Lay Summary

Multimorbidity and Pathways of Inpatient Care at the End-of-Life: a national study in Switzerland

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1. Background

Over the past 50 years, acute care hospitals and long-term care facilities have increasingly become places of death for the terminally ill. Despite this "institutionalization of the final phase of life", most people prefer to die at home with the expectation of a more favorable dying experience for themselves and for their relatives. However, at the same time, the number of physician visits, particularly of those from medical specialties, the time spent in acute care hospitals and intensive care units, and the admission rate to long-term care facilities are increasing. Obviously, the amount of care patients receive is partially dependent on regional and hospital specific factors.

Chronic medical conditions and their multiples (multimorbidity) lead to intensive utilization of healthcare services. Multimorbidity is the most common "disease" found among the elderly. Patients with multimorbidity, especially those near their end-of-life, are highly vulnerable to undergo aggressive medical care, even if such care might be inappropriate or unwanted by the patients and their relatives.

To avoid or minimize inappropriate care at the end-of-life, a better understanding of the determinants of medical pathways at this stage of life is needed. We need to explore the impact of multimorbidity and other potentially important characteristics such as educational level, marital status, and household type on inpatient care at end-of-life. Such knowledge would contribute to a better understanding of the pathways of medical care at the end-of-life. It also would give deeper insight into the distribution of healthcare resources among those dying in older age.

To date, Switzerland has no reliable population based information on the prevalence and duration of inpatient care in acute care hospitals and long-term care facilities during the last years of life.

2. Goals of the project

The overall goal of our project was to explore the medical pathways of inpatient medical care (time spent in acute care hospitals, time spent in intensive care units, time to admission to long-term care, and time spent in long-term care facilities) in the last two years of life in the Swiss population. We focused on elderly patients with multiple chronic conditions, with the aim to identify chronic conditions with high impact on pathways of inpatient care provided near the end-of-life. We also explored the impact of other, patient-related characteristics (e.g., educational level, single person household, type of health insurance) and regional (e.g. prevailing language or supply of long-term care beds) and institutional characteristics (size and type of the medical institution) regarding inpatient medical care at the end-of-life.

We hypothesized, that multimorbidity concerns a majority of the hospitalized eldery patients in Switzerland, and that multimorbidity is an important driver of inpatient and intensive unit care use. Furthermore, we hypothesized, that patients with multiple chronic conditions are admitted earlier to nursing homes and tend to dy earlier than patients without multimorbidity.
We also hypothesized that socio-cultural patient characteristics, characteristics of the residential region and of the health care providers have an important impact on the pathways of inpatient care including place of death.

3. Methods

Based on anonymous record linkage procedures we congregated individual patient data using three national data sources: Swiss Hospital Discharge Statistics (acute care hospitals), Statistics of the Socio-medical Institutions (long-term care facilities), and Swiss National Cohort (combined individual data from the Swiss Censuses and the Cause of Death Registry).

This data base provided access to a wealth of socio-demographic, medical and administrative information on a nationwide level and allowed comprehensive analyses of factors influencing pathways of inpatient care at the end-of-life and location of death.

Though the linked data base covered only two years of fully documented inpatient history (acute care hospitals and long-term care facilities), for people still alive at the beginning of 2007 it provided fairly complete data for the five preceding years 2002-2006.

For comparing and examining our study population we performed various descriptive analyses. Testing of hypotheses was conducted with state of the art statistical models.

4. Results

In Switzerland, linkage of individual patient data is difficult due to restrictive data protection, especially the non-availability of personal identifiers such as the social security number in administrative and hospital discharge data. However, since the full date of birth is available for those who died, record linkage based on anonymous identification variables is possible for deceased inpatients. Due to the high specificity of the date of death, individuals deceased in a long-term care facility can be traced as well. Via a common anonymous person number, all preceding hospitalizations of an individual can be tracked. With this approach we could link data from the Swiss Federal Statistical Office to perform nationwide analyses. We established a new database consisting of the Swiss National Cohort SNC (linked individual data from the Swiss Censuses and the Cause of Death Registry), the Hospital Discharge Statistics MEDSTAT (covering all hospitals in the country) and the Statistics of the Socio-medical Institutions SOMED (covering all long-term care facilities in the country), providing access to a vast amount of information on acute and long-term health care use and respective outcomes.

Operationalization and prevalence of chronic conditions and multimorbidity
Already before the official start of this project we began to examine prevalence data in Switzerland (Rizza et al. 2012, Bopp & Holzer 2012). In the first paper elaborated within this project (Zellweger et al. 2014), we showed that complementary data sources provided different prevalence estimates of chronic medical conditions in the general population; however, common age and sex patterns indicated that a careful harmonization of the definition of each chronic medical condition allowed a high degree of concordance. We also showed that prevalence rates of multimorbidity were higher than those of isolated diseases, and that among the elderly, more than one out of three individuals suffered from multimorbidity.

In a first paper and in the context of determining the burden of multimorbidity in populations, we developed an algorithm enabling mutual predictions of prevalence estimates based on two or more vs. three or more chronic conditions (Holzer et al. 2014). This allowed extending comparisons of prevalence estimates for two or more chronic conditions to those of three or more chronic conditions.

A similar approach seemed promising for other fundamental determinants of the prevalence of multimorbidity (setting, age, gender, geographical area).

In a second paper (Holzer et al. 2015), we aimed at formulating empirically based recommendations on a standard format for future epidemiological studies of multimorbidity. In our systematic literature review database, we searched for population and design factors showing significant associations with multimorbidity prevalence estimates. Meta regression identified mean age of the population, the number of age groups used in the study, data reporting quality and type of classification to be highly significant predictors, whereas the number of disease categories and the setting (general population, general practice, hospital/nursing home, health insurance) were only weakly significant. Based on this empirical evaluation we formulated recommendations regarding minimum standards:

- Prevalence information should be presented broken down by gender and age groups
- The use of 10-year age groups is desirable. In case of small study populations, stratification into 2-4 age groups with definite upper and lower limit may be an alternative.
- Preferentially, the list of chronic conditions used should comprise between 25 and 75 items. We strongly support inclusion of mental health conditions like depression, anxiety and dementia.
- Point prevalence is the most appropriate measure for multimorbidity. This judgment is based on theoretical deliberations but also on the observation that studies of longer duration tend to yield smaller prevalence estimates.

Pathways of inpatient care in the last 1-2 years of life

We showed in a first paper (Hedinger et al. 2014) that place of death substantially depended on socio-demographic determinants such as household characteristics and living conditions as well as on regional factors such as nursing home bed supply. In spite of a general wish to die at home, among those aged 65 years and more, only 28% of men and 20% of women died at home. Death at home was significantly more likely for both men and women in the German speaking than in the French or Italian speaking part of Switzerland – probably due to cultural differences regarding attitudes towards death and life-prolonging measures. Also home ownership, high educational level and having children were associated with dying at home. Conversely, regional density of nursing home beds, being single, divorced or widowed, or living in a single-person household were predictive of death in an institution, especially among women. While hospital deaths appeared to be mostly due to medical reasons, dying in a nursing home was mainly determined by socio-demographic, familial and regional characteristics. Strikingly, individuals with a lower socio-economic status and those living alone or having no children were much more prone to die in a nursing home.

In a second paper (Hedinger et al. 2015a), we highlighted that nursing home admission as well as the length of the last nursing home stay before death were substantially determined by socio-demographic factors such as educational level, homeownership, and marital status. We showed that men with a lower educational level spent more time in long-term care facilities than men with a higher educational level. We also found that men living in a partnership spent less time in long-term care facilities than men who were single, divorced, or widowed. We also showed that chronic medical conditions and their multiples (multimorbidity) were independent drivers of inpatient care near the end-of-life, i.e., regarding long-term care admission and death within an institution.

In future, due to demographic aging, multimorbidity will have an even greater impact on health care worldwide. Shortage of financial resources and healthcare professionals may demand to promote forms of life and health care, which minimize admission to hospitals and long-term care facilities near the end-of-life.

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In a third paper (Hedinger et al. 2015b), we examined among those deceased in a hospital the potential impact of medical (e.g. use of ICU, multimorbidity) and social determinants (e.g. education, homeownership, marital status) as well as regional characteristics (e.g., language region and nursing home bed supply) on the aggregate length of hospital stay in the last year of life. Expectedly, increasing age, being divorced, and multimorbidity prolonged the aggregate hospital stay, whereas a larger regional nursing home bed supply shortened the aggregate hospital lengths of stay. Slightly longer mean stays among foreign nationals as well as slightly shorter mean stays among homeowners may point to differential health and therefore differential need of care. This does not apply to the substantially increased duration of the aggregate hospital length of stay in the Italian and particularly in the French speaking part of the country. Also the slightly increased duration among those with higher education and those with private complementary health insurance compared to those with compulsory insurance cannot be explained by differential health. An intriguing finding concerned intensive care unit use during the terminal hospital stay: Compared to persons without ICU use or ICU use of more than 24 hours, those with a short ICU use (less than 24 hours) had on average a much shorter terminal hospital stay.

Pathways of inpatient care among patients hospitalized for a specific condition
For a first paper (Kaplan et al. 2015), we extracted all patients $\geq$65 years admitted to a hospital after January 1, 2003, and discharged before December 31, 2006 with one of the following index conditions: stroke; heart attack; pneumonia; hip replacement. With the choice of these four conditions, we wanted to take into account different survival and treatment scenarios. During a follow-up of two years, we tracked aggregate length of stays in acute care hospitals and intensive care units, admissions to long-term care facilities, and deaths that occurred in institutions. During follow-up, almost 60% of all heart attack patients and more than 45% of those with one of the other conditions were readmitted to acute care hospitals. Increasing number of chronic medical conditions had a moderate effect on aggregate acute care hospital length of stay, a small effect on aggregate ICU length of stay, and a large effect on long-term care admission and death within an institution. There was unexplained variation in average aggregate length of hospital stay and ICU use between hospitals of different size, potentially pointing to inappropriate medical care at the end-of-life.

5. Significance of the results for science and practice

With demographic aging, research on end-of-life care has become increasingly important. Healthcare costs, but not necessarily quality of care or patient preferences, are directly related to the intensity of care patients receive at the end-of-life. A key question is whether end-of-life hospitalizations are necessary and whether they benefit the patient. Another key question arises from the institutionalized nature of the final phase of life. In developed countries most people die in hospitals or long-term care facilities although an overwhelming majority of people reports private home to be their preferred choice of place of death. What are the reasons for this obvious gap?
For tackling these challenging issues, a better understanding of medical and non-medical determinants of pathways and intensity of end-of-life care is urgently needed. This is of international interest, since evidence in this field is rather scant and controversial. In Switzerland, in spite of a strong involvement of the public authorities in planning and management of healthcare facilities and regulation of tariffs

and reimbursement systems, the lack of solid information on medical and non-medical determinants of pathways of end-of-life care is quasi ubiquitous and increasingly poses serious problems.

With our work, we proved that it is feasible to link data from the Swiss Federal Statistical Office covering entire Switzerland. Our new database consisting of the Swiss National Cohort, hospital discharge statistics and statistics of long-term care facilities provided access to a vast amount of information on acute and long-term health care use and respective outcomes. Particular strengths of this database were the inclusion of information regarding chronic medical conditions and their multiples (multimorbidity), socio-demographic determinants, and regional and institutional characteristics.

In a first direction of work, we made a significant contribution to the **definition and operationalization of chronic medical conditions and their multiples**. We showed that, after a careful harmonization of definitions, a high degree of concordance between complementary data sources could be achieved. As a consequence, we suggested a pragmatic empirical approach to facilitate uniform methodologies to increase the comparability of international prevalence data. Using a literature database established and maintained by a member of our team (K. Siebenhüner), this issue was further developed by methodological work enabling valid comparison of international prevalence estimates generated from different settings and populations. Based on empirical evaluation we formulated recommendations regarding minimum standards for future epidemiological studies of multimorbidity.

In our second direction of work, we focused on the **pathways of inpatient care in the last 1-2 years of life** and showed that place of death substantially depended on socio-demographic determinants such as household characteristics and living conditions as well as on regional factors such as nursing home bed supply. Health policy should aim at diminishing the role of situational, non-health-related factors in order to empower people to spend the last years of life according to their individual preferences. A special focus on vulnerable groups is indicated, since less advantaged individuals (lower socio-economic position, living alone, and having no children) had a higher probability to die in a nursing home, which for most individuals is the least preferred choice of the place of death.

We expected that social determinants in terminal hospital stays – contrarily to nursing home stays – would play an unimportant role. However, this was only partially true. Educational level, homeownership, nationality and marital status, as well as language region and nursing home bed supply impacted on the aggregate length of hospital stay in the last year of life. A part of this variation may point to differential health and therefore differential need of care. More worrying is the substantially increased duration of the terminal hospital stay in the Italian and even more so in the French speaking part of the country. Another worrisome finding is the slightly increased duration of hospital stays among those with private health insurance, since worse than average health is highly improbable among this rather wealthy population group.

As hypothesized, health care use in the last period preceding death was dependent on medical and socio-cultural characteristics of the patient. Also regional characteristics proved to have a substantial impact, especially concerning place of death. Our results also corroborated a fundamental difference between long-term care facilities and acute care hospitals regarding determinants of length of stay and rate of admission. As hypothesized, most associations remained significant also after multivariate adjustment.

Our study covers a period before the introduction of DRG-based payment systems in Switzerland. A new analysis including additional data from 2012, the first year after the nationwide implementation of DRG-based payment, is of paramount interest (however probably not feasible before 2016). If the suspicion of supply-side induced costs, which are not justified by health care needs of the patients,

should be corroborated, the development and implementation of improved incentives for adequate and patient-centred care will be strongly advisable.

In our third direction of work, we followed the second focus of our project – the **pathways of inpatient care among elderly patients hospitalized for a specific condition**. As expected, chronic medical conditions and their multiples concerned a very substantial part of the population. We also hypothesized that multimorbidity is an important driver of inpatient care near the end-of-life even after adjusting for common confounders. This could only partially be substantiated: An increasing number of chronic medical conditions had a large effect on nursing home admission and death within an institution, but only a moderate effect on aggregate acute care hospital length of stay and a rather negligible effect on aggregate ICU length of stay. There was an unexplained variation in average aggregate length of hospital and ICU stay between hospitals of different size. This might indicate potentially inappropriate medical care at the end-of-life, and will need more in-depth analysis in the future.
Due to unforeseen delay in the construction of an extended database including additional years of registration, the hypothesis that specific combinations of chronic conditions are more relevant than others could not be tested. However, the last hypothesis for this project part – that pathways of care of patients with identical chronic conditions do vary due to patient, regional and institutional characteristics – was clearly confirmed.

To sum up, the rapidly growing provision of healthcare services near the end-of-life is turning into an urgent challenge for individuals, healthcare providers, policy makers, and the entire society. We hope that our findings will guide stakeholders in the transition of the healthcare system from a disease- to a patient-centered health care system, and that it will contribute to healthy aging and wellbeing for the elderly and those at the end-of-life, while, at the same time enabling a "good death" to as much individuals as possible.
With our work we contribute to the international discussion about potential improvements of health care at the end-of-life. However, further research investigating the associations between socio-demographic characteristics, patient preferences, characteristics and availability of existing healthcare services with more specified healthcare outcomes (e.g., survival, types of treatments, resource use) is needed. The strong influence of determinants primarily not dependent on health (e.g., language region, socio-economic status, type of health insurance, regional bed density) reveals a vast potential for improving quality of end-of-life care in Switzerland, e.g., preventing unnecessary hospital admissions and facilitating dying at preferred places.

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