

Lay Summary

Regional and temporal variation in end of life care in Switzerland

Project team

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1. Background

Previous research has documented consistent and wide variation in frequency of use of hospitals, intensive care units (ICU), hospices and physicians visits for seriously ill and dying patients. There is generally little scientific evidence about determinants of this variation and how to overcome these in order to improve quality of care in this field. Existing evidence shows, however, that local capacity (supply of physicians, hospital and nursing home beds etc.) is a more powerful predictor of resource utilization than patient characteristics. This significance of local context is confirmed by more general research on medical practice variation indicating that sources of variation depend largely on the setting in which care takes place. Research also shows that local structure and practice of end of life care are not necessarily reflecting patient preferences and that more supply of health care capacity generally results in higher resource use but not always in better outcomes. These findings suggest avoidable hospital admissions and unnecessary high-intensity treatments and there is concern whether care is

overused and is driving up costs. Swiss National Science Foundation. Given the importance of structure of care delivery on medical decision making it is not surprising that nature and scale of medical practice variation differ between countries and that end of life care may particularly be vulnerable to variation not warranted by effective medical needs and patient preferences. Today, little is known about how these different factors interact and impact the utilization of health services for terminally ill and dying patients in Switzerland, with a health system in place characterized by considerable fragmentation and lack of coordination. It is therefore important to quantify the extent of variation of end of life health care across the country and to identify sources of variation that would be amenable to societal interventions.

2. Goals of the project

- SA1: To investigate regional and temporal variation in the proportion of persons who die in acute hospitals versus those who die in other non-acute facilities accounting for socio-demographic factors (e.g. age, gender, language regions, urbanicity).
- SA2: To describe regional and temporal variation in EOL care costs received during the last 12 months of life and to identify patient (e.g. age, gender), regional (e.g. urbanicity, language region, Swiss-SEP) and institutional (e.g. per geographic unit number of hospitals, physicians and specialists) characteristics associated with variation.
- SA3: To describe regional and temporal variation of intensity of EOL care in the last 12 months of life and to identify patient (e.g. age, gender), regional (e.g. urbanicity, language region, Swiss-SEP) and institutional (e.g. per geographic unit number of hospitals, physicians and specialists) characteristics associated with variation.

3. Methods

The study data was sourced from six of the largest health insurance providers in Switzerland: Helsana, Visana, SWICA, Group Mutuel, Sanitas, CSS. The study population (N= 119,441) included all Swiss residents insured by one of the six participating insurance providers that died between 2008 and 2010. We probabilistically linked these persons to death certificates to get cause of death information. The project data was made up of four individual datasets. The datasets contain complete health insurance claims (N= 3,904,178) from the last 12 months of life for the entire study population. These data included detailed information on included persons' outpatient EOL care utilization (e.g. date of care, type of care, care provider, site of care, costs of care, etc.) and aggregated per-diem costs for inpatient billable medical services. The EOL Study included approximately 64% of all deaths in Switzerland 2008-2010 representing all areas of Switzerland, geographically ranging from 11%-89%. The data was suitable for evaluating multiple aspects of outpatient EOL care trajectories but is restricted to only cost trajectories of both in- and outpatient EOL medical services. We used multilevel regression models to estimate differences in EOL care across 564 regions of place of residence, nested within 71 hospital service areas. We examined to what extent variation was explained by characteristics of individuals and regions, including measures of healthcare supply.

4. Results

SA1: In our multilevel analysis, we found substantial variation across health service areas (HSAs) with regard to dying in hospitals versus nursing homes among people 66 years and older in Switzerland. The results show that dying in institutions in Switzerland is not only a function of individual factors. Patients living in French speaking part were more likely to die in hospital. Living in peri-urban areas was associated with higher probability of dying in hospital compared to urban and rural settings. There was also an association between institutional death and several healthcare supply measures. Our findings indicate that multiple factors at both the micro and meso levels influence dying in institutions in Switzerland. Our evidence for variation in institutional deaths across HSAs can partly be explained by individual, regional and healthcare supply characteristics. HSAs should be further explored for overuse and underuse of end of life (EOL) services. Further efforts are needed to examine the potential causes of these variations using additional data on individual-level (e.g. preferences), healthcare system (e.g., type of EOL services) as well as data to analyse trends of institutional deaths over time. Our findings have potentially important implications for patients, clinicians and policy makers alike. They can be used to inform Swiss policy towards addressing regional differences for reducing EOL costs and ensuring EOL care in line with patient preferences. HSAs with high proportion of hospital deaths might indicate overuse or inappropriate use of costly acute care hospital resources (e.g. patients living in nursing homes might be inappropriately admitted to acute care hospital). HSAs with low proportion of hospital deaths might indicate an underuse of needed acute care hospital services at EOL (e.g. a nursing homes resident is not offered needed acute care hospital admission). Therefore, an in-depth analysis with information on quality of care is needed and is a high priority. This work should also encourage future research that can account for patient preferences, cause of death and changes over time. These Swiss findings have relevance for other developed countries because of similar demographic and healthcare delivery problems effecting EOL care (e.g. aging, rising healthcare costs, concerns that patient preferences are not always followed). The unexplained variation in our analysis could be due to unmeasured factors (e.g., patient preferences, local practice patterns, underlying population health). Some variation may be expected as it may reflect differences in population need, and cultural characteristics of the population or patient preferences, which does not necessarily imply unwarranted variation. The focus should be on unwarranted variation or variation that cannot be explained by patient differences but by healthcare capacity amenable to change.

SA2: Studying geographical variation in cost of care in the last 12 months of life in Switzerland and assessing associations of costs with individual, regional and healthcare supply factors, we found cause of death and age of the decedent to be the most important determinants at the individual level. We found that costs varied substantially between regions and these differences were only partly explained by confounders. Measures of care supply showed no associations with costs. When we included language region, the spatial variation was reduced substantially, but especially for elderly women, relevant differences between small regions remained. The results of this study align with previous findings and point to the importance of assessing utilization and spending patterns at the local level. Large spatial units could be heterogeneous and too crude for planning policies. Additionally, we found

that cost of care was associated with language region; countries with culturally diverse populations and regions should consider these findings in future studies. Finally, our methodology and findings could contribute to understanding health care expenditures in countries with similar healthcare organisation and demographics in which the extent of variation has been documented, but the studies of its determinants are still scarce. Medical health insurance claims data show that in Switzerland health care expenditures in the last months of life vary strongly across regions, particularly among older individuals. The effect of language region might indicate that the organization of end of life care differs between cultural regions. However, supply of care does not seem to play a major role. In light of the 2012 Swiss-wide changes to a new inpatient reimbursement system, this study provides a baseline for tracking the effects of these changes on end of life care. Future Swiss and international studies should take into account cultural factors of delivery and utilization of healthcare.

SA3: To the best of our knowledge, we conducted the first systematic review of measures used for evaluating intensity of end of life care. We assessed studies measuring hospitalizations, life-sustaining invasive procedures and life-prolonging treatments in the last 12 months of life. Aims, populations studied definitions of intensity of end of life care and measures used were heterogeneous across studies. The number of intensity of end of life care studies grew over the last decade with over 50% of the studies included published within the last five years. Our findings show that intensity of end of life care is most commonly evaluated using a combination of measures, including two summary score measures. This review also highlights an important deficit in health services research of end of life care. Measures of intensity of end of life care, although widely used in health services research, lack validation and general agreement by experts in the field. Overall, we consider the evidence to be of moderate quality. It could be argued that the lack of prospective studies reflects the difficulty of conducting research with people who are approaching death. There is no consensus on the definition for intensity of end of life care. The associated measures are seldom validated and often used for varying aims, in differing populations and most commonly in combinations of more than one at a time. Definitions, methods, and strategies all vary across studies and countries. The choice and assessment of measures of intensity of care at the end of life should be based on the aim of the study although which measure suits specific aims best remains unclear. Our review is the first to attempt to identify measures used specifically for evaluating intensity of end of life care. It provides a synthesis for choosing measures based on their previous use but also highlights the crucial need for more validation studies.

Analyses of the intensity of inpatient end of life care (IIEC) measures showed that during their last six months of life patients who died in a hospital spent on average almost a month (29 days) in the hospital. Moreover, they spent more than half of their last month of life in a hospital. Over one in four (27%) had an intensive care unit (ICU) admission in the last six months of life. IIEC measures were mainly influenced by individual-level (age and the main reason for final hospitalization) and regional characteristics (language region). Older age showed more regional variation of hospital (length of stay) LOS. Within the older groups, regional variation existed that could not be explained by our adjustment for individual, regional, and health services characteristics. IIEC varies between regions, particularly for older patients and across language regions. The availability of local health care services appears to have only a small effect on IIEC measures in Switzerland. Studies in Switzerland and from abroad show that the regional availability of health care services influences use of care. However, we could only establish that association in Switzerland in subgroups, and with small effect sizes. For older females, more



hospital beds near their place of residence was associated with an increased length of their hospital stay, but a decreased probability of ICU admission. More nursing home beds decreased ICU LOS, perhaps because older females may more often live alone and may be more dependent on the services of professional health care providers. Further, the higher availability of nursing home and hospital beds may prevent the need for ICU admission or a long ICU stay. Our study showed that within young patients regional variation could be almost completely explained by our adjustment for individual, regional, and health services characteristics. However, the older patients still showed unexplained regional variations of hospital LOS after adjustments. These variations may indicate under- or overuse of health care services. Not all variations in health care utilization are undesired. The effect from age and disease on hospital LOS may be largely explained by disease factors like the severity of comorbidities and patient preferences and therefore be warranted variation. Unfortunately, we do not have any data on this within our database. Variation in hospital LOS due to place of residence in a specific language region could be prone to unwarranted variation. Especially, as in our study results were adjusted for density of health care services in the HSA of the place of residence. Future studies should explore whether such variations are in line with patient preferences and equality of care or are caused by unequal access or unwarranted care. Future studies in countries with different cultural populations or regions should be encouraged to use this cultural variation as an explanatory factor, for our study suggests that language regions constitute an important explanatory factor in Switzerland for IIEC. Although language is unlikely to influence care utilization, it may be used as an easily available proxy for other characteristics that could reduce unexplained variations. Our work also shows the importance of providing information on regional variation in nationwide studies of health services measures. Additional information on regional variation better reflects the actual intensity of care patients are receiving across a country. Health services researchers and policymakers could use our data as a starting point for monitoring IIEC over time. For follow-up analyses, it would be especially interesting to measure the influence of the 2010-2015 national strategy for developing palliative care in Switzerland on IIEC, for which this study might provide a benchmark and starting point. Future Swiss and international studies on variation in IIEC should take into account the influence of cultural factors and should be challenged to identify the specific cultural mechanism that influence IIEC. Policymakers may use these outcomes to better understand warranted and unwarranted variation in IIEC.

5. Significance of the results for science and practice

Studies of the intensity of end of life care require reliable and valid measures that work in different care settings, populations and diseases. Although our systematic review of intensity of care measures has advanced current knowledge, it remains unclear what tools have adequate validity and should be recommended for measuring intensity of end of life care. In our systematic review, we provide a comprehensive overview of the measures of intensity of end of life care that are currently used in published original research. We summarize their features (i.e., type of measures) and describe characteristics of their use (i.e., population, timeframe) and reported validity and recommend that experts in the field utilise this information for future research. There is no consensus on the definition for intensity of end of life care. The associated measures are seldom validated and often used for varying aims, in differing populations and most commonly in combinations of more than one at a time. Definitions, methods, and strategies all vary across studies and countries. The choice and assessment of measures of intensity of care at the end of life should be based on the aim of the study although which measure suits specific aims best remains unclear. Our review is the first to attempt to identify measures

used specifically for evaluating intensity of end of life care. Importantly, it provides a synthesis for choosing measures based on their previous use but also highlights the crucial need for more validation studies – all work that should be emphasised by policy makers and experts alike.

The conceptual framework we developed builds on a comprehensive literature search that allowed a broad understanding of determinants of variation in end of life care. Strength is that, the literature review was supplemented by involvement of multidisciplinary expert panel, including an international expert in (health services research) HSR. Our conceptual framework identifies key health care determinants on multiple levels that can be modified to address a wide range of HSR questions. Experts and policy makers should encourage using such a conceptual framework as it helps a researcher to identify key pathways and identify potential data sources.

Our study on place of death have potentially important implications for patients, clinicians and policy makers alike. They should be used to inform Swiss policy towards addressing regional differences for reducing EOL costs and ensuring EOL care in line with patient preferences. (health service areas) HSAs with high proportion of hospital deaths might indicate overuse or inappropriate use of costly acute care hospital resources (e.g. patients living in nursing homes might be inappropriately admitted to acute care hospital). HSAs with low proportion of hospital deaths might indicate an underuse of needed acute care hospital services at EOL (e.g. a nursing homes resident is not offered needed acute care hospital admission). Therefore, we recommend an in-depth analysis with information on quality of care that is a high priority. This work should also encourage future research that can account for patient preferences, cause of death and changes over time. These Swiss findings have relevance for other developed countries because of similar demographic and healthcare delivery problems effecting EOL care (e.g. aging, rising healthcare costs, concerns that patient preferences are not always followed). The unexplained variation in our analysis could be due to unmeasured factors (e.g., patient preferences, local practice patterns, underlying population health). Some variation may be expected as it may reflect differences in population need, and cultural characteristics of the population or patient preferences, which does not necessarily imply unwarranted variation. Experts in the field should focus on unwarranted variation or variation that cannot be explained by patient differences but by healthcare capacity amenable to change.

Previous studies tracked variation in (end of life care) EOLC cost in Switzerland across place of death and across time. Our cost study adds regional analyses, which should be used to involve stakeholders and guide future EOLC studies in Switzerland. Geographical variation in prevailing type of EOLC, the coverage and strength of palliative care institutions, or family and social support may be important determinants of cost. High EOLC cost might not only indicate potential waste of resources, but also potential overuse of costly hospital-based services instead of appropriate palliative care. Moreover, past EOLC spending in a region might be used as an exposure in studies tracking variation in other areas of healthcare. All factors that need further exploration by policy makes and experts alike. Furthermore, supply of care did not seem to play a role, however we did identify significant variation that may indicate under- or overuse of services. But if regions that spend more offer better quality of care and have higher patient satisfaction, the rest of the country should follow suit. If future research finds that this is not the case, then the areas highlighted by our findings should become the focus of regionally tailored interventions. Finally, regional findings may point to different patient preferences between regions. If meeting these preferences, independent of medical needs, is considered a valid social goal, then



substantial variation in cost of care in the last months of life in Switzerland will persist. The results of EOLC costs study align with previous findings and point to the importance of assessing utilization and spending patterns at the local level. Large spatial units could be heterogeneous and too crude for planning policies. Additionally, we found that cost of care was associated with language region; countries with culturally diverse populations and regions should consider these findings in future studies and policy decision-making. Our methodology and findings contribute to understanding HCE in countries with similar healthcare organisation and demographics in which the extent of variation has been documented, but the studies of its determinants are still scarce and we recommend future research.

Our study on intensity of EOL in Switzerland shows the importance of providing information on regional variation in nationwide studies of health services measures. Additional information on regional variation better reflects the actual intensity of care patients are receiving across a country. Health services researchers and policymakers should use our data as a starting point for monitoring (intensity of inpatient end of life care) IIEC over time. We recommend follow-up analyses. It would be especially interesting to measure the influence of the 2010-2015 national strategy for developing palliative care in Switzerland on IIEC, for which our study provides a benchmark and starting point. In our study, patients who died in a hospital spent on average almost a month in the hospital during their last six months of life, but varied between regions, particularly for older patients and across language regions. The availability of local health care services appears to have only a small effect on IIEC measures in Switzerland. Our findings suggest future Swiss and international studies on variation in IIEC should take into account the influence of cultural factors and should be challenged to identify the specific cultural mechanism that influence IIEC. Policymakers can use our outcomes to better understand warranted and unwarranted variation in IIEC.

Lastly, policy makers and experts should put pressure on healthservice providers and insurers to make patient data available for health services research. Every healthcare encounter generates important information about the quality of care provided in Switzerland. When accessible and aggregated these data are an accurate invaluable source of real life information that should directly inform decision making within the patient, healthcare system and policy realms. Without adequate access to pre-existing healthcare data the real life experience of patients can not feedback into the decision making process.