A population-based study of patients in Danish hospitals who are in their last year of life

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ABSTRACT

INTRODUCTION: Little is known about the prevalence and distribution in Denmark of hospital inpatients who are in their last year of life. Knowledge about these patients could attract attention towards needs for their identification and for optimisation of end-of-life care initiatives. The aims of this study were to determine the proportion of prevalent inpatients who died during the following 12 months, to present characteristics among deceased and survivors, and to identify in which hospitals, departments or specialities imminently dying patients appear most frequently. METHODS: This was a record-linkage cohort study of all patients, who were in public somatic hospitals in Denmark on 10 April 2013. Patients were followed for one year. RESULTS: A total of 13,412 inpatients were resident in 26 Danish hospitals on 10 April 2013 (range: 1,173-106 patients per hospital). 22% died during the one-year follow-up (range: 17-37% per hospital. 24% men, 20% women); 27% in medical, 15% in surgical and 50% in oncological/haematological departments. The median time to death was 59 days (54/66 days for women/men). 61% died in hospital. Deceased patients were older than survivors (76 versus 64 years, median) and had longer hospital index-stays (13 versus six days, median), 25% of the deceased (n = 740) died during the index episode, corresponding to 5.5% of all the prevalent

CONCLUSIONS: More than one in five inpatients in Danish hospitals are imminently dying or in their last year of life. Knowledge of the patients' uneven distribution in the hospital system can underpin organisational strategies to focus on end-of-life care provision.

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Place of death has increasingly become an important outcome measure in end-of-life care [1]. In Denmark, 43% of all deaths occur in hospitals [2]. In the year prior to death, many people experience one or more hospital admissions [3, 4]. However, very little is known about the prevalence of patients in Danish hospitals wards who are in their last year of life. In this study, we investigated the quantity and characteristics of inpatients in Danish hospitals who die within one year. Specifically, we studied where they are located within the hospitals, and whether they die inside or outside the hospital.

Two similar studies were performed in Scotland [5] and in New Zealand [6]. In this study of hospitalised patients in Denmark, we used the same population-based cohort design and study dates.

The aims of this study were 1) to determine the proportion of inpatients on a given date who died within 12 months, and 2) to describe characteristics of deceased and surviving inpatients and 3) to identify in which hospitals, departments or specialities these patients appear most frequently.

METHODS

The study was a nationwide cohort study using record linkage between national healthcare and death registration registries.

The cohort

The cohort included all patients in Denmark who were in public somatic hospitals or were admitted on the index date, Wednesday 10 April 2013, and stayed overnight. The patients were followed for one year with regard to death, based on a statement by the NHS in United Kingdom, saying: "people are considered to be approaching the end of life when they are likely to die within the next 12 months" [7]. Excluded were: 1) patients in private hospitals and hospices on the index date, 2) patients entering and leaving the hospital on the index date (in-date and out-date both 10 April 2013) and 3) patients in obstetric sections in gynaecological-obstetric departments on the index date (obstetric patients are primarily healthy women giving birth).

Public somatic hospitals in Denmark

The number of public somatic hospitals in Denmark was determined using an official classification code (the SOK code) registering both public and private hospitals, which report their activities to the Danish National Patient Registry. In 2013, 26 public somatic hospital units were identified, with an official number of 12,894 available somatic beds and 2,955 psychiatric beds [8]. In Denmark, a large majority of secondary health care is provided by public hospitals [9]. There are few private hospitals, and these are small and treat a limited number of diagnoses. Only 2.4% of all hospitalisations in Denmark in 2010 were in private hospitals [10]. The mean duration of hospital admissions in 2013 was 3.8 days [11].

ORIGINAL ARTICLE

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TABLE 1 / Patients prevalent in Danish hospitals at the index date: demographic data, length of index episode, and survivorship.

| Deceased within 1 yr aft | er the index date |
|--------------------------|-------------------|
|--------------------------|-------------------|

| | All in the cohort | | Survivors | | all deceased | | dead in hospital | | | dead outside hospital | | | | | |
|---|--------------------------------|----------------------------|---------------------------|--------------------------------|---------------------------|--------------------------------|----------------------------|----------------------------|----------------------------|----------------------------------|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|
| | all | women | men | all | women | men | all | women | men | all | women | men | all | women | men |
| Patients, n | 13,412 | 6,786 | 6,626 | 10,465 | 5,410 | 5,055 | 2,947 | 1,376 | 1,571 | 1,807 | 816 | 991 | 1,140 | 560 | 580 |
| Speciality*, % of patients Medical Surgical Oncological/haematological Other | 49 36 5 | 48 37 5 10 | 51 34 5 | 46 39 3 | 45 41 3 | 48 37 3 11 | 60 24 12 4 | 60 23 12 4 | 60 25 12 4 | 58 25 13 5 | 57 24 13 5 | 58 25 13 5 | 64 23 10 3 | 64 22 10 3 | 63 24 11 2 |
| | | | | | 110 | | - | • | • | | | | | | |
| Total | 100 | 100 | 100 | 100 | 100 | 100 | 100 | 100 | 100 | 100 | 100 | 100 | 100 | 100 | 100 |
| Age of patients in speciality, yrs, median Medical Surgical Oncological/haematological Other All specialities Index episode, duration, days, median | 71 65 66 8 67 8 | 74 64 66 11 68 | 69 65 66 6 66 | 69 63 64 6 64 6 | 71 62 64 8 65 | 67 64 65 5 63 7 | 78 75 68 66 76 | 81 79 68 69 78 | 76 73 68 63 73 | 76 73 67 62 74 14 | 79 76 66 64 76 | 74 71 67 59 72 | 81 78 70 77 79 | 83 82 71 77 82 | 78 75 69 74 76 |
| Time from index date to death, days, median | - | - | - | - | - | - | 59 | 54 | 66 | 44 | 41 | 48 | 86 | 77 | 95 |

a) Referring to the speciality of the department, where the 1st index record was registered.

Registries

Admission records were drawn from the Danish National Patient Registry (DNPR) [12]. For each patient contact, the registry holds data on the patient's Civil Personal Register (CPR) number (a unique ten-digit number provided to all persons residing in Denmark), admission date, discharge date, hospital, department, along with one primary and one optional secondary diagnosis according to the International Classification of Diseases, version 10 (ICD-10).

For each patient, all registrations in the DNPR from public somatic hospitals were drawn from one year prior to one year after the index date (10 April 2012 to 9 April 2014). Using the CPR number, data from the DNPR were linked with data from three other population-based registries as part of a larger study: the Civil Registration System [13], the Danish Cause of Death Register [14] and the Danish Cancer Registry [15].

Admission episodes

During a hospital stay, a patient may be transferred from one department to another. In the DNPR records, each department has its own admission and discharge date registered. In this study, hospitalisations are termed "admission episodes". The duration of an episode counts from the patient's first admission date in hospital to the discharge date, where no other department's admission date overlaps. Hence, the index episode refers to a patient's continuous and unbroken hospital stay, which includes 10 April 2013, the index date.

Statistical analyses

Explanatory variables were drawn from the datasets and presented using descriptive statistics made in Stata 14. The variables were: gender, age, speciality of admission, survival status and death in- or outside the hospital. The time variable used ("days to death") was the number of days from the index date to the date of death, up to one year from the index date. Proportions among binominal events are presented with 95% confidence intervals (CI).

Trial registration: not relevant.

RESULTS

At the index date, 13,412 inpatients were registered in 26 public somatic hospitals in Denmark. Within one year, 22% (95% CI: 21.3-22.7) of the patients had died, 20% (95% CI: 19.3-21.3) of the women and 24% (95% CI: 22.7-24.8) of the men. During the index episode 740 patients died, corresponding to 25% (95% CI: 23.6-26.7) of the deceased and to 5.5% (95% CI: 5.1-5.9) of all prevalent inpatients. Place of death was in the hospital for 61% (95% CI: 59.5-63.1) of the deceased. The patients' demographic data are shown in Table 1 distributed by type of speciality, length of index episode and time from the index date to death.

Age and sex

The population of inpatients had a median age of 67 years (interquartile range (IQR): 51-78) and 37% were

younger than 60 years, whereas 21% were 80 years or older. Among the deceased, 37% were 80 years or older, whereas 14% were younger than 60 years. Deceased patients were older than survivors with a median age of 76 years and 64 years, respectively. Patients who died outside hospital were older than those who died in a hospital department with median ages of 79 years (IQR: 69-87) and 74 years (IQR: 64-82), respectively (Table 1). The low median age of eight years (IQR: 0.4-53) in the "other" group was explained by the fact that 54% of the patients in this group came from paediatric departments (Table 1).

Deceased women were generally older than deceased men with the largest differences observed in the medical and surgical specialities (Table 1). In the oncology/haematology departments, there was almost no difference in age between men and women (Table 1). Hospitals with older inpatient populations also tended to have a higher proportion of deceased (Table 2).

The index episode

The median duration of the index episode was eight days (IQR: 3-20) and the mean duration was 18 days. The median duration of the survivors' index episode was around half as long (six days, IQR: 2-17) as for the deceased patients (13 days, IQR: 7-26). No marked differences were observed between women and men. The median duration of the index episode among the 740 patients who died during their index episode was 19 days (IQR: 9-37).

At least 38% of all patients experienced one or more transfers between departments during their index episode. Among the 740 patients who died during their index episode, 67% experienced at least one transfer and 35% experienced two or more transfers between departments.

Days from the index date to death

The median number of days from the index date to death (DTOD) was 59 days (IQR: 18-167), and the mean number was 101 days. For patients who died outside the hospital, the DTOD was 86 days (IQR: 33-206) compared with 44 days (IQR: 11-141) among those who died in the hospital. Men had a slightly longer DTOD than women, regardless of whether they died inside or outside the hospital (Table 1). In the sub-group of 740 patients who died in hospital during the index episode, the DTOD was eight days (IQR: 3-20).

Hospitals

Due to large variations in the size of hospitals in Denmark, the number of inpatients present on the index date also varied considerably (range: 1,173 to 106 patients per hospital). The proportion of deceased patients in each hospital showed less variation (range:

TABLE 2 / Number of inpatients in the hospitals at the index date and the patients' median age sorted by proportions of deceased.

| | | | Age at in | Age at index date, yrs, median | | | | |
|-------------|---------------|-----------------|-----------|--------------------------------|-----------|--|--|--|
| Hospital ID | Inpatients, n | Deceased, n (%) | all | deceased | survivors | | | |
| 1 | 120 | 45 (38) | 78 | 80 | 77 | | | |
| 2 | 116 | 37 (32) | 78 | 82 | 75 | | | |
| 3 | 513 | 141 (27) | 71 | 80 | 68 | | | |
| 4 | 750 | 195 (26) | 69 | 75 | 67 | | | |
| 5 | 873 | 225 (26) | 70 | 78 | 67 | | | |
| 6 | 106 | 27 (25) | 70 | 81 | 68 | | | |
| 7 | 446 | 113 (25) | 69 | 77 | 65 | | | |
| 8 | 264 | 66 (25) | 75 | 82 | 71 | | | |
| 9 | 491 | 122 (25) | 70 | 76 | 67 | | | |
| 10 | 130 | 32 (25) | 66 | 78 | 63 | | | |
| 11 | 993 | 239 (24) | 69 | 74 | 67 | | | |
| 12 | 402 | 92 (23) | 70 | 78 | 66 | | | |
| 13 | 177 | 40 (23) | 75 | 81 | 72 | | | |
| 14 | 240 | 54 (23) | 67 | 79 | 63 | | | |
| 15 | 1,173 | 259 (22) | 67 | 76 | 64 | | | |
| 16 | 291 | 63 (22) | 67 | 79 | 63 | | | |
| 17 | 322 | 69 (21) | 68 | 79 | 64 | | | |
| 18 | 404 | 86 (21) | 67 | 79 | 61 | | | |
| 19 | 291 | 60 (21) | 69 | 74 | 68 | | | |
| 20 | 560 | 115 (21) | 63 | 74 | 60 | | | |
| 21 | 762 | 154 (20) | 68 | 76 | 66 | | | |
| 22 | 309 | 58 (19) | 67 | 79 | 65 | | | |
| 23 | 594 | 109 (18) | 65 | 76 | 63 | | | |
| 24 | 851 | 156 (18) | 64 | 74 | 60 | | | |
| 25 | 1,165 | 211 (18) | 63 | 71 | 59 | | | |
| 26 | 1,069 | 179 (17) | 56 | 64 | 53 | | | |
| Total | 13,412 | 2,947 (22) | 67 | 76 | 64 | | | |

17% to 38%) (Table 2). The median age among the patients in each hospital varied between 78 years and 56 years (Table 2). The table shows a tendency for the hospitals with the oldest patient populations to have the highest proportions of deceased patients.

Specialities involved

The specialities involved in the patients' first admissions during the index episodes were categorised into four main groups; medical, surgical, oncological/haematological, and other. The proportion of deceased within one year in medical departments was 27% (95% CI: 25.6-27.8) (n = 1,770), compared to 15% (95% CI: 13.8-15.9) (n = 713) in the surgical departments. The oncology/haematology departments had the highest proportion of deaths within one year, with 50% (95% CI: 46.2-53.8) (n = 352), while the "other" group of specialities had 9% (95% CI: 7.9-10.5) (n = 112) of deaths.

Within each of the four main groups, the proportion of inpatients who died differed significantly between the different specialities (**Figure 1**). The highest pro-

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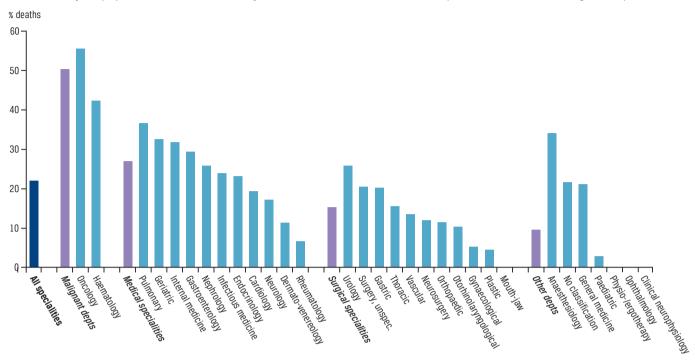


FIGURE 1 / The proportions of deceased within one year after the index date in the different sub-specialities in the four main categories of specialities.

portions were 56% (95% CI: 50.6-60.5) in oncology departments, 36% (95% CI: 31.9-41.6) in lung departments, 33% (95% CI: 24.2-45.2) in anaesthesiology departments and 26% (95% CI: 21.8-30.4) in urology departments.

Diagnoses of action on the index admissions

At the index admission, three groups of diagnoses accounted for 35% (95% CI: 34.3-35.9) of the prevalent inpatients; 13% circulatory diseases (95% CI: 12.0-13.2), 12% respiratory diseases (95% CI: 11.8-12.9) and 10% cancer (95% CI: 9.6-10.6) (**Table 3**). The patients in these three groups covered 49% (95% CI: 46.8-50.4) of deaths in the study, of which two thirds occurred in hospital. In Table 3, the diagnoses are ranked according to the proportion of deceased inpatients. Diagnoses where 20% or more of patients died are shown in the table. "Other diagnoses" are the diagnoses where less than 20% died.

DISCUSSION

In this population-based study, one in five patients in Danish somatic hospitals on a specific day had died one year later. Half of the deceased patients died within two months of the index date, and one in four died during the index episode. Six out of ten patients died in a hospital department. Hospitals and specialities with older patients had higher proportions of deceased patients. Overall, medical specialities had higher propor-

tions of deceased patients than surgical specialities did. Nevertheless, there were notably large differences in the sub-specialities' proportions of deaths within each category of specialities. The results suggest that some departments should have increased vigilance towards their patients' needs for end-of-life care. The most frequent underlying diseases of deceased patients were respiratory and circulatory diseases and cancer. Hospitalised patients with these diagnoses often experience trajectories characteristic of chronic and progressive diseases leading to death. The results suggest that hospital admissions could provide relevant opportunities for identification of palliative care needs and for discussions about preferred treatment options for the patients' underlying disease and their wishes for endof-life care and place of death. Discussions which also point to the importance that the hospital staff are aware and knowledgeable of the possibilities for endof-life care provided by general practitioners and municipalities.

The Danish result adds to results from Scotland and New Zealand using the same study design and index date. In Scotland, two studies have shown that 30% of a cohort of hospital inpatients on a given date died within 12 months [5, 16], while in New Zealand the corresponding figure was 15% [6]. Due to legal and data protection barriers, we were unable to perform direct comparisons between the three countries. Therefore, we could not reveal to which extent the dif-

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ferences in inpatient populations and/or healthcare systems may add to the observed differences. However, in all three studies, age appeared to be a major predictor of death within one year from the index date.

Despite providing unique new insights, the study has several weaknesses. The design of the study did not allow for discrimination between patients who died suddenly, and those who followed longer disease trajectories before dying, which is the usual target group for palliative care. However, in the World Health Organization European Region, chronic diseases account for around 80% of deaths [17], and in Denmark the three major causes of death - cardiovascular diseases, cancer and respiratory diseases - account for 60% of deaths [18]. The index date was in April 2013. We have no knowledge of factors implemented in the Danish health care system in the interim, which might have changed the relevance of our results, and we were unable to identify other Danish studies for comparison. In 2013, the proportion of patients who died in hospital was 45% [18] compared with 43% in the latest figures from the Danish Cause of Death Register [2].

We have no information about the individual patients' end-of-life care needs in this study. Our assumptions about these needs are therefore extrapolations based on the knowledge of the patients' time to death from the index date, and they are therefore ecological in nature [19]. The strength of the study is the population-based approach using valid databases and the fact that almost all Danish inpatients use the publicly financed healthcare system with free access to hospital treatment [10, 20]. The number of inpatients registered on the index date was slightly larger than the official number of available somatic hospital beds. We interpret this to be a result of hospital overcrowding.

CONCLUSIONS

This study identified one in five patients in Danish somatic hospitals on a specific day had died one year later. The results suggest that hospital admissions can provide opportunities for palliative care advocacy, endof-life care planning and treatment modifications for patients with advanced diseases in order to accommodate patients' and relatives' wishes for end-of-life care and place of death where possible.

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TABLE 3 / Diagnoses at the index admission: distribution, proportions of deceased and proportions of deceased dying in hospital.

| | n (% of deceased) | | | | | |
|----------------------|-------------------|----------|--|--|--|--|
| ceased, % of all) | no | VOC | | | | |
| | | yes | | | | |
| 544 (40) | 201 | 343 (63) | | | | |
| 538 (32) | 199 | 339 (63) | | | | |
| 49 (31) | 26 | 23 (47) | | | | |
| 84 (31) | 66 | 118 (64) | | | | |

Death in hospital,

| | | Deceased, | | |
|--|--------|--------------|-------|------------|
| Diagnose at index admission (ICD-10-codes) | All, n | n (% of all) | no | yes |
| Cancers and benign tumours (DC00-DD48) | 1,358 | 544 (40) | 201 | 343 (63) |
| Respiratory organs (DJ00-DJ99) | 1,659 | 538 (32) | 199 | 339 (63) |
| Blood and immune system (DD50-DD89) | 158 | 49 (31) | 26 | 23 (47) |
| Infections (DAOO-DB99) | 603 | 184 (31) | 66 | 118 (64) |
| Abnormal symptoms (DR00-DR99) | 804 | 192 (24) | 65 | 127 (66) |
| Endocrine/metabolism (DE00-DE90) | 497 | 112 (23) | 50 | 62 (55) |
| Circulatory organs (DIOO-DI99) | 1,687 | 350 (21) | 116 | 234 (67) |
| Other diagnoses ^a | 6,646 | 978 (15) | 417 | 561 (57) |
| Total | 13,412 | 2,947 (22) | 1,140 | 1,807 (61) |
| | | | | |

ICD-10 = International Classification of Diseases version 10 a) Include 14 diagnostic categories in the Danish National Patient Registry, grouped because they had < 20% deceased in each category.

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