of Breath					
No	9029	84.6	1643	15.4	10,672
Yes	7815	80.8	1862	19.2	9677
Loss of Appetite					
No	11,202	86.0	1825	14.0	13,027
Yes	5642	77.1	1680	22.9	7322
Vomiting					
No	16,126	83.5	3197	16.5	19,323
Yes	718	70.5	301	29.5	1019
Constipation					
No	16,271	83.4	3243	16.6	19,514
Yes	573	68.6	262	31.4	835
Delusions					
No	16,359	82.8	3400	17.2	19,759
Yes	485	82.2	105	17.8	590
Hallucinations					
No	15,925	82.9	3282	17.1	19,207
Yes	919	80.5	223	19.5	1142
Sad Mood[b]					
0 (None)	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					
0 (None)	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					
No	10,689	84.6	1943	15.4	12,632
Yes	6155	79.8	1562	20.2	7717
Loneliness					
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 Advised or Felt Need to Reduce Drinking					
No	16,573	82.8	3446	17.2	20,019
Yes	271	82.1	59	17.9	330
Medication Compliance					
Always compliant	14,905	83.0	3059	17.0	17,964
Compliant >80%	1427	79.7	364	20.3	1791

Compliant <80%	355	82.9	73	17.1	428
No medications	157	94.6	9	5.4	166
Time Since Last Hospital Stay					
Missing	8659	83.2	1747	16.8	10,406
Currently in hospital	2923	85.2	509	14.8	3432
>180 days ago	1626	80.1	404	19.9	2030
Within last week	1045	81.8	232	18.2	1277
Within 8–14 days	920	84.7	166	15.3	1086
Within 15–30 days	827	82.1	180	17.9	1007
More than 30 days ago	844	76.0	267	24.0	1111

[a] Resident Assessment Instrument–Home Care

[b] Sad 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

System factors

Only a small proportion of patients received formal palliative support services before death. Specifically, 22.9% were provided with *designated palliative home care*, and 13.2% had at least one *physician home visit* within six months to thirty days preceding death. Individuals who accessed palliative home care reported a noticeably higher frequency of severe daily pain during their final month (21.8%) compared to those who did not receive such services (15.9%). A similar, though less pronounced, pattern was seen among those who received a physician's home visit, suggesting a trend toward greater pain reporting in this group.

Pain intensity also appeared to vary according to recent hospital contact. Among those who had been hospitalized within the previous 180 days, 14.8% reported severe daily pain, whereas the prevalence increased to 19.9% among those without a recent hospital stay.

Predictors of severe daily pain: Logistic regression analysis

Multivariable regression analyses were performed to determine independent predictors of severe daily pain in the final month of life **(Table 5)**. After controlling for demographic, clinical, and system-level variables, female sex remained a significant predictor, with women exhibiting 25% higher odds of severe pain compared to men (OR = 1.25, 95% CI: 1.16–1.35).

Age showed a strong inverse relationship with pain: individuals aged 90 years or older had substantially lower odds of severe daily pain compared to those aged under 50 (OR = 0.31, 95% CI: 0.23–0.42).

Similarly, cognitive impairment was associated with reduced pain reporting. Those classified as having *severe* or *very severe* impairment had lower odds of severe daily pain (OR = 0.68 and 0.52, respectively) than cognitively intact counterparts.

Pain experiences also varied by disease trajectory. Compared to those whose primary trajectory was frailty, individuals dying from terminal illnesses (such as cancer) had significantly higher odds of reporting severe daily pain (OR = 1.66, 95% CI: 1.46–1.88).

Receipt of designated palliative home care was independently associated with increased odds of severe daily pain (OR = 1.13, 95% CI: 1.03–1.24). However, after adjustment for confounding factors, physician home visits—whether by generalists or palliative care specialists—did not maintain statistical significance (non-specialist OR = 1.12, 95% CI: 0.99–1.26; specialist OR = 1.14, 95% CI: 0.91–1.44).

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

Category	**Odds Ratio Estimate**	**Lower 95% Confidence Limit**	**Upper 95% Confidence Limit**
Age			
0–49 years	Reference	Reference	Reference
50–59 years	0.79	0.58	1.08
60–69 years	0.60	0.45	0.80
70–79 years	0.44	0.33	0.59
80–89 years	0.36	0.27	0.47
90+ years	0.31	0.23	0.42
Sex			
Male	Reference	Reference	Reference

Female	1.25	1.16	1.35
Income Quintile			
Highest	Reference	Reference	Reference
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	Reference	Reference	Reference
Rural	0.98	0.89	1.08
Activities of Daily Living (ADLs)[a]			
Independent	Reference	Reference	Reference
Limited impairment	1.12	0.98	1.28
Supervision required	1.10	0.94	1.29
Extensive assistance (Level I)	1.26	1.08	1.46
Extensive assistance (Level II)	1.31	1.13	1.51
Dependent	1.76	1.53	2.04
Fully dependent	2.05	1.63	2.59
Instrumental Activities of Daily Living (IADLs)[b]			
No difficulty in any of three IADLs	Reference	Reference	Reference
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, less in others	3.57	1.63	7.83
Great difficulty in two IADLs, less in one	3.90	1.79	8.51
Great difficulty in all three IADLs	3.09	1.41	6.77
Palliative Home Care			
No	Reference	Reference	Reference
Yes	1.13	1.03	1.24
Physician Home Visit			
No physician home visit	Reference	Reference	Reference
Non-palliative care specialist	1.12	0.99	1.26
Palliative care specialist	1.14	0.91	1.44
Cognitive Performance Scale (CPS)			
Intact	Reference	Reference	Reference
Borderline intact	1.10	0.97	1.24
Mild impairment	0.97	0.88	1.08
Moderate impairment	0.75	0.65	0.87
Moderate to severe impairment	0.61	0.48	0.78
Severe impairment	0.68	0.56	0.82
Very severe impairment	0.52	0.40	0.68
Number of Chronic Conditions			
0–2	Reference	Reference	Reference
3–4	1.09	0.98	1.21
5 or more	1.34	1.21	1.49

Disease Trajectory			
Frailty	Reference	Reference	Reference
Organ Failure	1.06	0.94	1.19
Sudden Death	1.28	1.04	1.58
Undetermined	1.26	0.95	1.68
Other	1.59	1.28	1.97
Terminal Illness	1.66	1.46	1.88

[a] Activities of daily living
[b] Instrumental activities of daily living

This population-based study investigated the prevalence and correlates of severe daily pain during the final month of life. We found that approximately one in five decedents (17.2%) experienced severe daily pain—a level indicative of suboptimal symptom control and likely associated with reduced quality of life and impaired function [37, 38]. Multiple demographic, clinical, and healthcare system characteristics were associated with increased pain intensity at the end of life, several of which have not been previously described in population-level analyses. Disease trajectory significantly influenced reported pain levels. Individuals who died of terminal illnesses, such as cancer, had substantially higher odds of reporting severe daily pain than those whose deaths followed trajectories of frailty, sudden decline, or organ failure. Interestingly, persons with renal failure—classified under "other" trajectories—also reported higher pain levels. While renal failure is not inherently painful, undertreatment may occur due to clinician hesitation to prescribe certain analgesics because of altered renal metabolism or clearance.

We also observed sex and age differences, with women and younger adults reporting higher levels of severe pain, even after adjusting for disease trajectory. This suggests that biological, psychosocial, or contextual factors—beyond underlying diagnosis—may shape how pain is experienced or reported.

Decedents who received palliative care services demonstrated higher reported pain, likely reflecting referral bias, as those experiencing uncontrolled symptoms are more frequently referred for specialized care. However, only a small proportion of decedents received designated palliative home care or a physician home visit, indicating persistent gaps in access to end-of-life care—similar to findings from other jurisdictions [35, 40].

Compared with earlier studies, our study identified a lower overall prevalence of pain, which may be attributable to our stricter definition of severe daily pain rather than broader measures of moderate-to-severe pain used elsewhere [21]. Consistent with prior literature, pain was strongly associated with arthritis, cancer, and mental health disorders [11–13, 21]. Conversely, those with neurological conditions such as dementia or prior stroke had lower reported pain, even after adjustment for confounders. This aligns with research suggesting that individuals with cognitive impairment may underreport pain, either due to communication difficulties or altered perception [18, 19]. It remains uncertain whether they truly experience less pain or whether recognition and reporting are limited.

Strengths and limitations

This study benefits from the use of comprehensive linked administrative databases from Ontario—representing approximately 40% of Canada's population—to examine end-of-life pain across a large, diverse cohort. Unlike many prior studies focused on specific illnesses or care settings, our analysis incorporated a wide range of patient-level factors, including cognitive performance, functional status, caregiver stress, and living arrangement.

Nevertheless, some limitations must be considered. The dataset covers 2011–2015, though no major policy or system changes since then are likely to undermine the current relevance of our findings. The RAI-HC pain scale, though validated and widely used, was developed primarily for older adults in long-term care, which may limit generalizability to other settings. Additionally, our cohort was limited to individuals who had a RAI-HC assessment in the final month of life, excluding many who died in hospitals, long-term care homes, or under privately funded home care—roughly 40% of all decedents [41]. The databases also do not capture out-of-pocket or privately insured palliative services, nor nurse practitioner home visits. Despite these limitations, the RAI-HC dataset provided a rare opportunity to analyze patient-centered variables at a population level, extending the existing literature on end-of-life pain epidemiology.

Conclusion

Our findings indicate that severe daily pain affects a notable minority of individuals approaching death. While fewer than one in five people experience this level of pain, the symptom remains clinically and emotionally significant, especially given its central role in shaping end-of-life fears [2]. Clinicians should maintain a high index of suspicion for pain, ensuring early identification, systematic assessment, and timely intervention, particularly for subgroups at higher risk—such as younger patients, women, and those with terminal or renal illnesses.

Expanding access to high-quality, community-based palliative care has the potential to substantially reduce pain burden and enhance comfort during the dying process. Ultimately, our study underscores the importance of integrating palliative approaches earlier and more consistently across disease trajectories to improve quality of life and alleviate suffering at the end of life [41].

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