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# Unplanned hospitalisations in older people: illness trajectories in the last year of life

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## ABSTRACT

**Objective** Unplanned hospitalisations can be burdensome for older people who approach the end of life. Hospitalisations disrupt the continuity of care and often run against patients' preference for comfort and palliative goals of care. This study aimed to describe the patterns of unplanned hospitalisations across illness trajectories in the last year of life.

**Methods** Longitudinal, retrospective cohort study of decedents, including all older adults (≥65 years) who died in Sweden in 2015. We used nationwide data from the National Cause of Death Register linked at the individual level with several other administrative and healthcare registers. Illness trajectories were defined based on multiple-cause-of-death data to approximate functional decline near the end of life. Incidence rate ratios (IRR) for unplanned hospitalisations were modelled with zero-inflated Poisson regressions.

**Results** In a total of 77 315 older decedents (53% women, median age 85.2 years), the overall incidence rate of unplanned hospitalisations during the last year of life was 175 per 100 patient-years. The adjusted IRR for unplanned hospitalisation was 1.20 (95%CI 1.18 to 1.21) times higher than average among decedents who followed a trajectory of cancer. Conversely, decedents who followed the trajectory of prolonged dwindling had a lower-than-average risk of unplanned hospitalisation (IRR 0.66, 95% CI 0.65 to 0.68). However, these differences between illness trajectories only became evident during the last 3 months of life.

**Conclusion** Our study highlights that, during the last 3 months of life, unplanned hospitalisations are increasingly frequent. Policies aiming to reduce burdensome care transitions should consider the underlying illness trajectories.

## Key messages

**What was already known?**

- Most older adults prefer avoiding care transitions near the end of life, yet prior studies have found an acceleration of hospital admissions close to death.
- Although hospital admissions are not necessarily unwarranted, avoiding burdensome emergency room visits and unplanned hospitalisations is often an important goal for patients with severe illness.

**What are the new findings?**

- Differences in unplanned hospitalisation across illness trajectories become evident during the last 3 months of life.
- Older people who died with cancer bear the highest burden of unplanned hospitalisations at the end of life.

**What is their significance?**

- Illness trajectories defined based on causes of death have obvious limitations but are nonetheless useful to differentiate end-of-life care patterns.
- Policies aiming at avoiding unwarranted care transitions near the end of life should tailor interventions to specific illness trajectories.

## INTRODUCTION

Most older adults prefer to avoid care transitions at the end of life.[1 2] Yet, such transitions—including hospital admissions and emergency department visits—are common and increasingly frequent as death approaches.[3–8] Hospitalisation close to death can fragment the care continuity and planning, and have negative functional and psychological consequences.[4] It can also lead to suboptimal quality of care,[9] overdiagnosis and overtreatment.[10] Hospitalisations are often stressful for patients and caregivers;

disproportionately so for individuals with advanced age and/or physical and cognitive impairments.[11]

A substantial body of research has documented the accelerating pattern of hospital admissions at the end of life. However, most studies have not been able to distinguish between planned and unplanned hospitalisations.[3 5–8] Yet, this distinction is essential since unplanned admissions have the potential to disorganise patient care.[4] Although it should be noted that unplanned hospitalisations are not necessarily unwarranted or avoidable (and may even sometimes be in line with the patients' preferences), avoiding burdensome admissions becomes an important goal when the main priority of care is to maximise comfort and quality of life as death approaches.[5 12–14]

There is a lack of knowledge about which groups of individuals are at the highest risk of unplanned hospitalisations and at which point these are likely to occur throughout the end of life. Seriously ill individuals are expected to follow different trajectories of functional decline at the end of life, depending on their underlying illness.[15 16] Hence, their use of hospital care at the end of life might also differ substantially. To verify this hypothesis, the present study aimed to describe the patterns of unplanned hospitalisations across illness trajectories in the last year of life. We used longitudinal administrative and healthcare data and assembled a mortality follow-back cohort including all older people who died in 2015 in Sweden.

## METHODS

### Study design and population

This was a retrospective cohort study of decedents including all older adults (age ≥65 years) who died between 1 January and 31 December 2015 in Sweden. Decedents were excluded if their exact date of death was unknown, if their unique personal identifier had been reallocated to another person, or if their cause of death was either unknown, not reported or unspecific (online supplemental eFigure 1).

### Data sources

We used routinely collected administrative data with national coverage in Sweden. Data from the National Cause of Death Register were linked to the National Patient Register, the Swedish Prescribed Drug Register, the Total Population Register and the Swedish Register of Education with a pseudonymised identifier (online supplemental eTable 1).[17]

### Illness trajectories

Causes of death recorded on the death certificates were categorised into four distinct illness trajectories at the end of life, as proposed by Lunney *et al*[18] : (1) cancer, characterised by a short period of functional decline; (2) organ failure, marked by a longer period of functional limitations with intermittent acute decompensations; (3) prolonged dwindling, typical of older persons with neurodegenerative conditions and/or frailty; (4) sudden death, namely none of the three abovementioned trajectories.[19] International Classification of Disease-10th revision codes used to operationalise each illness trajectory are available in online supplemental eTable 2. In keeping with previous studies, we used a rule-based algorithm to allocate decedents to a single illness trajectory if the underlying and contributing causes of death were compatible with two or more trajectories.[18 20] The following hierarchy was applied: cancer>prolonged dwindling>organ failure>sudden death. This hierarchy is based on the assumption that, when multiple trajectories are present, the faster progressing trajectory will determine most of the burden of functional decline over time. For instance, cancer is at the top of the hierarchy because a diagnosis of cancer have been shown to dominate other co-occurring diseases when included in the list of multiple causes of death.[19 21] The conceptual and operational difficulties of creating definite, clear-cut categories from complex events leading to death have been pointed out by others.[15 18 22] A particular challenge of delineating illness trajectories is that some decedents might follow none, some or all of these trajectories at the same time. However, in the absence of fine-grain data about actual longitudinal changes in physical and cognitive functions experienced near the end of life—which require extensive clinical information typically not available in routinely collected data—these four groups of illnesses have been found to be a good proxy for the pattern of late-life functional decline and care needs at the end of life.[23]

### Outcome

Unplanned hospital admissions throughout the last year of life were captured in the National Patient Register, which covers >99.9% of all inpatient care admissions and >85% of specialised outpatient care visits.[24] Unplanned hospitalisations were defined as admissions recorded as being non-elective in the National Patient Register. We calculated the incidence rate of unplanned hospitalisations during the entire last year of life and during each of the 52 weeks (7-day hazard periods) before death. To prevent immortal-time bias—namely, considering hazard periods during which the study outcome cannot occur, time at risk was defined as the number of days when the persons were not hospitalised.[25] Hospitalisations separated by 1 day or less were concatenated into a single episode in order to avoid counting transfers from one hospital unit to another as separate admissions. Incidence rates and their 95% CIs were calculated per 100 person-years or per 100 person-weeks, as appropriate.

### Patient-level characteristics

We extracted the main sociodemographic characteristics of decedents (eg, sex, age at death, marital status) from national registries. Chronic multimorbidity was

operationalised as the number of chronic diseases out of a list of 60 pre-defined conditions,[26] which were captured in the National Patient Register during the period ranging from 5 to 1 year before death (online supplemental eTable 3). We estimated the Hospital Frailty Risk Score[27] based on the same data (online supplemental eTable 4). Education was defined as the lifetime highest attained educational level, and was categorised into primary, secondary and tertiary education based on the International Standard Classification of Education 1997 system[28] (online supplemental eTable 5). Polypharmacy was assessed during week 56–53 before death. It was calculated as the average number of prescription drugs (at the therapeutic/pharmacological subgroup level of the Anatomical Therapeutic Chemical classification system) that the decedents were exposed to across each of the 4 weeks preceding the last year of life.[29]

### Statistical analysis

In the main analysis, we calculated the incidence rate of unplanned hospitalisations during the last year of life. Zero-inflated Poisson regression models were used to compute incidence rate ratios (IRRs) to compare the risk of unplanned hospitalisation across illness trajectories with regard to the average risk in the cohort. Zero-inflated Poisson models were warranted because of the substantial number of individuals with no unplanned admission ('excess zeros'). To confirm the appropriateness of the zero-inflated model, we first plotted the quantiles of the observed values of unplanned hospitalisations against the quantiles of their normal distribution (online supplemental eFigure 2). Second, we plotted the individual predicted probabilities under the zero-inflated model against that of the Poisson model[30] (online supplemental eFigure 3). In both instances, deviations from the reference line indicated overdispersion with excess zeros. Finally, we compared the Akaike Information Criterion of the Poisson and zero-inflated models to see whether the latter obtained a better fit. Potential confounders were identified in the published literature and selected based on subject-matter knowledge. Analyses were thereafter adjusted for age at time of death, sex, marital status (married, single/divorced and widowed), chronic multimorbidity,[26] Hospital Frailty Risk Score,[27] polypharmacy[29] and level of education (primary, secondary and tertiary). The logit function used to model the excess zeros was adjusted on the Hospital Frailty Risk Score and the cumulated length of hospital stays between 731 and 366 days before death. We also investigated the average weekly change in the rate of unplanned hospitalisations throughout the last year of life according to the decedents' illness trajectory. We calculated the relative IRRs as the effect estimate for the interaction between illness trajectory and time. For this, a generalised estimating equations model with Poisson family and log link function was fitted by using restricted cubic spline with knots at 9, 6 and 3 weeks before death, with double-robust SEs to estimate unbiased 95% CIs. This analysis was adjusted for the same confounders as the primary analysis.

In prespecified sensitivity analysis, decedents with acute and potentially unexpected cause of death were identified by using a previously published algorithm[31] (online supplemental eTable 6) and thereafter excluded. The rational for this analysis was that death can still be largely unexpected regardless of the underlying illness trajectory: it is likely that these patients experienced unplanned hospitalisations that were clinically justified by an acute and life-threatening event, in a context where the goals of care were essentially curative. In post-hoc analysis, we repeated the IRR calculation of unplanned hospitalisation across illness trajectories during the last year of life using regular Poisson models, instead of the zero-inflated model. All analyses were performed with SAS software V.9.4[32] and R statistical software V.3.6.1,[33] The present study was reported in keeping with the Reporting of studies Conducted using Observational Routinely-collected Data guidelines[34] (online supplemental eTable 7).

## RESULTS

### Characteristics of the study population

Out of 79 473 individuals who died in 2015, 77 315 (97.3%) met our eligibility criteria (online supplemental eFigure 4). Their characteristics are shown in table 1. Overall, 30% of decedents followed a trajectory typical of cancer, 37% organ failure and 26% prolonged dwindling. Over 60% of those who followed a trajectory of prolonged dwindling were women, and only the cancer trajectory included more men than women. Median age at death was 85.2 years (IQR 77.7–90.7) with the decedents of the prolonged dwindling trajectory being the oldest while cancer decedents the youngest. One year before death, older people had a median of 4 (IQR 2–7) chronic diseases and were prescribed 5 (IQR 3–8) medications. Among the 5700 (7%) older people who followed a trajectory of 'sudden death', the most common causes of death included acute myocardial infarction, pneumonia, sepsis, aortic aneurysm and dissection and fall-related injuries (online supplemental eTable 8).

### Incidence rate of unplanned hospitalisations

Overall, decedents had on average 1.66 unplanned hospitalisations during their last year of life, with an incidence rate of 175 per 100 patient-years (table 2). Decedents who followed a trajectory of cancer had the highest incidence rate (231 per 100 patient-years), while individuals following a trajectory of prolonged dwindling had the lowest (99 per 100 patient-years). After adjusting on available confounders, decedents with cancer had 1.20 (95% CI 1.18 to 1.21) times higher risk of unplanned

**Table 1** Characteristics of the study population

| | | Illness trajectory | | | |
|---|---|---|---|---|---|
| | Overall | Cancer | Organ failure | Prolonged dwindling | Sudden death |
| **Decedents, no.** | 77 315 | 23 213 | 28 338 | 20 064 | 5700 |
| **Sex, no. (%)** | | | | | |
| Men | 36 245 (46.9) | 12 413 (53.5) | 13 712 (48.4) | 7283 (36.3) | 2837 (49.8) |
| Women | 41 070 (53.1) | 10 800 (46.5) | 14 626 (51.6) | 12 781 (63.7) | 2863 (50.2) |
| **Age at time of death, years** | | | | | |
| Median ($P_{25}$–$P_{75}$) | 85.2 (77.7–90.7) | 80.7 (73.7–87) | 85.5 (78.3–90.8) | 88.6 (83.3–93.0) | 85.8 (77.6–91.3) |
| No. (%) | | | | | |
| 65–74 years | 14 140 (18.3) | 6797 (29.3) | 4804 (17.0) | 1427 (7.1) | 1112 (19.5) |
| 75–84 years | 23 993 (31.0) | 8706 (37.5) | 8720 (30.8) | 4997 (24.9) | 1570 (27.5) |
| 85–94 years | 32 527 (42.1) | 6991 (30.1) | 12 433 (43.9) | 10 647 (53.1) | 2456 (43.1) |
| 95 years and older | 6655 (8.6) | 719 (3.1) | 2381 (8.4) | 2993 (14.9) | 562 (9.9) |
| **Level of education, no. (%)** | | | | | |
| Primary education | 35 013 (45.3) | 9119 (39.3) | 13 503 (47.6) | 9769 (48.7) | 2622 (46.0) |
| Secondary education | 31 443 (40.7) | 10 365 (44.7) | 11 175 (39.4) | 7645 (38.1) | 2258 (39.6) |
| Tertiary education | 9249 (12.0) | 3352 (14.4) | 3002 (10.6) | 2197 (10.9) | 698 (12.2) |
| *Missing* | *1610 (2.1)* | *377 (1.6)* | *658 (2.3)* | *453 (2.3)* | *122 (2.1)* |
| **Marital status, no. (%)** | | | | | |
| Married | 25 368 (32.8) | 10 191 (43.9) | 8406 (29.7) | 5149 (25.7) | 1622 (28.5) |
| Single/divorced | 19 067 (24.7) | 5826 (25.1) | 7493 (26.4) | 4123 (20.5) | 1625 (28.5) |
| Widowed | 32 880 (42.5) | 7196 (31.0) | 12 439 (43.9) | 10 792 (53.8) | 2453 (43.0) |
| **Frailty Risk Score** | | | | | |
| Median ($P_{25}$–$P_{75}$) | 2.5 (0.0–6.7) | 1.4 (0.0–4.7) | 2.6 (0.0–6.7) | 4.3 (0.8–9.9) | 1.8 (0.0–5.4) |
| No. (%) | | | | | |
| Low | 51 552 (66.7) | 17 716 (76.3) | 18 839 (66.5) | 10 853 (54.1) | 4144 (72.7) |
| Moderate | 14 210 (18.4) | 3456 (14.9) | 5598 (19.8) | 4237 (21.1) | 919 (16.1) |
| High | 11 553 (14.9) | 2041 (8.8) | 3901 (13.8) | 4974 (24.8) | 637 (11.2) |
| **Number of chronic diseases** | | | | | |
| Median ($P_{25}$–$P_{75}$) | 4 (2–7) | 4 (2–6) | 5 (3–8) | 4 (2–6) | 3 (2–6) |
| No. (%) | | | | | |
| None | 5012 (6.5) | 1480 (6.4) | 1525 (5.4) | 1331 (6.6) | 676 (11.9) |
| One | 7725 (10.0) | 2455 (10.6) | 2231 (7.9) | 2323 (11.6) | 716 (12.6) |
| Two | 8940 (11.6) | 2917 (12.6) | 2538 (9.0) | 2736 (13.6) | 749 (13.1) |
| Three | 9418 (12.2) | 3100 (13.4) | 2835 (10.0) | 2771 (13.8) | 712 (12.5) |
| Four | 9155 (11.8) | 2913 (12.5) | 3105 (11.0) | 2478 (12.4) | 659 (11.6) |
| Five or more | 37 065 (47.9) | 10 348 (44.6) | 16 104 (56.8) | 8425 (42.0) | 2188 (38.4) |
| **Number of drugs** | | | | | |
| Median ($P_{25}$–$P_{75}$) | 5 (3–8) | 5 (2–7) | 6 (4–9) | 5 (3–8) | 4 (2–7) |
| No. (%) | | | | | |
| 0–4 | 31 964 (41.3) | 11 469 (49.4) | 9556 (33.7) | 8009 (39.9) | 2930 (51.4) |
| 5–9 | 34 376 (44.5) | 9188 (39.6) | 13 267 (46.8) | 9669 (48.2) | 2252 (39.5) |
| ≥10 | 10 975 (14.2) | 2556 (11.0) | 5515 (19.5) | 2386 (11.9) | 518 (9.1) |

hospitalisation than average. Conversely, decedents who followed a trajectory of prolonged dwindling and those who died in the sudden death trajectory had lower-than-average risks of unplanned hospitalisation (IRRs: 0.66 (0.65–0.68) and 0.79 (0.77–0.82), respectively).

### Longitudinal changes in the incidence of unplanned hospitalisation

Throughout the last year of life, the incidence rate of unplanned hospitalisation increased from 1.5 to 26.2 per 100 patient-weeks, regardless of illness trajectory or age (figure 1). There was a particularly steep increase among decedents who died suddenly (from 1.0 to 43.9 per 100 patient-weeks) and those with organ failure (from 1.8 to 38.0 per 100 patient-weeks). Detailed data are provided in online supplemental eTables 9 and 10, eFigure 5. We found that these incidence rates did not increase in a linear fashion and that differences between illness trajectories were marginal until the third month before death. Among decedents who followed a cancer trajectory, the rate of unplanned hospitalisations started increasing ~16 weeks before death, compared with ~8 weeks before death among older adults who died from organ failure and ~4 weeks

**Table 2** Incidence of unplanned hospitalisation during the last year of life, by illness trajectory

| | No. decedents | Unplanned hospitalisation | | Number of person-years* | Incidence rate per 100 person-years | Incidence rate ratio (95% CIs)† | |
|---|---|---|---|---|---|---|---|
| | | No. events | Mean | | | Unadjusted | Adjusted‡ |
| Overall | 77 315 | 128 156 | 1.66 | 73 326 | 175 | 1.0 (Ref)§ | 1.0 (Ref) |
| Trajectories | | | | | | | |
| Cancer | 23 213 | 49 459 | 2.13 | 21 447 | 231 | 1.22 (1.21 to 1.24) | 1.20 (1.18 to 1.21) |
| Organ failure | 28 338 | 52 184 | 1.84 | 26 824 | 195 | 1.09 (1.08 to 1.11) | 1.04 (1.03 to 1.06) |
| Prolonged dwindling | 20 064 | 19 326 | 0.96 | 19 552 | 99 | 0.57 (0.56 to 0.59) | 0.66 (0.65 to 0.68) |
| Sudden death | 5700 | 7187 | 1.26 | 5503 | 131 | 0.73 (0.71 to 0.76) | 0.79 (0.77 to 0.82) |

*The number of person-years at risk is not equal to the number of decedents because time at risk was defined as the number of days when the persons were not already hospitalised (ie, when the decedents were truly at risk of unplanned hospitalisation).

†Robust SEs were used to estimate the 95% CIs; incidence rate ratio obtained from zero-inflated Poisson models.

‡Adjusted for sex, age, education, marital status, frailty, number of chronic diseases, polypharmacy; decedents with missing data about education (2.1% of total) were excluded from this analysis.

§The total study population was used as the reference category to compare the risks across illness trajectories to the average risk in the cohort.

among those who followed a trajectory of prolonged dwindling or sudden death.

During the last 3 months of life, we found substantial variations in the speed at which the rate of unplanned hospitalisations increased across the different illness trajectories. Older people who died from sudden causes had the fastest increase in the risks of unplanned hospitalisation (relative IRR: 1.12, 95% CI 1.11 to 1.13), while decedents who followed a trajectory of cancer or prolonged dwindling trajectories had slower-than-average increases (table 3).

A more nuanced pattern emerged after we used restricted cubic splines to relax the assumption that the change in the risk of unplanned hospitalisation was linear over time. Figure 2 shows the relative IRRs of unplanned hospitalisations during the last 12 weeks of life for each illness trajectory compared with the overall study population. Relative IRRs correspond to the speed at which the incidence of unplanned hospitalisation increased over time, $week_{12}$ being the reference period. Hence, the rate of unplanned hospitalisations among older people who followed a trajectory of cancer increased at a faster-than-average speed between the 12th and the 3rd week before death, after which we observed an acceleration among individuals who died from organ failure or sudden death while older people who followed a trajectory of prolonged dwindling experienced a substantially slower-than-average increase.

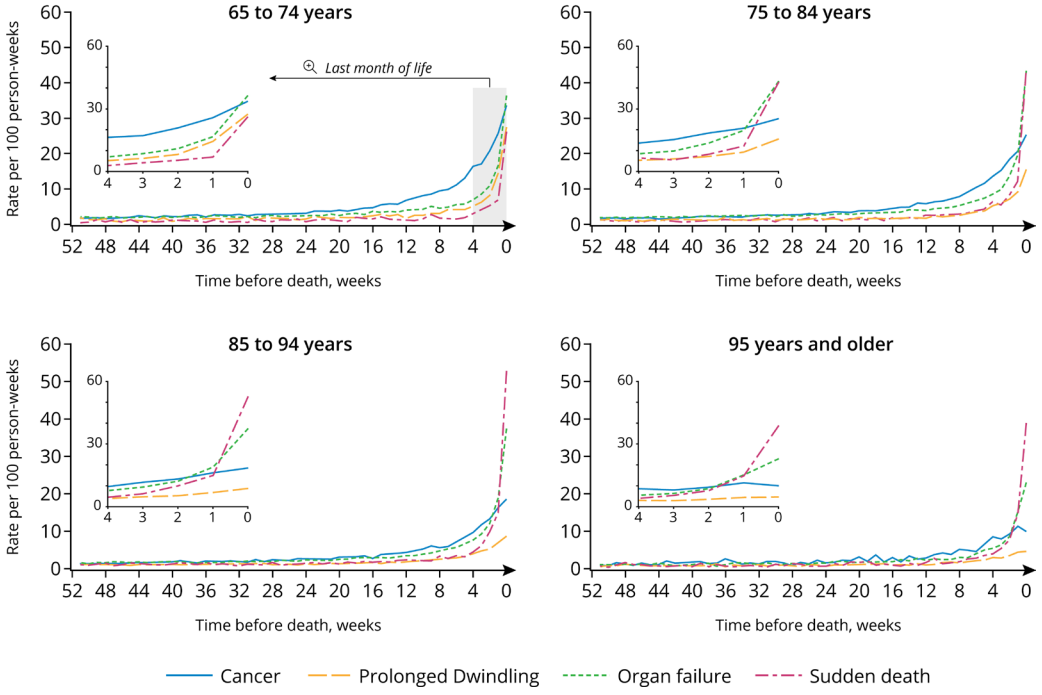


**Figure 1** Incidence rate of unplanned hospitalisations throughout the last year of life, by age group and illness trajectory.

**Table 3** Average weekly change in the rate of unplanned hospitalisations throughout the last year of life, by illness trajectory

| | Relative incidence rate ratio (95% CIs)* | | | |
|---|---|---|---|---|
| | 52–40 weeks before death | 39–27 weeks before death | 26–14 weeks before death | 13–1 weeks before death† |
| Overall‡ | 1.0 (Ref) | 1.0 (Ref) | 1.0 (Ref) | 1.0 (Ref) |
| Trajectories | | | | |
| Cancer | 1.01 (1.01 to 1.02) | 1.01 (1.01 to 1.02) | 1.01 (1.01 to 1.02) | 0.97 (0.96 to 0.97) |
| Organ failure | 1.00 (0.99 to 1.00) | 1.00 (0.99 to 1.00) | 1.00 (0.99 to 1.00) | 1.04 (1.03 to 1.04) |
| Prolonged dwindling | 0.99 (0.98 to 0.99) | 0.99 (0.98 to 1.00) | 0.99 (0.98 to 1.00) | 0.97 (0.96 to 0.97) |
| Sudden death | 1.00 (0.98 to 1.02) | 0.99 (0.97 to 1.00) | 0.99 (0.98 to 1.00) | 1.12 (1.11 to 1.13) |

*Adjusted relative incidence rate ratio for the interaction between illness trajectory time, obtained from a log binomial model adjusted for sex, age, education, marital status, frailty, number of chronic diseases, polypharmacy. Decedents with missing data about education (2.1% of total) were excluded from this analysis. Robust SEs were used to estimate the 95% CIs. Relative incidence rate ratios can be interpreted as follow: the risk of unplanned hospitalisation among older people who follow a given illness trajectory changes in average at a faster (eg, 1.12 times faster) or slower (eg, 0.97 times slower) rate, considering the earliest week within the period (ie, $week_{52}$, $week_{39}$, $week_{26}$, $week_{13}$) as the reference time point, than it does on average in the overall study population.

†Week 1 corresponds to the last week before death.

‡The total study population was used as the reference category to compare the risks across illness trajectories to the average risk in the cohort.

### Sensitivity analyses

The prespecified sensitivity analysis showed that about 45% of the study population had a potentially unexpected cause of death, regardless of their illness trajectory (online supplemental eTable 11). Repeating the main analysis after excluding decedents with potentially unexpected cause of death did not change the direction or magnitude of our results (online supplemental eTables 12 and 13, eFigure 6). In non-prespecified post-hoc analyses, the IRRs for unplanned hospitalisations throughout the entire last year of life did not change in a scientifically important or clinically relevant manner when fitting a regular Poisson model instead of the zero-inflated variant used in primary analysis (online supplemental eTable 14).

## DISCUSSION

In this large, register-based cohort study, we found that the incidence of unplanned hospitalisations during the last year of life was comparable across illness trajectories until the third month before death. After this time point, unplanned hospitalisations became increasingly frequent and differences between illness trajectories became evident. The incidence of unplanned hospitalisations started increasing among decedents with cancer trajectory, followed by those with organ failure. Older people with a trajectory of prolonged dwindling (often characterised by dementia) experienced a more modest increase in the risk of unplanned hospitalisation, mostly during the final month of life.

Unplanned hospitalisations are frequent at the end of life. We found that 18% of older adults in Sweden have at least one unplanned hospitalisation during their last week of life. In comparison, 11% of US Medicare beneficiaries in 2015 had at least one healthcare transition in their last 3 days of life. Overall, the incidence rate of unplanned hospitalisation in our cohort was low between 12 and 3 months before death and illness trajectories seem to offer little discriminative ability to differentiate unplanned hospitalisation during this

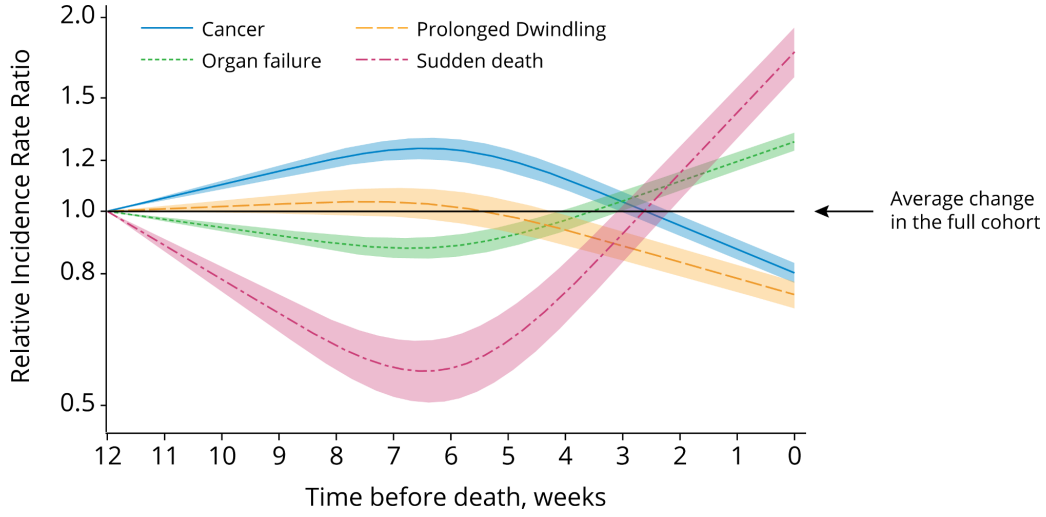


**Figure 2** Change in the incidence rate of unplanned hospitalisations throughout the last 12 weeks of life, by illness trajectory.

period. However, the patterns of unplanned hospitalisations started to diverge across illness trajectories during the last 3 months before death. Our finding that the incidence rate of unplanned hospitalisations increases close to death is consistent with previous studies, although with somewhat different timings.[3–8]

Overall, cancer decedents bear the highest burden of unplanned admissions during the last year of life, a finding well in line with a recent report from Public Health England.[35] This may be partly attributable to the worsening of pain and other distressing symptoms as death approaches. Older people who died from organ failure had the second highest incidence of unplanned hospitalisation, with a steep acceleration near the end of life. This pattern may be connected with the increasingly frequent exacerbation of symptoms and acute deterioration of disease close to death, which sometimes warrant immediate inpatient care. Finally, individuals who followed a trajectory of 'prolonged dwindling' (most often characterised by dementia) had the lowest and slowest increase in incidence of unplanned admission during the last year of life. Their significant symptom burden, poorer-than-average access to symptom relief[36 37] and high levels of physical frailty at the end of life would suggest greater utilisation of emergency hospitalisation. However, their observed lower propensity of unplanned hospitalisation may be explained by difficulties in communicating and relatives acting as gatekeepers, and by the fact that they are more likely to live in nursing homes[38] that provide more medical care than home-based care.[39] Older adults with sudden death had the highest incidence rate of unplanned hospitalisation during the last weeks of life. Their most common causes of death included events that are likely to result in necessary unplanned hospitalisation followed by imminent death, for example, acute myocardial infarction.

Unplanned hospitalisations close to death are not always avoidable and are sometimes in line with patients' preferences, but they can nonetheless have adverse outcomes.[4 9–11 40 41] Studies suggest that a substantial fraction of unplanned hospitalisations can be reduced by integrative anticipatory palliative care and advanced care planning.[42–45] It has been also reported that routinely collected administrative data can be used to identify persons with potential palliative care needs.[46] Our results indicate that the patterns of different illness trajectories should be considered when planning policies aiming to reduce unplanned hospitalisations, especially in the very last months before death. The unique hospitalisation pattern of decedents in the sudden death trajectory suggests that it is relevant to differentiate them from older people who could potentially benefit from integrated palliative care. However, basing decisions on the illness trajectories requires that the trajectories are identified prospectively and not based on causes of death. Future studies should investigate how well register data can be used to identify illness trajectories as older people near death.

Strengths of the study include routinely collected data with nearly 100% nationwide coverage which eliminates non-participation bias and reduces the risk of outcome misclassification as there is no recall or information bias. However, our findings should be interpreted with the following limitations in mind. First, retrospective cohorts of decedents have the potential to introduce selection effects and immortal-time bias,[47] which we addressed by conducting thorough sensitivity analyses. Second, illness trajectories were identified at the time of death and not at the outset of the underlying condition, which may have led to some degree of exposure misclassification (ie, the applied illness trajectory hierarchy might have caused overestimation of the cancer trajectory) and immortal-time bias (exposure time might have been misclassified for those who did not have any condition in a portion of the last year of life that could explain unplanned hospitalisations). Second, defining illness trajectories into four broad categories is an oversimplification of the clinical processes that lead to death in old age. Yet, despite their obvious limitations, these illness trajectories remain a useful tool to approximate the late-life functional decline patterns that warrant different health services needs at the end of life.[23] Third, the data used in the present study do not allow for forming a judgement about whether or not each individual unplanned hospitalisation was clinically and ethically appropriate, or whether it resulted in health gains or losses for the patients. Our population-level findings can thus be used to inform public health strategies and care commissioning choices, but not to evaluate individual decisions in clinical practice, which are made case-by-case with more detailed information about the healthcare needs of patients and about their preferences and priorities. Finally, our findings stem from the context of the Swedish universal healthcare system and may thus not be entirely transportable to other countries with different healthcare systems.

## CONCLUSION

Unplanned hospitalisations are common at the end of life, especially during the last 3 months. Decedents belonging to different underlying illness trajectories had divergent patterns of unplanned hospitalisations during their last 3 months of life. This should be considered in healthcare policies aiming to reduce burdensome care transitions and improve comfort at the end of life. Future studies are warranted to investigate how illness trajectories can inform advance care planning and whether the observed trends in late-life unplanned hospitalisations are in keeping with patients' preferences and goals of care.

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# Supplementary data

Szilcz *et al*. Unplanned hospitalisations in older people: illness trajectories in the last year of life

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***eTable 1. Data sources***

| Register | Register holder | Start | Completeness | Geographical coverage | Content | Externally validated |
|---|---|---|---|---|---|---|
| Total Population Register[48] | Statistics Sweden | 1968 | The over-coverage has been estimated to 0.1 % for Nordic citizens but substantially higher for individuals born outside the Nordic countries (potentially 4–8 %) | Nationwide | Sex, date of birth, country of birth, municipality of residence, living arrangement, civil status, year of first and last immigration, year of last emigration | Yes |
| National Cause Of Death Register[49] | National Board of Health and Welfare | Complete since 1952 | 99% of all deaths are documented with an underlying cause of death | Nationwide | Sex, date of birth, underlying and contributing causes of death (ICD-10), place of death, civil status | Yes |
| National Patient Register[24] | National Board of Health and Welfare | Inpatient care coverage complete since 1987<br>Specialised outpatient care since 2001 | 99% of all somatic and psychiatric hospital discharges are registered.<br>Outpatient diagnoses coverage lower than inpatient data but above 80% | Nationwide | Sex, age, date of admission and discharge, planned/unplanned admission, main diagnosis, secondary diagnoses, injuries, medical or surgical procedures, department of admission, provenance, destination. | The inpatient register part has an overall positive predictive value of diagnosis of 85%-95% |
| Swedish Prescribed Drug Register[50,51] | National Board of Health and Welfare | July 2005 | 85% of all sold defined daily doses (DDDs) are covered by the register<br>The remaining 15% are Over-the-counter medications (12% of DDDs), drugs administered in hospitals (3% of DDDs) | Nationwide | Sex, age, date of prescription, date of dispensing, type of dispensing (e.g. multi-dose), total dose, prescribed daily dose (free text), number of DDDs dispensed, ATC code, generic name, costs, characteristics of prescribers | Yes |
| Swedish Register of Education[28] | | 1985 (annual updates from 2000), earlier versions have been produced in the 1930 and 1970 census, | Population aged 16-74 years old registered as resident in Sweden at 1 January each year. From 2007, information for the group 75+ is also collected | Nationwide | Highest educational attainment | Yes |

***eTable 2. Classification of causes of death into illness trajectories***

| Trajectory | ICD-10 codes |
|---|---|
| **1 – Cancer, leading to a short decline with evident terminal phase** | |
| Neoplasm | C00-C26, C30-C34, C37-C41, C43-C58, C60-C85, C88, C90-C97, D00-D09, D32, D33, D37-D48 |
| **2 - Organ failure leading to long-term limitations with intermittent acute episodes** | |
| Diabetes | E10-E14, G590, G632, H360, M142, N083 |
| Other endocrinal diseases | E70-E72, E75-E77, E84-E85 |
| Certain infectious and parasitic diseases | A520-A523, A527, A810, A812, B15-B19, B20-B24 |
| Diseases of the blood | D60, D61, D69, D70, D752, D758, D86 |
| Diseases of the cardiovascular system (incl. cerebrovascular diseases) | I231-I233, I238, I25, I50, I60-I64, I67, I688, I69, G46, I65, I66, I680-I682, I27, I42, I43, I51, I520, I70, I73, I74, I792, I970, I971, I978, I980, I981, I988 |
| Diseases of the respiratory system (incl. abnormalities of breathing) | J40-J44, J47, J60-J62, J66, J701, J80, J841, J951-J953, J96, J980-J984, R060, R062-R065, R068 |
| Diseases of the digestive system (incl. liver diseases) | K70-K77, K44, K50, K51, K55, K56, K85, K86, K871, K90 |
| Diseases of the skin | L305, L40-L42, L44, L93, L945 |
| Diseases of the musculoskeletal system | M360, M361, M05, M06, M13, M15, M21, M30-M35, M40-M43, M45-M51, M53, M54, M638, M80, M81, M820, M821, M843, M844, M86-M88, M907, M961 |
| Diseases of the genitourinary system (incl. renal failure) | N02-N05, N11, N12, N136, N160, N18, N19, N25, N312, N318, N319, N82 |
| Other (incl. congenital conditions) | Q01-Q06, Q078, Q079, Q20-Q28, Q31, Q33, Q40-Q45, Q60-Q68, Q714, Q75-Q79, Q850, Q86-87, Q89-Q93, Q95-Q97, Q99 |
| **3 – Prolonged dwindling, characterized by a progressive loss of both physical and cognitive capacities** | |
| Alzheimer's disease | G30-G32 |
| Mental and behavioural disorders | F00, F01, F02, F03, F05, F06, R54 |
| Parkinson's disease | G20-G23 |
| Multiple sclerosis | G35-G37 |
| Other diseases of the nervous system | G10, G12, G70-G73, G03-G05, G07, G478, G518, G551, G608, G80-G83, G90-G99 |
| **4 - Sudden death** | |
| None of the three trajectories above | |

Abbreviations: ICD-10, International Classification of Diseases 10th revision

***eTable 3. Details of diagnosis codes and drugs used to detect chronic conditions***

| **Chronic disease** | **ICD-10 Codes** | **ATC Codes** |
|---|---|---|
| Source(s) of data: | National cause of death register (all contributing causes of death)<br>National patient register (all inpatient and specialized outpatient diagnoses) | Swedish Prescribed Drugs Register |
| 1. Allergy | J30.1-J30.4; J45.0; K52.2; L20; L23; L50.0; Z51.6 | |
| 2. Anaemia | D50-D53; D55-D59 (excl. D56.3; D59.0; D59.2; D59.3; D59.6); D60-D64 (excl. D60.1; D61.1; D61.2; D62; D64.2) | B03A, B03XA |
| 3. Asthma | J45 | R03DC; R03BC |
| 4. Atrial fibrillation | I48 | |
| 5. Autoimmune diseases | I73.1; L10 (excl. L10.5); L12; L40; L41; L93-L95; M30-M36 (excl. M32.0; M34.2; M35.7-M35.9; M36.0; M36.1; M36.2; M36.3) | D05 |
| 6. Blindness, visual loss | H54 (excl. H54.3); Z44.2; Z97.0 | |
| 7. Blood and blood forming organ diseases | D66-D69 (excl. D68.3; D68.4; D69.5); D71; D72.0; D73.0-D73.2; D74 (excl. D74.8); D75.0; D76.1; D76.3; D77; D80 (excl. D80.7); D81-D84; D86; D89 (excl. D89.1; D89.3) | |
| 8. Bradycardias and conduction diseases | I44.1-I44.3; I45.3; I45.5; Z95.0 | |
| 9. Cardiac valve diseases | I05-I08; I09.1; I09.8; I34-I38; I39.0-I39.4; Q22; Q23; Z95.2-Z95.4 | |
| 10. Cataract and other lens diseases | H25-H28; Q12; Z96.1 | |
| 11. Cerebrovascular disease | G45; G46; I60-I64; I67; I69 | |
| 12. Chromosomal abnormalities | Q90-Q99 | |
| 13. Chronic infectious diseases | A15-A19; A30; A31; A50-A53 (excl. A51); A65-A67; A69.2; A81; B20-B24; B38.1; B39.1; B40.1; B57.2-B57.5; B65; B92; B94; J65; M86.3-M86.6 | J04A, excl. J04AB01, J04AB02, J04AB03 and J04AC |
| 14. Chronic kidney disease | I12.0; I13.0-I13.9; N01, N02, N04, N05; N07; N08; N11; N18.3-N18.9; Q60; Q61.1-Q61.9; Z90.5; Z94.0 | |
| 15. Chronic liver disease | B18; K70 (excl. K70.0; K70.1); K71.3-K71.5; K71.7; K72.1; K73; K74; K75.3-K75.8; K76.1; K76.6; K76.7; K77.8; Q44.6; Z94.4 | |
| 16. Chronic pancreas, biliary tract and gallbladder diseases | K80.0; K80.1; K80.2; K80.8; K81.1; K86 (excl. K86.2; K86.3; K86.9); Q44.0-Q44.5; Q45.0 | A09AA02 |
| 17. Chronic ulcer of the skin | I83.0; I83.2; L89; L97; L98.4 | |

| **Chronic disease** | **ICD-10 Codes** | **ATC Codes** |
|---|---|---|
| Source(s) of data: | National cause of death register (all contributing causes of death)<br>National patient register (all inpatient and specialized outpatient diagnoses) | Swedish Prescribed Drugs Register |
| 18. Colitis and related diseases | K52.0; K52.8; K55.1; K55.2; K57.2-K57.5; K57.8; K57.9; K58; K59.0; K59.2; K62 (excl. K62.0; K62.1; K62.5; K62.6); K63.4; K64 (excl. K64.5); | |
| 19. COPD, emphysema, chronic bronchitis | J41-J44; J47 | R03BB |
| 20. Deafness, hearing loss | H80; H90; H91.1; H91.3; H91.9; Q16; Z45.3; Z46.1; Z96.2; Z97.4 | |
| 21. Dementia | F00-F03; F05.1; G30; G31 | N06DA, N06DX01 |
| 22. Depression and mood diseases | F30-F34; F38; F39; F41.2 | |
| 23. Diabetes | E10; E11; E13; E14; E89.1 | A10 |
| 24. Dorsopathies | M40-M43; M47-M53; Q67.5; Q76.4; Q76.1; | |
| 25. Dyslipidemia | E78 | |
| 26. Ear, nose, throat diseases | H60.4; H66.1-H66.3; H70.1; H71; H73.1; H74.1; H81.0; H83.1; H83.2; H95; J30.0; J31-J33; J34.1-J34.3; J35; J37; J38.0; J38.6; K05.1; K05.3; K07; K11.0; K11.7; Q30-Q32; Q35-Q38 | |
| 27. Epilepsy | G40 (excl. G40.5) | |
| 28. Esophagus, stomach and duodenum diseases | I85; I86.4; I98.2; I98.3; K21; K22.0; K22.2; K22.4; K22.5; K22.7; K23.0; K23.1; K25.4-K25.7; K26.4-K26.7; K27.4-K27.7; K28.4-K28.7; K29.3-K29.9; K31.1-K31.5; Q39; Q40; Z90.3 | A02BX |
| 29. Glaucoma | H40.1-H40.9 | S01ED |
| 30. Heart failure | I11.0; I13.0; I13.2; I27; I28.0; I42; I43; I50; I51.5; I51.7; I52.8; Z94.1; Z94.3 | |
| 31. Hematological neoplasms | C81-C96 | |
| 32. Hypertension | I10-I15 | |
| 33. Inflammatory arthropathies | M02.3; M05-M14; M45; M46.0; M46.1; M46.8; M46.9 | M01CB |
| 34. Inflammatory bowel disease | K50; K51 | A07E |
| 35. Ischemic heart disease | I20-I22; I24; I25; Z95.1; Z95.5 | C01DA, C01EB18 |
| 36. Migraine and facial pain syndromes | G43; G44.0-G44.3; G44.8; G50 | N02C |
| 37. Multiple sclerosis | G35 | |
| 38. Neurotic, stress-related and somatoform diseases | F40-F48 (excl. F43.0; F43.2) | |
| 39. Obesity | E66 | |

| **Chronic disease** | **ICD-10 Codes** | **ATC Codes** |
|---|---|---|
| Source(s) of data: | National cause of death register (all contributing causes of death)<br>National patient register (all inpatient and specialized outpatient diagnoses) | Swedish Prescribed Drugs Register |
| 40. Osteoarthritis and other degenerative joint diseases | M15-M19; M36.2; M36.3 | |
| 41. Osteoporosis | M80-M82 | M05BA; M05BB; M05BX03; M05BX53 |
| 42. Other cardiovascular diseases | I09 (excl. I09.1; I09.8); I28.1; I31.0; I31.1; I45.6; I49.5; I49.8; I70-I72 (excl. I70.2); I79.0; I79.1; I95.0; I95.1; I95.8; Q20; Q21; Q24-Q28; Z95.8; Z95.9 | |
| 43. Other digestive diseases | K66.0; K90.0-K90.2; K91.1; K93; Q41-Q43; R15; Z90.4; Z98.0 | |
| 44. Other eye diseases | H02.2-H02.5; H04 (excl. H04.3); H05 (excl. H05.0); H10.4; H17; H18.4-H18.9; H19.3; H19.8; H20.1; H21; H31.0-H31.2; H31.8; H31.9; H33; H35.2-H35.5; H35.7-H35.9; H36; H47-H49 (excl. H47.0; H47.1; H48.1); H51; Q10-Q15 (excl. Q12); Z94.7 | |
| 45. Other genitourinary diseases | B90.1; N20.0; N20.2; N20.9; N21.0; N21.8; N21.9; N22; N30.1-N30.4; N31; N32.0; N32.3; N32.8; N32.9; N33; N35; N39.3; N39.4; N48.0; N48.4; N48.9; N70.1; N71.1; N73.1; N73.4; N73.6; N76.1; N76.3; N81; N88; N89.5; N90.5; N95.2; Q54; Q62.0-Q62.4; Q62.7; Q62.8; Q63.8; Q63.9; Q64.0; Q64.1; Q64.3-Q64.9; Z90.6; Z90.7; Z96.0 | |
| 46. Other metabolic diseases | E20-E31 (excl. E23.1; E24.2; E24.4; E27.3; E30); E34 (excl. E34.3; E34.4); E35 (excl. E35.0); E40-E46 (excl. E44.1); E64; E70-E72; E74-E77; E79 (excl. E79.0); E80 (excl. E80.4); E83-E89 (excl. E86; E87; E88.3; E89.0; E89.1); K90.3; K90.4; K90.8; K90.9; K91.2; M83; M88; N25 | |
| 47. Other musculoskeletal and joint diseases | B90.2; M21.2-M21.9; M22-M24; M25.2; M25.3; M35.7; M61; M65.2-M65.4; M70.0; M72.0; M72.2; M72.4; M75.0; M75.1; M75.3; M75.4; M79.7; M84.1; M89; M91; M93; M94; M96; M99; S38.2; S48; S58; S68; S78; S88; S98; T05; T09.6; T11.6; T13.6; T14.7; T90-T98; Q65; Q66; Q68; Q71-Q74; Q77; Q78; Q79.6; Q79.8; Q87; Z44.0; Z44.1; Z89.1-Z89.9; Z94.6; Z96.6; Z97.1 | |
| 48. Other neurological diseases | B90.0; D48.2; G04.1; G09-G14 (excl. G13.0; G13.1); G24-G26 (excl. G25.1; G25.4; G25.6); G32; G37; G51-G53 (excl. G51.0); G70; G71; G72.3-72.9; G73 (excl. G73.2-G73.4); G80-G83 (excl. G83.8); G90; G91; G93.8; G93.9; G95; G99; M47.1; Q00-Q07; Q76.0 | |

| **Chronic disease** | **ICD-10 Codes** | **ATC Codes** |
|---|---|---|
| Source(s) of data: | National cause of death register (all contributing causes of death)<br>National patient register (all inpatient and specialized outpatient diagnoses) | Swedish Prescribed Drugs Register |
| 49. Other psychiatric and behavioral diseases | F04; F06; F07; F09; F10.2; F10.6; F10.7; F11.2; F11.6; F11.7; F12.2; F12.6; F12.7; F13.2; F13.6; F13.7; F14.2; F14.6; F14.7; F15.2; F15.6; F15.7; F16.2; F16.6; F16.7; F17.2; F17.6; F17.7; F18.2; F18.6; F18.7; F19.2; F19.6; F19.7; F50; F52; F60-F63; F68; F70-F89; F95; F99 | N07BB |
| 50. Other respiratory diseases | B90.9; E66.2; J60-J67; J68.4; J70.1; J70.3; J70.4; J84; J92; J94.1; J95.3; J95.5; J96.1; J98 (excl. J98.1); Q33; Q34; Z90.2; Z94.2; Z94.3; Z96.3 | |
| 51. Other skin diseases | L13; L28; L30.1; L43 (excl. L43.2); L50.8; L58.1; L85; Q80; Q81; Q82.1; Q82.2; Q82.9 | |
| 52. Parkinson and parkinsonism | G20-G23 (excl. G21.0) | N04BA; N04BX |
| 53. Peripheral neuropathy | B91; G54-G60; G62.8; G62.9; G63 (excl. G63.1); M47.2; M53.1; M54.1 | |
| 54. Peripheral vascular disease | I70.2; I73 (excl. I73.1; I73.8); I79.2; I79.8 | B01AC23 |
| 55. Prostate diseases | N40; N41.1; N41.8 | G04C (excl. G04CB) |
| 56. Schizophrenia and delusional diseases | F20; F22; F24; F25; F28 | |
| 57. Sleep disorders | G47; F51.0-F51.3 | |
| 58. Solid neoplasms | All C (excl. C81-C96); D00-D09; D32.0; D32.1; D32.9; D33.0-D33.4; Q85 | |
| 59. Thyroid disease | E00-E03 (excl. E03.5); E05; E06.2; E06.3; E06.5; E07; E35.0; E89.0 | H03AA; H03B |
| 60. Venous and lymphatic diseases | I78.0; I83; I87; I89; I97.2; Q82.0 | |

Abbreviations: ICD-10: International Classification of Diseases, 10th revision; ATC: Anatomical Therapeutic Chemical classification system

***eTable 4. Diagnosis codes and weights used to calculate the Hospital Frailty Risk score***[27]

| Conditions | ICD10-codes | Weight |
|---|---|---|
| Dementia in Alzheimer's disease | F00 | 7.1 |
| Hemiplegia | G81 | 4.4 |
| Alzheimer's disease | G30 | 4 |
| Sequelae of cerebrovascular disease (secondary codes) | I69 | 3.7 |
| Other symptoms and signs involving the nervous and musculoskeletal systems (R29·6 Tendency to fall) | R29 | 3.6 |
| Other disorders of urinary system (includes urinary tract infection and urinary incontinence) | N39 | 3.2 |
| Delirium, not induced by alcohol and other psychoactive substances | F05 | 3.2 |
| Unspecified fall | W19 | 3.2 |
| Superficial injury of head | S00 | 3.2 |
| Unspecified haematuria | R31 | 3 |
| Other bacterial agents as the cause of diseases classified to other chapters (secondary code) | B96 | 2.9 |
| Other symptoms and signs involving cognitive functions and awareness | R41 | 2.7 |
| Abnormalities of gait and mobility | R26 | 2.6 |
| Other cerebrovascular diseases | I67 | 2.6 |
| Convulsions, not elsewhere classified | R56 | 2.6 |
| Somnolence, stupor and coma | R40 | 2.5 |
| Complications of genitourinary prosthetic devices, implants and grafts | T83 | 2.4 |
| Intracranial injury | S06 | 2.4 |
| Fracture of shoulder and upper arm | S42 | 2.3 |
| Other disorders of fluid, electrolyte and acid-base balance | E87 | 2.3 |
| Other joint disorders, not elsewhere classified | M25 | 2.3 |
| Volume depletion | E86 | 2.3 |
| Senility | R54 | 2.2 |
| Care involving use of rehabilitation procedures | Z50 | 2.1 |
| Unspecified dementia | F03 | 2.1 |
| Other fall on same level | W18 | 2.1 |
| Problems related to medical facilities and other health care | Z75 | 2 |
| Vascular dementia | F01 | 2 |
| Superficial injury of lower leg | S80 | 2 |
| Cellulitis | L03 | 2 |
| Blindness and low vision | H54 | 1.9 |
| Deficiency of other B group vitamins | E53 | 1.9 |
| Problems related to social environment | Z60 | 1.8 |
| Parkinson's disease | G20 | 1.8 |
| Syncope and collapse | R55 | 1.8 |
| Fracture of rib(s), sternum and thoracic spine | S22 | 1.8 |
| Other functional intestinal disorders | K59 | 1.8 |
| Acute renal failure | N17 | 1.8 |
| Decubitus ulcer | L89 | 1.7 |
| Carrier of infectious disease | Z22 | 1.7 |
| Streptococcus and staphylococcus as the cause of diseases classified to other chapters | B95 | 1.7 |
| Ulcer of lower limb, not elsewhere classified | L97 | 1.6 |

| | | |
|---|---|---|
| Other symptoms and signs involving general sensations and perceptions | R44 | 1.6 |
| Duodenal ulcer | K26 | 1.6 |
| Hypotension | I95 | 1.6 |
| Unspecified renal failure | N19 | 1.6 |
| Other septicaemia | A41 | 1.6 |
| Personal history of other diseases and conditions | Z87 | 1.5 |
| Respiratory failure, not elsewhere classified | J96 | 1.5 |
| Exposure to unspecified factor | X59 | 1.5 |
| Other arthrosis | M19 | 1.5 |
| Epilepsy | G40 | 1.5 |
| Osteoporosis without pathological fracture | M81 | 1.4 |
| Fracture of femur | S72 | 1.4 |
| Fracture of lumbar spine and pelvis | S32 | 1.4 |
| Other disorders of pancreatic internal secretion | E16 | 1.4 |
| Abnormal results of function studies | R94 | 1.4 |
| Chronic renal failure | N18 | 1.4 |
| Retention of urine | R33 | 1.3 |
| Unknown and unspecified causes of morbidity | R69 | 1.3 |
| Other disorders of kidney and ureter, not elsewhere classified | N28 | 1.3 |
| Unspecified urinary incontinence | R32 | 1.2 |
| Other degenerative diseases of nervous system, not elsewhere classified | G31 | 1.2 |
| Nosocomial condition | Y95 | 1.2 |
| Other and unspecified injuries of head | S09 | 1.2 |
| Symptoms and signs involving emotional state | R45 | 1.2 |
| Transient cerebral ischaemic attacks and related syndromes | G45 | 1.2 |
| Problems related to care-provider dependency | Z74 | 1.1 |
| Other soft tissue disorders, not elsewhere classified | M79 | 1.1 |
| Fall involving bed | W06 | 1.1 |
| Open wound of head | S01 | 1.1 |
| Other bacterial intestinal infections | A04 | 1.1 |
| Diarrhoea and gastroenteritis of presumed infectious origin | A09 | 1.1 |
| Pneumonia, organism unspecified | J18 | 1.1 |
| Pneumonitis due to solids and liquids | J69 | 1 |
| Speech disturbances, not elsewhere classified | R47 | 1 |
| Vitamin D deficiency | E55 | 1 |
| Artificial opening status | Z93 | 1 |
| Gangrene, not elsewhere classified | R02 | 1 |
| Symptoms and signs concerning food and fluid intake | R63 | 0.9 |
| Other hearing loss | H91 | 0.9 |
| Fall on and from stairs and steps | W10 | 0.9 |
| Fall on same level from slipping, tripping and stumbling | W01 | 0.9 |
| Thyrotoxicosis [hyperthyroidism] | E05 | 0.9 |
| Scoliosis | M41 | 0.9 |
| Dysphagia | R13 | 0.8 |
| Dependence on enabling machines and devices | Z99 | 0.8 |
| Agent resistant to penicillin and related antibiotics | U80 | 0.8 |
| Osteoporosis with pathological fracture | M80 | 0.8 |
| Other diseases of digestive system | K92 | 0.8 |
| Cerebral Infarction | I63 | 0.8 |
| Calculus of kidney and ureter | N20 | 0.7 |
| Mental and behavioural disorders due to use of alcohol | F10 | 0.7 |
| Other medical procedures as the cause of abnormal reaction | Y84 | 0.7 |

| | | |
|---|---|---|
| Abnormalities of heart beat | R00 | 0.7 |
| Unspecified acute lower respiratory infection | J22 | 0.7 |
| Problems related to life-management difficulty | Z73 | 0.6 |
| Other abnormal findings of blood chemistry | R79 | 0.6 |
| Personal history of risk-factors, not elsewhere classified | Z91 | 0.5 |
| Open wound of forearm | S51 | 0.5 |
| Depressive episode | F32 | 0.5 |
| Spinal stenosis (secondary code only) | M48 | 0.5 |
| Disorders of mineral metabolism | E83 | 0.4 |
| Polyarthrosis | M15 | 0.4 |
| Other anaemias | D64 | 0.4 |
| Other local infections of skin and subcutaneous tissue | L08 | 0.4 |
| Nausea and vomiting | R11 | 0.3 |
| Other noninfective gastroenteritis and colitis | K52 | 0.3 |
| Fever of unknown origin | R50 | 0.1 |

Abbreviations: ICD-10: International Classification of Diseases, 10th revision;

***eTable 5. Categorization of levels of education***

| Category | ISCED 97 | No. decedents |
|---|---|---|
| Primary education | Primary level of education (1) | 34 983 |
| | Unspecified | 30 |
| Secondary education | Lower secondary education (2A) | 5 194 |
| | Upper secondary education ≤2 years (3C) | 18 935 |
| | Upper secondary education 3 years (3A) | 6 413 |
| | Post-secondary non tertiary education (4) | 803 |
| | Unspecified | 98 |
| Tertiary education | Post-secondary education <3 years (5B) | 3 498 |
| | Post-secondary education ≥3 years (5A) | 5 335 |
| | Post-graduate education (6) | 384 |
| | Unspecified | 32 |
| Missing | | 1 610 |

Abbreviations: ISCED 97: International Standard Classification of Education 1997

***eTable 6. Details of diagnosis codes used to identify potentially unexpected causes of death in older adults***

| **ICD Chapter** | **Multiple cause of death** | **Inpatient and specialized care admissions** |
|---|---|---|
| *Source(s) of data:* | *National cause of death register (underlying and contributing causes of death)* | *National patient register (all inpatient and specialized outpatient care diagnoses[a])* |
| Certain infectious and parasitic diseases | A00; A01; A02; A03; A04; A05; A06; A07; A08; A09; A39; A40; A41; A499; A80; A81; A87; B371; B375; B377; B440; B441; B448; B449; B99 | |
| Diseases of the blood and blood-forming organs | D611; D619; D649 | |
| Endocrine, nutritional and metabolic diseases | E86 | |
| Diseases of the nervous system | G000; G001; G002; G003; G009; G039; G040; G048; G049; G060; G062; G931; G936 | |
| Ischaemic heart diseases and pulmonary heart diseases | I21; I23; I25; I249; I249; I255; I26; I28 | No history of ischemic heart disease (I20-I25) or pulmonary embolism (I26) |
| Other forms of heart disease | I30; I33; I40; I461; I469 | |
| Cerebrovascular diseases | I60; I61; I62; I63; I64; I65; I66; I67 | No history of cerebrovascular disease (I60-I69) |
| Diseases of arteries, arterioles and capillaries | I71; I72; I74; I97 | |
| Diseases of the respiratory system | J069; J09; J10; J11; J12; J13; J14; J15; J18; J22; J690; J81; J851; J852; J93; J958; J960 | |
| Diseases of the digestive system | K250; K251; K252; K253; K254; K255; K256; K257; K259; K260; K261; K263; K264; K265; K266; K269; K550; K65; K720; K810; K859 | |
| Diseases of the musculoskeletal system and connective tissue | M726 | |
| Diseases of the genitourinary system | N00; N04; N10; N17; N390; N990; N998 | No history of diabetes (E10-14) or renal failure (N18-19) |
| Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified | R02; R572; R570; R571 | |
| Injury, poisoning and certain other consequences of external causes | S065; S066; S068; S069; S071; S10-99; T00-T99 | |
| External causes of morbidity and mortality | V00-V99; X60-79; X80-84 | |

Abbreviations: ICD-10: International Classification of Diseases, 10th revision;
*a: Diagnoses codes were captured in the National Patient Register during the period ranging from 5 year before death until death.*

***eTable 7. RECORD Checklist***

| Item No | | Recommendation | Section |
|---|---|---|---|
| **Title and abstract** | 1 | (1)The type of data used should be specified in the title or abstract. When possible, the name of the databases used should be included. | Abstract |
| | | (2) If applicable, the geographic region and timeframe within which the study took place should be reported in the title or abstract. | Abstract |
| | | (3) If linkage between databases was conducted for the study, this should be clearly stated in the title or abstract. | Abstract |
| **Introduction** | | | |
| Background/rationale | 2 | Explain the scientific background and rationale for the investigation being reported | Introduction |
| Objectives | 3 | State specific objectives, including any prespecified hypotheses | Introduction - last paragraph |
| **Methods** | | | |
| Study design | 4 | Present key elements of study design early in the paper | Methods – Study design and population section, Supplementary eFigure 1 |
| Setting | 5 | Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection | Methods – Study design and population section |
| Participants | 6 | (*1*) The methods of study population selection (such as codes or algorithms used to identify subjects) should be listed in detail. If this is not possible, an explanation should be provided. | Methods – Study design and population section |
| | | (*2*) Any validation studies of the codes or algorithms used to select the population should be referenced. If validation was conducted for this study and not published elsewhere, detailed methods and results should be provided. | NA |
| | | (3) If the study involved linkage of databases, consider use of a flow diagram or other graphical display to demonstrate the data linkage process, including the number of individuals with linked data at each stage. | Supplementary eFigure 4 |
| Variables | 7 | A complete list of codes and algorithms used to classify exposures, outcomes, confounders, and effect modifiers should be provided. If these cannot be reported, an explanation should be provided. | Methods – Outcome/Illness trajectories and individual charachteristics/Covariates Supplementary eTable 2-6 |
| Data sources/ measurement | 8* | For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group | Methods – Outcome/Illness trajectories and individual charachteristics/Covariates Supplementary eTable 2-6 |
| Bias | 9 | Describe any efforts to address potential sources of bias | Methods - Outcome |
| Study size | 10 | Explain how the study size was arrived at | Supplementary eFigure 4 |

| | | | |
|---|---|---|---|
| Quantitative variables | 11 | Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why | Methods – Outcome/Illness trajectories and individual charachteristics/Covariates |
| Statistical methods | 12 | (*a*) Describe all statistical methods, including those used to control for confounding | Methods – Statistical analysis |
| | | (*b*) Describe any methods used to examine subgroups and interactions | NA |
| | | (*c*) Explain how missing data were addressed | Table 2, Figure 2 |
| | | (*d*) If applicable, explain how loss to follow-up was addressed | NA |
| | | (*e*) Describe any sensitivity analyses | Methods – Statistical analysis |
| Data access and cleaning methods | | Authors should describe the extent to which the investigators had access to the database population used to create the study population. | Methods – Study design and population |
| | | Authors should provide information on the data cleaning methods used in the study. | NA |
| | | State whether the study included person-level, institutional-level, or other data linkage across two or more databases. The methods of linkage and methods of linkage quality evaluation should be provided. | Methods – Data sources |
| **Results** | | | |
| Participants | 13* | (a) Describe in detail the selection of the persons included in the study (i.e., study population selection) including filtering based on data quality, data availability and linkage. The selection of included persons can be described in the text and/or by means of the study flow diagram. | Supplementary eFigure 4 |
| | | (b) Give reasons for non-participation at each stage | Supplementary eFigure 4 |
| | | (c) Consider use of a flow diagram | Supplementary eFigure 4 |
| Descriptive data | 14* | (a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders | Table 1 |
| | | (b) Indicate number of participants with missing data for each variable of interest | Table 1 |
| | | (c) Summarise follow-up time (eg, average and total amount) | Table 2 |
| Outcome data | 15* | Report numbers of outcome events or summary measures over time | |
| Main results | 16 | (*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included | Table 2, Methods – Statistical analysis |
| | | (*b*) Report category boundaries when continuous variables were categorized | NA |
| | | (*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period | NA |

| | | | |
|---|---|---|---|
| Other analyses | 17 | Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses | Results – Sensitivity analysis |
| **Discussion** | | | |
| Key results | 18 | Summarise key results with reference to study objectives | Discussion – first paragraph |
| Limitations | 19 | Discuss the implications of using data that were not created or collected to answer the specific research question(s). Include discussion of misclassification bias, unmeasured confounding, missing data, and changing eligibility over time, as they pertain to the study being reported. | Discussion – last paragraph |
| Interpretation | 20 | Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence | Discussion first and second paragraphs |
| Generalisability | 21 | Discuss the generalisability (external validity) of the study results | Discussion – last paragraph |
| **Other information** | | | |
| Funding | 22 | Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based | Acknowledgements: Funding |
| Accessibility of protocol, raw data, and programming code | | Authors should provide information on how to access any supplemental information such as the study protocol, raw data, or programming code. | Acknowledgements: Availability of data and materials |

***eTable 8. Fifteen most common main underlying cause of deaths of the decedents of sudden death illness trajectory (N=5700)***

| Main underlying cause of death (ICD-10) | ICD-10 Description | Frequency (N) | Share (%) of total |
|---|---|---|---|
| I21 | Acute myocardial infarction | 862 | 15.12 |
| J18 | Pneumonia, unspecified | 719 | 12.61 |
| I71 | Aortic aneurysm and dissection | 331 | 5.81 |
| A41 | Other sepsis | 288 | 5.05 |
| X59 | Exposure to unspecified factor | 229 | 4.02 |
| W19 | Unspecified fall | 221 | 3.88 |
| I46 | Cardiac arrest | 214 | 3.75 |
| I10 | Essential (primary) hypertension | 144 | 2.53 |
| R68 | Other general symptoms and signs | 138 | 2.42 |
| I26 | Pulmonary embolism | 116 | 2.04 |
| N39 | Urinary tract infection, site not specified | 111 | 1.95 |
| K92 | Other diseases of digestive system | 96 | 1.68 |
| R64 | Cachexia | 93 | 1.63 |
| X70 | Intentional self-harm by hanging, strangulation and suffocation | 89 | 1.56 |
| I48 | Atrial fibrillation and flutter | 82 | 1.44 |

Abbreviations: ICD-10: International Classification of Diseases, 10th revision

***eTable 9. Incidence rate of unplanned hospitalisation by week, stratified by illness trajectory, sex- and age-standardised (direct standardization)***

| Weeks before death | Overall | Cancer | Organ failure | Prolonged dwindling | Sudden death |
|---|---|---|---|---|---|
| 52 | 1.5 | 1.6 | 1.8 | 1.1 | 1.0 |
| 51 | 1.5 | 1.7 | 1.7 | 1.2 | 0.8 |
| 50 | 1.6 | 1.8 | 1.8 | 1.1 | 1.1 |
| 49 | 1.5 | 1.6 | 1.8 | 1.1 | 1.3 |
| 48 | 1.6 | 1.6 | 2.0 | 1.1 | 0.9 |
| 47 | 1.5 | 1.7 | 1.8 | 0.9 | 0.9 |
| 46 | 1.6 | 1.8 | 1.8 | 1.0 | 1.3 |
| 45 | 1.6 | 1.8 | 2.0 | 1.1 | 1.0 |
| 44 | 1.6 | 1.9 | 1.9 | 1.1 | 1.1 |
| 43 | 1.5 | 1.8 | 1.7 | 1.1 | 0.9 |
| 42 | 1.7 | 2.0 | 2.0 | 1.1 | 0.9 |
| 41 | 1.7 | 2.0 | 2.0 | 1.2 | 1.1 |
| 40 | 1.8 | 2.2 | 1.9 | 1.1 | 1.5 |
| 39 | 1.8 | 2.2 | 2.0 | 1.1 | 1.2 |
| 38 | 1.7 | 2.1 | 1.8 | 1.2 | 1.2 |
| 37 | 1.8 | 2.1 | 2.0 | 1.2 | 1.3 |
| 36 | 1.9 | 2.3 | 2.1 | 1.2 | 1.2 |
| 35 | 1.8 | 2.2 | 2.1 | 1.1 | 1.2 |
| 34 | 1.8 | 2.4 | 2.1 | 1.1 | 1.0 |
| 33 | 1.9 | 2.5 | 2.0 | 1.3 | 1.1 |
| 32 | 1.9 | 2.3 | 2.3 | 1.3 | 1.1 |
| 31 | 1.9 | 2.6 | 1.9 | 1.2 | 1.1 |
| 30 | 2.0 | 2.4 | 2.3 | 1.4 | 1.2 |
| 29 | 2.0 | 2.6 | 2.1 | 1.2 | 1.3 |
| 28 | 2.0 | 2.7 | 2.2 | 1.1 | 1.2 |
| 27 | 2.1 | 2.7 | 2.3 | 1.3 | 1.3 |
| 26 | 2.1 | 2.8 | 2.3 | 1.2 | 1.2 |
| 25 | 2.2 | 2.8 | 2.4 | 1.3 | 1.2 |
| 24 | 2.3 | 3.2 | 2.4 | 1.3 | 1.6 |
| 23 | 2.3 | 3.2 | 2.6 | 1.3 | 1.3 |
| 22 | 2.3 | 3.1 | 2.5 | 1.4 | 1.7 |
| 21 | 2.5 | 3.6 | 2.7 | 1.5 | 1.3 |
| 20 | 2.5 | 3.4 | 2.8 | 1.4 | 1.5 |
| 19 | 2.8 | 3.7 | 3.1 | 1.6 | 1.7 |
| 18 | 2.8 | 3.9 | 3.1 | 1.6 | 1.6 |
| 17 | 2.9 | 3.9 | 3.2 | 1.6 | 1.7 |
| 16 | 3.1 | 4.6 | 3.2 | 1.6 | 1.7 |
| 15 | 3.2 | 4.7 | 3.3 | 1.8 | 1.8 |
| 14 | 3.4 | 5.2 | 3.6 | 1.7 | 1.8 |
| 13 | 3.6 | 5.5 | 3.7 | 1.7 | 2.2 |
| 12 | 3.9 | 6.1 | 3.8 | 2.0 | 2.3 |
| 11 | 4.1 | 6.5 | 4.1 | 2.1 | 2.1 |
| 10 | 4.5 | 7.1 | 4.4 | 2.3 | 2.4 |
| 9 | 4.8 | 7.5 | 4.8 | 2.4 | 2.8 |
| 8 | 5.2 | 8.2 | 5.2 | 2.7 | 2.8 |
| 7 | 5.9 | 9.3 | 6.0 | 3.0 | 3.1 |

| Weeks before death | Overall | Cancer | Organ failure | Prolonged dwindling | Sudden death |
|---|---|---|---|---|---|
| 6 | 6.7 | 10.8 | 6.6 | 3.4 | 3.3 |
| 5 | 7.9 | 12.9 | 7.7 | 4.2 | 4.5 |
| 4 | 9.2 | 14.4 | 9.2 | 4.9 | 5.6 |
| 3 | 11.3 | 16.9 | 12.2 | 5.7 | 8.4 |
| 2 | 15.3 | 20.2 | 18.7 | 7.6 | 12.9 |
| 1 | 26.2 | 24.2 | 38.0 | 11.0 | 43.9 |

***eTable 10. Proportion of decedents with ≥1 unplanned hospitalisation during each of the 52 weeks before death, stratified by illness trajectory***

| | | Illness trajectory | | | |
|---|---|---|---|---|---|
| **Weeks before death** | **Overall (%) N= 77 315** | **Cancer (%) N= 23 213** | **Organ failure (%) N= 28 338** | **Prolonged dwindling (%) N= 20 064** | **Sudden death (%) N= 5 700** |
| 52 | 1.47 | 1.56 | 1.78 | 1.08 | 0.98 |
| 51 | 1.42 | 1.61 | 1.58 | 1.16 | 0.82 |
| 50 | 1.50 | 1.71 | 1.75 | 1.03 | 1.07 |
| 49 | 1.46 | 1.51 | 1.71 | 1.10 | 1.26 |
| 48 | 1.51 | 1.56 | 1.88 | 1.11 | 0.91 |
| 47 | 1.44 | 1.68 | 1.75 | 0.90 | 0.86 |
| 46 | 1.51 | 1.75 | 1.76 | 0.93 | 1.28 |
| 45 | 1.55 | 1.75 | 1.90 | 0.99 | 1.00 |
| 44 | 1.57 | 1.84 | 1.82 | 1.06 | 1.05 |
| 43 | 1.48 | 1.73 | 1.67 | 1.08 | 0.91 |
| 42 | 1.63 | 1.93 | 1.93 | 1.08 | 0.86 |
| 41 | 1.64 | 1.95 | 1.87 | 1.13 | 1.05 |
| 40 | 1.69 | 2.13 | 1.84 | 1.04 | 1.37 |
| 39 | 1.72 | 2.09 | 1.98 | 1.10 | 1.16 |
| 38 | 1.64 | 2.04 | 1.75 | 1.16 | 1.12 |
| 37 | 1.70 | 2.03 | 1.91 | 1.13 | 1.28 |
| 36 | 1.80 | 2.22 | 2.07 | 1.13 | 1.11 |
| 35 | 1.72 | 2.09 | 2.01 | 1.06 | 1.14 |
| 34 | 1.76 | 2.26 | 2.00 | 1.04 | 1.02 |
| 33 | 1.81 | 2.33 | 1.93 | 1.26 | 1.00 |
| 32 | 1.85 | 2.20 | 2.20 | 1.18 | 1.02 |
| 31 | 1.81 | 2.47 | 1.87 | 1.20 | 1.05 |
| 30 | 1.92 | 2.30 | 2.18 | 1.34 | 1.14 |
| 29 | 1.90 | 2.52 | 2.00 | 1.18 | 1.35 |
| 28 | 1.91 | 2.58 | 2.14 | 1.01 | 1.12 |
| 27 | 1.98 | 2.57 | 2.16 | 1.26 | 1.28 |
| 26 | 2.01 | 2.71 | 2.20 | 1.18 | 1.16 |
| 25 | 2.07 | 2.75 | 2.30 | 1.21 | 1.18 |
| 24 | 2.20 | 3.02 | 2.33 | 1.25 | 1.60 |
| 23 | 2.23 | 3.04 | 2.48 | 1.22 | 1.19 |
| 22 | 2.21 | 2.96 | 2.37 | 1.31 | 1.54 |
| 21 | 2.42 | 3.38 | 2.54 | 1.45 | 1.32 |
| 20 | 2.40 | 3.25 | 2.66 | 1.31 | 1.46 |
| 19 | 2.61 | 3.46 | 2.87 | 1.53 | 1.63 |
| 18 | 2.67 | 3.67 | 2.89 | 1.53 | 1.58 |
| 17 | 2.72 | 3.64 | 3.01 | 1.57 | 1.63 |
| 16 | 2.90 | 4.25 | 3.02 | 1.50 | 1.70 |
| 15 | 3.04 | 4.39 | 3.17 | 1.70 | 1.67 |
| 14 | 3.21 | 4.78 | 3.31 | 1.68 | 1.75 |
| 13 | 3.34 | 5.02 | 3.40 | 1.66 | 2.09 |
| 12 | 3.62 | 5.47 | 3.60 | 1.94 | 2.16 |
| 11 | 3.80 | 5.81 | 3.81 | 1.98 | 1.98 |
| 10 | 4.12 | 6.29 | 4.09 | 2.17 | 2.28 |

| | | Illness trajectory | | | |
|---|---|---|---|---|---|
| **Weeks before death** | **Overall (%) N= 77 315** | **Cancer (%) N= 23 213** | **Organ failure (%) N= 28 338** | **Prolonged dwindling (%) N= 20 064** | **Sudden death (%) N= 5 700** |
| 9 | 4.37 | 6.55 | 4.36 | 2.34 | 2.67 |
| 8 | 4.72 | 7.02 | 4.76 | 2.62 | 2.54 |
| 7 | 5.29 | 7.91 | 5.29 | 2.90 | 2.96 |
| 6 | 5.89 | 8.92 | 5.91 | 3.15 | 3.04 |
| 5 | 6.87 | 10.25 | 6.70 | 3.93 | 4.30 |
| 4 | 7.68 | 10.93 | 7.77 | 4.53 | 5.02 |
| 3 | 9.19 | 12.16 | 9.97 | 5.19 | 7.30 |
| 2 | 11.74 | 13.32 | 14.22 | 6.76 | 10.53 |
| 1 | 17.96 | 14.22 | 24.48 | 9.40 | 30.95 |

***eTable 11. Frequency of trajectories distribution after removing decedents with potentially unexpected cause of death compared to the study population***

| | Overall | Decedents with potentially unexepected cause of death excluded | |
|---|---|---|---|
| | | N | % |
| **Overall** | 77 315 | 42 760 | 55.3 |
| **Trajectories** | | | |
| Cancer | 23 213 | 17 305 | 74.6 |
| Organ failure | 28 338 | 12 844 | 45.3 |
| Prolonged dwindling | 20 064 | 11 437 | 57.0 |
| Sudden death | 5 700 | 1 174 | 20.6 |

***eTable 12. Incidence rate of unplanned hospitalisation during the last year of life by illness trajectory and rate ratios compared to the overall population, decedents with potentially unexpected cause of death are removed***

| | No. decedents | Unplanned hospitalisation | | Number of person-years | Incidence rate per 100 person-years | Incidence rate ratio[a] | |
|---|---|---|---|---|---|---|---|
| | | No. events | Mean | | | Unadjusted | Adjusted[b] |
| **Overall[c]** | 42 760 | 73 108 | 1.71 | 40 413 | 180.9 | 1.0 (Ref) | 1.0 (Ref) |
| **Trajectories** | | | | | | | |
| Cancer | 17 305 | 36 898 | 2.13 | 15 961 | 231.2 | 1.18 (1.16-1.2) | 1.13 (1.12-1.15) |
| Organ failure | 12 844 | 25 518 | 1.99 | 12 119 | 210.6 | 1.12 (1.1-1.15) | 1.09 (1.06-1.11) |
| Prolonged dwindling | 11 437 | 9 312 | 0.81 | 11 196 | 83.2 | 0.46 (0.45-0.48) | 0.57 (0.56-0.59) |
| Sudden death | 1 174 | 1 380 | 1.18 | 1 136 | 121.4 | 0.65 (0.61-0.7) | 0.73 (0.69-0.78) |

*a: Robust standard errors were used to estimate the confidence intervals; incidence rate ratio obtained from zero-inflated Poisson models*

*b: Adjusted for sex, age, education, marital status, frailty, number of chronic diseases, polypharmacy; Decedents with missing education variable information (1.95 % of total number of decedents without unexpected cause of death) were excluded from the adjusted analysis.*

*c: The total study population was used as the reference category to compare the risks across illness trajectories to the average risk in the cohort.*

***eTable 13. Crude Incidence rate of unplanned hospitalisation by week, stratified by illness trajectories in the last year of life, decedents with potentially unexpected cause of death are removed***

| | | Incidence Rate per 100 Patient weeks | | | |
|---|---|---|---|---|---|
| **Weeks before death** | **Overall** | **Cancer** | **Organ failure** | **Prolonged dwindling** | **Sudden death** |
| 52 | 1.5 | 1.6 | 2.0 | 1.1 | 1.0 |
| 51 | 1.5 | 1.7 | 1.8 | 1.1 | 0.7 |
| 50 | 1.6 | 1.7 | 1.9 | 1.0 | 1.0 |
| 49 | 1.5 | 1.5 | 2.0 | 1.0 | 1.4 |
| 48 | 1.6 | 1.7 | 2.2 | 1.0 | 0.8 |
| 47 | 1.5 | 1.7 | 1.9 | 0.9 | 0.8 |
| 46 | 1.6 | 1.7 | 2.0 | 0.9 | 1.3 |
| 45 | 1.7 | 1.8 | 2.1 | 0.9 | 1.0 |
| 44 | 1.7 | 1.9 | 2.0 | 1.0 | 0.8 |
| 43 | 1.6 | 1.8 | 1.9 | 1.0 | 1.2 |
| 42 | 1.8 | 2.0 | 2.4 | 1.0 | 0.8 |
| 41 | 1.8 | 2.1 | 2.1 | 1.0 | 1.0 |
| 40 | 1.9 | 2.2 | 2.2 | 1.0 | 1.4 |
| 39 | 1.9 | 2.2 | 2.2 | 1.1 | 1.6 |
| 38 | 1.9 | 2.2 | 2.1 | 1.2 | 1.1 |
| 37 | 1.8 | 2.2 | 2.1 | 1.0 | 1.1 |
| 36 | 2.0 | 2.3 | 2.4 | 1.1 | 1.3 |
| 35 | 1.9 | 2.2 | 2.2 | 1.0 | 1.6 |
| 34 | 2.0 | 2.4 | 2.4 | 1.0 | 0.9 |
| 33 | 2.0 | 2.5 | 2.3 | 1.1 | 1.1 |
| 32 | 2.0 | 2.3 | 2.6 | 1.1 | 1.7 |
| 31 | 2.1 | 2.6 | 2.3 | 1.2 | 1.6 |
| 30 | 2.1 | 2.5 | 2.5 | 1.3 | 1.4 |
| 29 | 2.1 | 2.8 | 2.3 | 1.0 | 1.4 |
| 28 | 2.1 | 2.7 | 2.5 | 1.0 | 1.1 |
| 27 | 2.2 | 2.7 | 2.6 | 1.1 | 1.1 |
| 26 | 2.3 | 2.9 | 2.6 | 1.1 | 1.0 |
| 25 | 2.4 | 3.0 | 2.7 | 1.2 | 1.2 |
| 24 | 2.5 | 3.3 | 2.7 | 1.2 | 1.9 |
| 23 | 2.5 | 3.1 | 3.0 | 1.1 | 1.2 |
| 22 | 2.5 | 3.3 | 2.9 | 1.2 | 1.7 |
| 21 | 2.7 | 3.6 | 3.0 | 1.3 | 1.3 |
| 20 | 2.7 | 3.5 | 3.0 | 1.2 | 1.6 |
| 19 | 3.0 | 3.8 | 3.5 | 1.5 | 2.1 |
| 18 | 3.1 | 4.1 | 3.4 | 1.4 | 1.8 |
| 17 | 3.2 | 4.0 | 3.7 | 1.5 | 2.3 |
| 16 | 3.5 | 4.8 | 3.8 | 1.5 | 1.5 |
| 15 | 3.6 | 4.8 | 3.9 | 1.6 | 1.6 |
| 14 | 3.8 | 5.4 | 4.0 | 1.5 | 2.2 |

| | Incidence Rate per 100 Patient weeks | | | | |
|---|---|---|---|---|---|
| **Weeks before death** | **Overall** | **Cancer** | **Organ failure** | **Prolonged dwindling** | **Sudden death** |
| 13 | 4.0 | 5.7 | 4.2 | 1.6 | 2.0 |
| 12 | 4.3 | 6.4 | 4.2 | 1.9 | 1.8 |
| 11 | 4.7 | 6.9 | 4.8 | 1.8 | 2.5 |
| 10 | 5.1 | 7.5 | 5.0 | 2.0 | 2.3 |
| 9 | 5.3 | 7.8 | 5.2 | 2.2 | 3.2 |
| 8 | 5.9 | 8.7 | 5.9 | 2.4 | 2.5 |
| 7 | 6.5 | 9.7 | 6.4 | 2.7 | 2.7 |
| 6 | 7.6 | 11.4 | 7.8 | 3.0 | 2.8 |
| 5 | 8.6 | 13.4 | 8.2 | 3.3 | 4.3 |
| 4 | 9.6 | 14.8 | 9.4 | 3.8 | 5.4 |
| 3 | 11.0 | 16.7 | 11.9 | 4.1 | 7.9 |
| 2 | 13.6 | 18.5 | 18.1 | 4.6 | 9.5 |
| 1 | 19.1 | 18.8 | 35.0 | 5.5 | 29.8 |

***eTable 14. Zero-inflated Poisson versus Poisson models' incidence rate ratios of unplanned hospitalisation by illness trajectory compared to the overall population***

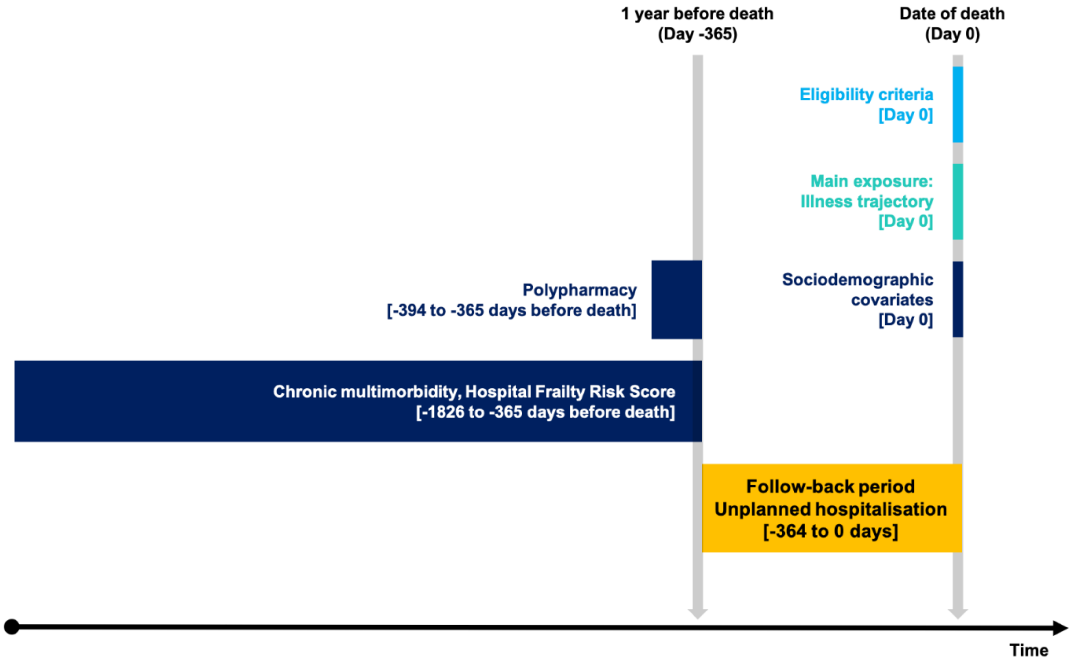
| | Adjusted incidence rate ratio[a] | |
|---|---|---|
| | **ZIP model[b]** | **Poisson model** |
| **Overall[c]** | 1.0 (Ref) | 1.0 (Ref) |
| **Trajectories** | | |
| Cancer | 1.2 (1.18-1.21) | 1.24 (1.23-1.26) |
| Organ failure | 1.04 (1.03-1.06) | 1.05 (1.03-1.06) |
| Prolonged dwindling | 0.66 (0.65-0.68) | 0.65 (0.64-0.67) |
| Sudden death | 0.79 (0.77-0.82) | 0.8 (0.77-0.82) |
| **Akaike information criterion** | 539 677 | 546 423 |

*a: Adjusted for sex, age, education, marital status, frailty, number of chronic diseases, polypharmacy; Decedents with missing education variable information (2.1% of total) were excluded from the analysis; Robust standard errors were used to estimate the confidence intervals*

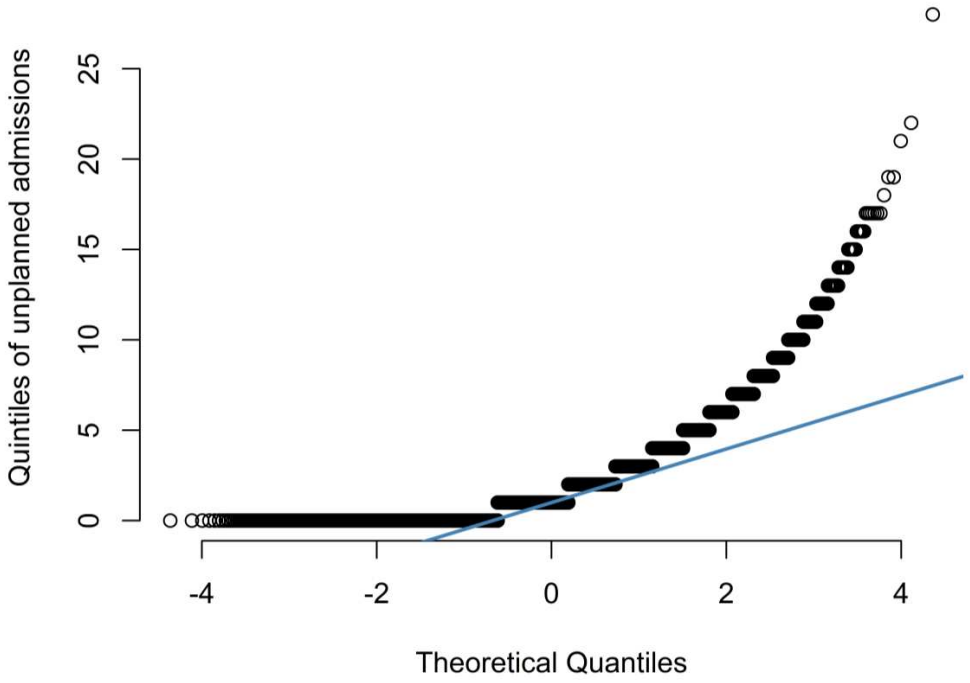
*b: Zero-inflated Poisson regression*

*c: The total study population was used as the reference category to compare the risks across illness trajectories to the average risk in the cohort.*

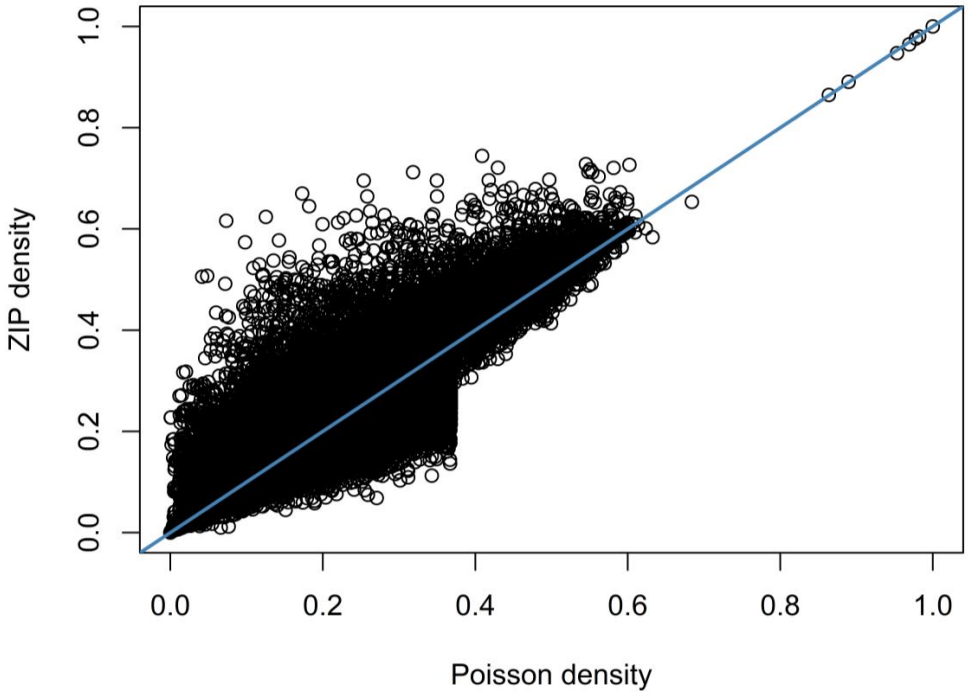
***eFigure 1. Illustration of the study design***



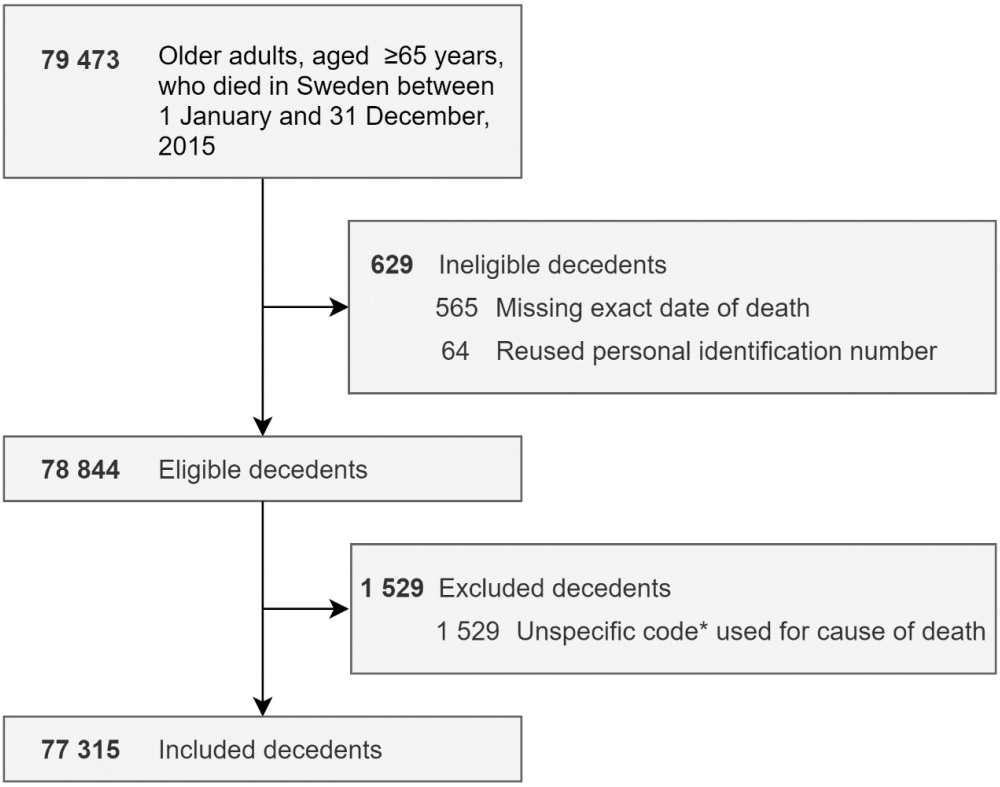
***eFigure 2. Normal quintiles-quintiles plot of the number of unplanned admission throughout the entire last year of life***



***eFigure 3. Fitted probabilities under Zero-inflated Poisson and Poisson models plotted against each other***

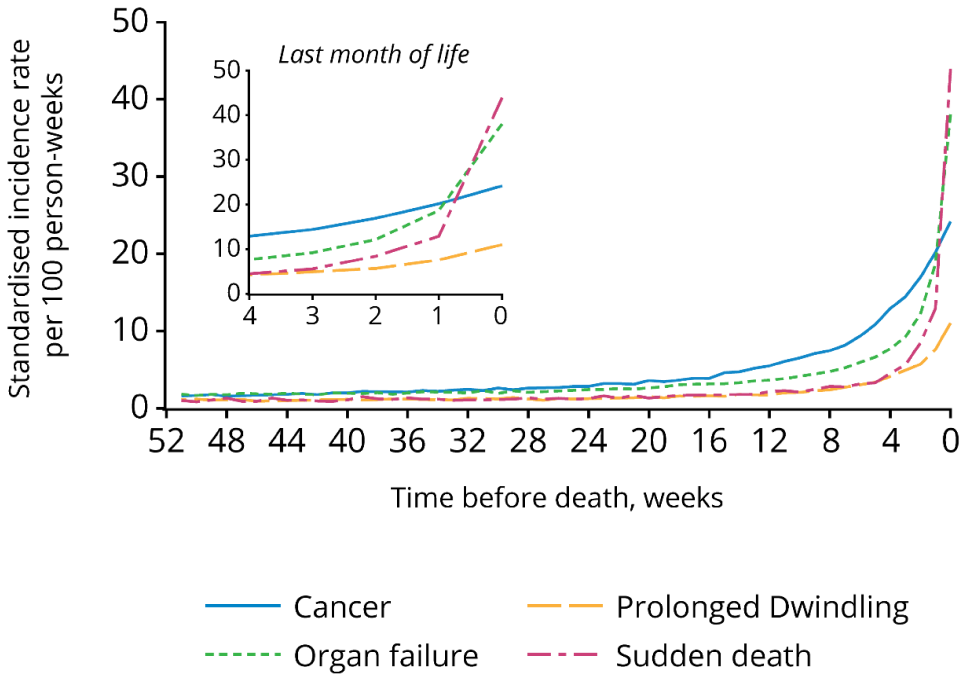


***eFigure 4. Flowchart diagram***




*Unspecific ICD-10 codes are B99, R96, R98, and R99

***eFigure 5. Incidence rate of unplanned hospitalisation by week, stratified by illness trajectories in the last year of life, sex- and age-standardised (direct standardization).***



***eFigure 6. Crude Incidence rate of unplanned hospitalisation by week, stratified by illness trajectories in the last year of life, decedents with potentially unexpected cause of death are removed***