BIG DATA & SOINS PALLIATIFS

ETAT DES LIEUX ET PERSPECTIVES

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A Second Chance to Get Causal Inference Right: A Classification of Data Science Tasks

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For much of the recent history of science, learning from data was the academic realm of statistics,[1,2] but in the early 20th century, the founders of modern statistics made a momentous decision about what could and could not be learned from data: They proclaimed that statistics could be applied to make causal inferences when using data from randomized experiments, but not when using nonexperimental (observational) data.[3,4,5] This decision classified an entire class of scientific questions in the health and social sciences as not amenable to formal quantitative inference.

Not surprisingly, many scientists ignored the statisticians' decree and continued to use observational data to study the unintended harms of medical treatments, health effects of lifestyle activities, or social impact of educational policies. Unfortunately, these scientists' causal questions often were mismatched with their statistical training. Perplexing paradoxes arose; for example, the famous "Simpson's paradox" stemmed from a failure to recognize that the choice of data analysis depends on the causal structure of the problem.[6] Mistakes occurred. For example, as a generation of medical researchers and clinicians believed that postmenopausal hormone therapy reduced the risk of heart disease because of data analyses that deviated from basic causal considerations. Even today, confusions generated by a century-old refusal to tackle causal questions explicitly are widespread in scientific research.[7]

To bridge science and data analysis, a few rogue statisticians, epidemiologists, econometricians, and computer scientists developed formal methods to quantify causal effects from observational data. Initially, each discipline emphasized different types of causal questions, developed different terminologies, and preferred different data analysis techniques. By the beginning of the 21st century, while some conceptual discrepancies remained, a unified theory of quantitative causal inference had emerged.[8,9]

We now have a historic opportunity to redefine data analysis in such a way that it naturally accommodates a science-wide framework for causal inference from observational data. A recent influx of data analysts, many not formally trained in statistical theory, bring a fresh attitude that does not a priori exclude causal questions. This new wave of data analysts refer to themselves as data scientists and to their activities as data science, a term popularized by technology companies and embraced by academic institutions.

Data science, as an umbrella term for all types of data analysis, can tear down the barriers erected by traditional statistics; put data analysis at the service of all scientific questions, including causal ones; and prevent unnecessary inferential mistakes. We may miss our chance to successfully integrate data analysis into all scientific

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Etablir un lien de cause à effet

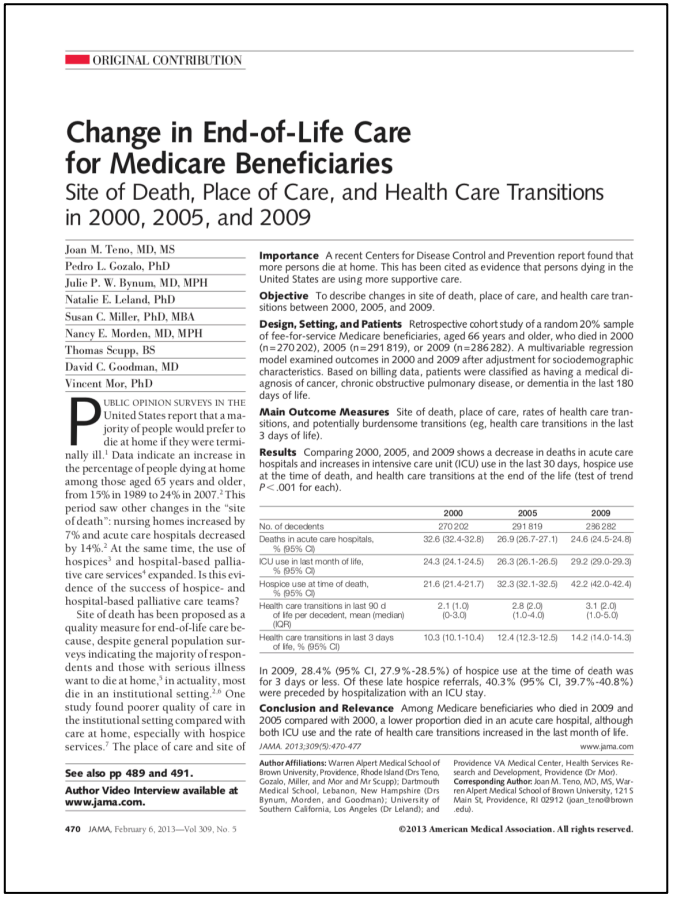
Le monde qui nous entoure aurait-il pu être différent?

01

Décrire

A quoi ressemble le monde qui nous entoure?

Evolution des lieux de décès



ORIGINAL CONTRIBUTION

Change in End-of-Life Care for Medicare Beneficiaries

Site of Death, Place of Care, and Health Care Transitions in 2000, 2005, and 2009

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PUBLIC OPINION SURVEYS IN THE United States report that a majority of people would prefer to die at home if they were terminally ill.[1] Data indicate an increase in the percentage of people dying at home among those aged 65 years and older, from 15% in 1989 to 24% in 2007.[2] This period saw other changes in the "site of death": nursing homes increased by 7% and acute care hospitals decreased by 14%.[2] At the same time, the use of hospices[3] and hospital-based palliative care services[4] expanded. Is this evidence of the success of hospice- and hospital-based palliative care teams?

Site of death has been proposed as a quality measure for end-of-life care because, despite general population surveys indicating the majority of respondents and those with serious illness want to die at home,[5] in actuality, most die in an institutional setting.[2,6] One study found poorer quality of care in the institutional setting compared with care at home, especially with hospice services.[7] The place of care and site of

See also pp 489 and 491.

Author Video Interview available at www.jama.com.

Importance A recent Centers for Disease Control and Prevention report found that more persons die at home. This has been cited as evidence that persons dying in the United States are using more supportive care.

Objective To describe changes in site of death, place of care, and health care transitions between 2000, 2005, and 2009.

Design, Setting, and Patients Retrospective cohort study of a random 20% sample of fee-for-service Medicare beneficiaries, aged 66 years and older, who died in 2000 (n=270 202), 2005 (n=291 819), or 2009 (n=286 282). A multivariable regression model examined outcomes in 2000 and 2009 after adjustment for sociodemographic characteristics. Based on billing data, patients were classified as having a medical diagnosis of cancer, chronic obstructive pulmonary disease, or dementia in the last 180 days of life.

Main Outcome Measures Site of death, place of care, rates of health care transitions, and potentially burdensome transitions (eg, health care transitions in the last 3 days of life).

Results Comparing 2000, 2005, and 2009 shows a decrease in deaths in acute care hospitals and increases in intensive care unit (ICU) use in the last 30 days, hospice use at the time of death, and health care transitions at the end of the life (test of trend $P<.001$ for each).

	2000	2005	2009
No. of decedents	270 202	291 819	286 282
Deaths in acute care hospitals, % (95% CI)	32.6 (32.4-32.8)	26.9 (26.7-27.1)	24.6 (24.5-24.8)
ICU use in last month of life, % (95% CI)	24.3 (24.1-24.5)	26.3 (26.1-26.5)	29.2 (29.0-29.3)
Hospice use at time of death, % (95% CI)	21.6 (21.4-21.7)	32.3 (32.1-32.5)	42.2 (42.0-42.4)
Health care transitions in last 90 d of life per decedent, mean (median) (IQR)	2.1 (1.0) (0-3.0)	2.8 (2.0) (1.0-4.0)	3.1 (2.0) (1.0-5.0)
Health care transitions in last 3 days of life, % (95% CI)	10.3 (10.1-10.4)	12.4 (12.3-12.5)	14.2 (14.0-14.3)

In 2009, 28.4% (95% CI, 27.9%-28.5%) of hospice use at the time of death was for 3 days or less. Of these late hospice referrals, 40.3% (95% CI, 39.7%-40.8%) were preceded by hospitalization with an ICU stay.

Conclusion and Relevance Among Medicare beneficiaries who died in 2009 and 2005 compared with 2000, a lower proportion died in an acute care hospital, although both ICU use and the rate of health care transitions increased in the last month of life.

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Place of death in the population dying from diseases indicative of palliative care need: a cross-national population-level study in 14 countries

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ABSTRACT

Background Studying where people die across countries can serve as an evidence base for health policy on end-of-life care. This study describes the place of death of people who died from diseases indicative of palliative care need in 14 countries, the association of place of death with cause of death, sociodemographic and healthcare availability characteristics in each country and the extent to which these characteristics explain country differences in the place of death.

Methods Death certificate data for all deaths in 2008 (age ≥1 year) in Belgium, Canada, the Czech Republic, England, France, Hungary, Italy, Mexico, the Netherlands, New Zealand, South Korea, Spain (Andalusia), the USA and Wales caused by cancer, heart/renal/liver failure, chronic obstructive pulmonary disease, diseases of the nervous system or HIV/AIDS were linked with national or regional healthcare statistics (N=2 220 997).

Results 13% (Canada) to 53% (Mexico) of people died at home and 25% (the Netherlands) to 85% (South Korea) died in hospital. The strength and direction of associations between home death and cause of death, sociodemographic and healthcare availability factors differed between countries. Differences between countries in home versus hospital death were only partly explained by differences in these factors.

Conclusions The large differences between countries in and beyond Europe in the place of death of people in potential need of palliative care are not entirely attributable to sociodemographic characteristics, cause of death or availability of healthcare resources, which suggests that countries' palliative and end-of-life care policies may influence where people die.

Linked

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INTRODUCTION

The number of people who die as a result of prolonged chronic illnesses is increasing worldwide.[1] Prior to dying, these people typically experience a wide range of complex needs and symptoms that require palliative care.[2] In line with the view of the WHO, palliative care is an approach to care that goes beyond a medical specialty and that aims to control the various physical, psychological, social and other problems associated with a life-threatening illness.[3] One important aspect of the palliative care approach is planning of care, including the location in which patients wish to receive care towards the end of life and the location in which they wish to die.

Twenty-six studies from 13 countries found that more than half of the patients preferred to die at home. Eight of these studies were conducted in the UK, four in the USA, three in Spain, two in Japan, two in South Korea and one each in Australia, Ethiopia, Rwanda, Sweden, Taiwan, Uganda and Zimbabwe, respectively.[4] Furthermore, a population-based survey in seven European countries found that between 50% and 83% would prefer to die at home if faced with advanced cancer.[5] However, it appears that this wish is often not met as in many countries people mainly die in hospitals,[6–8] and in certain countries the percentage of hospital deaths is rapidly increasing.[8 9] Research evidence has raised concerns that many hospital deaths are preceded by potentially burdensome and inappropriate hospital admissions and aggressive treatments shortly before death, which could be a threat to good end-of-life care, quality of life and ultimately a good death.[10–13] Enabling people to die at home also has important cost implications as end-of-life care in hospital may incur higher costs than end-of-life care in community-care settings.[14 15] Of course, a home death may be easier to achieve in countries that have developed adequate home care arrangements and may be different in certain middle-income or low-income countries where people may be more likely to receive appropriate care only in hospitals, for instance because formal home care is not available or not affordable (eg, in Mexico).[16]

Where people with palliative care needs die has been determined to be an issue for public health,[17] and it should therefore be subject to the first function of public health: assessment and monitoring.[18 19] Assessment and monitoring provide the scientific foundation that is needed to inform policies and interventions on a subject that has been determined to be relevant for public health. Continuous and systematic monitoring of the place of death in a population that died from causes indicative of palliative care need is therefore an essential cornerstone in the planning, implementation and evaluation of policies and programmes aimed at enabling people with chronic diseases to die in their place of choice, and it contributes to the

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Décrire

A quoi ressemble le monde qui nous entoure?

Consommation de soins

Research

Original Investigation

Comparison of Site of Death, Health Care Utilization, and Hospital Expenditures for Patients Dying With Cancer in 7 Developed Countries

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IMPORTANCE Differences in utilization and costs of end-of-life care among developed countries are of considerable policy interest.

OBJECTIVE To compare site of death, health care utilization, and hospital expenditures in 7 countries: Belgium, Canada, England, Germany, the Netherlands, Norway, and the United States.

DESIGN, SETTING, AND PARTICIPANTS Retrospective cohort study using administrative and registry data from 2010. Participants were decedents older than 65 years who died with cancer. Secondary analyses included decedents of any age, decedents older than 65 years with lung cancer, and decedents older than 65 years in the United States and Germany from 2012.

MAIN OUTCOMES AND MEASURES Deaths in acute care hospitals, 3 inpatient measures (hospitalizations in acute care hospitals, admissions to intensive care units, and emergency department visits), 1 outpatient measure (chemotherapy episodes), and hospital expenditures paid by insurers (commercial or governmental) during the 180-day and 30-day periods before death. Expenditures were derived from country-specific methods for costing inpatient services.

RESULTS The United States (cohort of decedents aged >65 years, N = 211 816) and the Netherlands (N = 7216) had the lowest proportion of decedents die in acute care hospitals (22.2.% and 29.4%, respectively). A higher proportion of decedents died in acute care hospitals in Belgium (N = 21 054; 51.2%), Canada (N = 20 818; 52.1%), England (N = 97 099; 41.7%), Germany (N = 24 434; 38.3%), and Norway (N = 6636; 44.7%). In the last 180 days of life, 40.3% of US decedents had an intensive care unit admission compared with less than 18% in other reporting nations. In the last 180 days of life, mean per capita hospital expenditures were higher in Canada (US $21 840), Norway (US $19 783), and the United States (US $18 500), intermediate in Germany (US $16 221) and Belgium (US $15 699), and lower in the Netherlands (US $10 936) and England (US $9342). Secondary analyses showed similar results.

CONCLUSIONS AND RELEVANCE Among patients older than 65 years who died with cancer in 7 developed countries in 2010, end-of-life care was more hospital-centric in Belgium, Canada, England, Germany, and Norway than in the Netherlands or the United States. Hospital expenditures near the end of life were higher in the United States, Norway, and Canada, intermediate in Germany and Belgium, and lower in the Netherlands and England. However, intensive care unit admissions were more than twice as common in the United States as in other countries.

Author Video Interview and JAMA Report Video at jama.com

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CME Quiz at jamanetworkcme.com and CME Questions page 299

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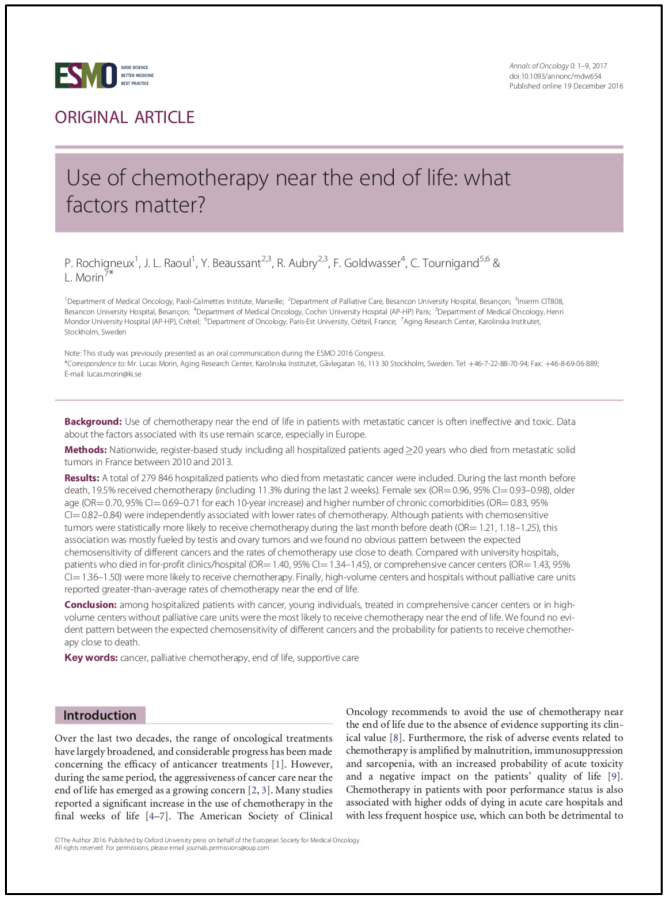

ESMO 2000 SCIENCE BETTER MEDICINE BEST PRACTICE

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ORIGINAL ARTICLE

Use of chemotherapy near the end of life: what factors matter?

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Note: This study was previously presented as an oral communication during the ESMO 2016 Congress.

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Background: Use of chemotherapy near the end of life in patients with metastatic cancer is often ineffective and toxic. Data about the factors associated with its use remain scarce, especially in Europe.

Methods: Nationwide, register-based study including all hospitalized patients aged ≥20 years who died from metastatic solid tumors in France between 2010 and 2013.

Results: A total of 279 846 hospitalized patients who died from metastatic cancer were included. During the last month before death, 19.5% received chemotherapy (including 11.3% during the last 2 weeks). Female sex (OR= 0.96, 95% CI= 0.93–0.98), older age (OR= 0.70, 95% CI= 0.69–0.71 for each 10-year increase) and higher number of chronic comorbidities (OR= 0.83, 95% CI= 0.82–0.84) were independently associated with lower rates of chemotherapy. Although patients with chemosensitive tumors were statistically more likely to receive chemotherapy during the last month before death (OR= 1.21, 1.18–1.25), this association was mostly fueled by testis and ovary tumors and we found no obvious pattern between the expected chemosensitivity of different cancers and the rates of chemotherapy use close to death. Compared with university hospitals, patients who died in for-profit clinics/hospital (OR= 1.40, 95% CI= 1.34–1.45), or comprehensive cancer centers (OR= 1.43, 95% CI= 1.36–1.50) were more likely to receive chemotherapy. Finally, high-volume centers and hospitals without palliative care units reported greater-than-average rates of chemotherapy near the end of life.

Conclusion: among hospitalized patients with cancer, young individuals, treated in comprehensive cancer centers or in high-volume centers without palliative care units were the most likely to receive chemotherapy near the end of life. We found no evident pattern between the expected chemosensitivity of different cancers and the probability for patients to receive chemotherapy close to death.

Key words: cancer, palliative chemotherapy, end of life, supportive care

Introduction

Over the last two decades, the range of oncological treatments have largely broadened, and considerable progress has been made concerning the efficacy of anticancer treatments [1]. However, during the same period, the aggressiveness of cancer care near the end of life has emerged as a growing concern [2, 3]. Many studies reported a significant increase in the use of chemotherapy in the final weeks of life [4–7]. The American Society of Clinical Oncology recommends to avoid the use of chemotherapy near the end of life due to the absence of evidence supporting its clinical value [8]. Furthermore, the risk of adverse events related to chemotherapy is amplified by malnutrition, immunosuppression and sarcopenia, with an increased probability of acute toxicity and a negative impact on the patients' quality of life [9]. Chemotherapy in patients with poor performance status is also associated with higher odds of dying in acute care hospitals and with less frequent hospice use, which can both be detrimental to

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RESEARCH LETTER

Tube Feeding in US Nursing Home Residents With Advanced Dementia, 2000-2014

Over the last 2 decades, research has failed to demonstrate benefits of tube feeding in patients with advanced dementia.[1,2] Expert opinion and position statements by national organizations increasingly advocate against this practice.[3] This study was conducted to describe feeding tube insertion rates from 2000-2014 among US nursing home residents with advanced dementia. Racial disparities were examined because black race has been strongly associated with greater feeding tube use.[4]

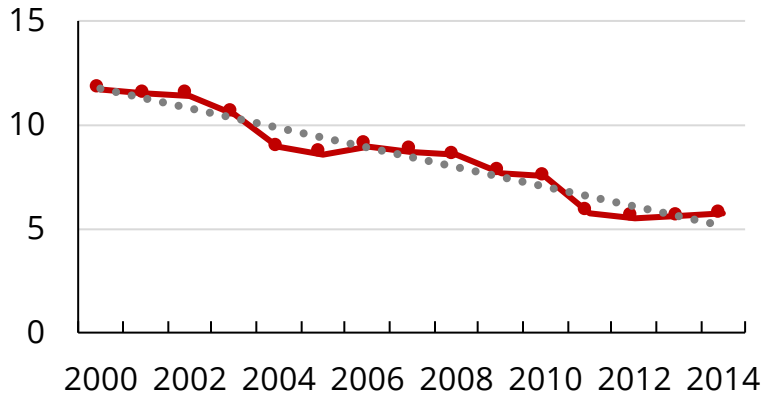

Table 2. Comparison of Feeding Tube Insertion Rates Among US Nursing Home Residents With Advanced Dementia in 2000 and 2014

	Residents With Advanced Dementia Receiving a Feeding Tube Within 12 Months of Becoming Dependent for Eating, %			Risk Ratio (95% CI)	
	2000	2014	Difference (95% CI)	Unadjusted	Adjusted
All	11.7	5.7	−6.0 (−7.6 to −4.5)	0.45 (0.41 to 0.50)	0.41 (0.38 to 0.45)[b]
White[a]	8.6	3.1	−5.5 (−7.0 to −4.3)	0.37 (0.31 to 0.43)	0.37 (0.33 to 0.41)[c]
Black[a]	37.5	17.5	−20.1 (−25.5 to −10.2)	0.47 (0.40 to 0.55)	0.47 (0.41 to 0.55)[c]

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Décrire

A quoi ressemble le monde qui nous entoure?

Consommation de soins

Research

Original Investigation | LESS IS MORE

Use of Medications of Questionable Benefit in Advanced Dementia

Jennifer Tjia, MD, MSCE; Becky A. Briesacher, PhD; Daniel Peterson, MA; Qin Liu, MD, PhD; Susan E. Andrade, ScD; Susan L. Mitchell, MD, MPH

IMPORTANCE Advanced dementia is characterized by severe cognitive impairment and complete functional dependence. Patients' goals of care should guide the prescribing of medication during such terminal illness. Medications that do not promote the primary goal of care should be minimized.

OBJECTIVES To estimate the prevalence of medications with questionable benefit used by nursing home residents with advanced dementia, identify resident- and facility-level characteristics associated with such use, and estimate associated medication expenditures.

DESIGN, SETTING, AND PARTICIPANTS Cross-sectional study of medication use by nursing home residents with advanced dementia using a nationwide long-term care pharmacy database linked to the Minimum Data Set (460 facilities) between October 1, 2009, and September 30, 2010.

MAIN OUTCOMES AND MEASURES Use of medication deemed of questionable benefit in advanced dementia based on previously published criteria and mean 90-day expenditures attributable to these medications per resident. Generalized estimating equations using the logit link function were used to identify resident- and facility-related factors independently associated with the likelihood of receiving medications of questionable benefit after accounting for clustering within nursing homes.

RESULTS Of 5406 nursing home residents with advanced dementia, 2911 (53.9%) received at least 1 medication with questionable benefit (range, 44.7% in the Mid-Atlantic census region to 65.0% in the West South Central census region). Cholinesterase inhibitors (36.4%), memantine hydrochloride (25.2%), and lipid-lowering agents (22.4%) were the most commonly prescribed. In adjusted analyses, having eating problems (adjusted odds ratio [AOR], 0.68; 95% CI, 0.59-0.78), a feeding tube (AOR, 0.58; 95% CI, 0.48-0.70), or a do-not-resuscitate order (AOR, 0.65; 95% CI, 0.57-0.75), and enrolling in hospice (AOR, 0.69; 95% CI, 0.58-0.82) lowered the likelihood of receiving these medications. High facility-level use of feeding tubes increased the likelihood of receiving these medications (AOR, 1.45; 95% CI, 1.12-1.87). The mean (SD) 90-day expenditure for medications with questionable benefit was $816 ($553), accounting for 35.2% of the total average 90-day medication expenditures for residents with advanced dementia who were prescribed these medications.

CONCLUSIONS AND RELEVANCE Most nursing home residents with advanced dementia receive medications with questionable benefit that incur substantial associated costs.

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CME Quiz at jamanetworkcme.com and CME Questions page 1880

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Original Article

Preventive Drugs in the Last Year of Life of Older Adults With Cancer: Is There Room for Deprescribing?

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BACKGROUND: The continuation of preventive drugs among older patients with advanced cancer has come under scrutiny because these drugs are unlikely to achieve their clinical benefit during the patients' remaining lifespan. **METHODS:** A nationwide cohort study of older adults (those aged ≥65 years) with solid tumors who died between 2007 and 2013 was performed in Sweden, using routinely collected data with record linkage. The authors calculated the monthly use and cost of preventive drugs throughout the last year before the patients' death. **RESULTS:** Among 151,201 older persons who died with cancer (mean age, 81.3 years [standard deviation, 8.1 years]), the average number of drugs increased from 6.9 to 10.1 over the course of the last year before death. Preventive drugs frequently were continued until the final month of life, including antihypertensives, platelet aggregation inhibitors, anticoagulants, statins, and oral antidiabetics. Median drug costs amounted to $1482 (interquartile range [IQR], $700-$2896]) per person, including $213 (IQR, $77-$490) for preventive therapies. Compared with older adults who died with lung cancer (median drug cost, $205; IQR, $61-$523), costs for preventive drugs were higher among older adults who died with pancreatic cancer (adjusted median difference, $13; 95% confidence interval, $5-$22) or gynecological cancers (adjusted median difference, $27; 95% confidence interval, $18-$36). There was no decrease noted with regard to the cost of preventive drugs throughout the last year of life. **CONCLUSIONS:** Preventive drugs commonly are prescribed during the last year of life among older adults with cancer, and often are continued until the final weeks before death. Adequate deprescribing strategies are warranted to reduce the burden of drugs with limited clinical benefit near the end of life. ***Cancer* 2019;0:1-9**. © *2019 American Cancer Society*.

KEYWORDS: deprescribing, drug prescribing, end of life, palliative care.

INTRODUCTION

In high-income countries, individuals aged ≥70 years now account for nearly two-thirds of cancer-related deaths.[1] Chronic multimorbidity thus has become the norm rather than the exception in oncology,[2] and is associated with poorer chances of survival and with a higher burden of functional impairments and physical symptoms.[3] Multimorbidity also comes with a higher burden of long-term pharmacological treatments. In the United States and in Europe, approximately 40% of individuals aged ≥65 years use ≥5 drugs concomitantly.[4,5] This polypharmacy is particularly problematic among older individuals with advanced cancer[6] because the potential to develop serious drug-drug interactions is amplified by the use of anticancer agents and complementary medicines.[7,8] Moreover, the probability of experiencing adverse drug reactions increases because the main pharmacokinetic parameters are affected not only by age but also by the physiological impact of cancer (eg, modified drug absorption due to gastrointestinal symptoms or to impairments in the gut wall function, a decrease in the volume of distribution caused by weight loss, or renal impairment due to the nephrotoxicity of chemotherapy).[9,10]

Beyond pharmacology, polypharmacy within the context of advanced cancer also raises important questions from a clinical and ethical viewpoint. As cancer progresses and the prognosis worsens, the net benefit of each additional medicine gradually decreases while the risk of harm increases. This "law of diminishing returns" makes the continuation or initiation of long-term treatments particularly questionable for older patients with advanced cancer. Preventive drugs are prescribed either to avert or delay the onset of a disease among individuals who are considered to be at high risk of developing that disease in the future (primary prevention), or to avoid the recurrence of a condition that the patient experienced in the past (secondary prevention). These drugs typically need several years before the

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Clinical data and individual data from the Swedish Prescribed Drug Register cannot be made publicly available. However, additional information can be made available upon reasonable request to the authors.

Additional supporting information may be found in the online version of this article.

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01

Décrire

A quoi ressemble le monde qui nous entoure?

Dépenses de santé

HealthAffairs

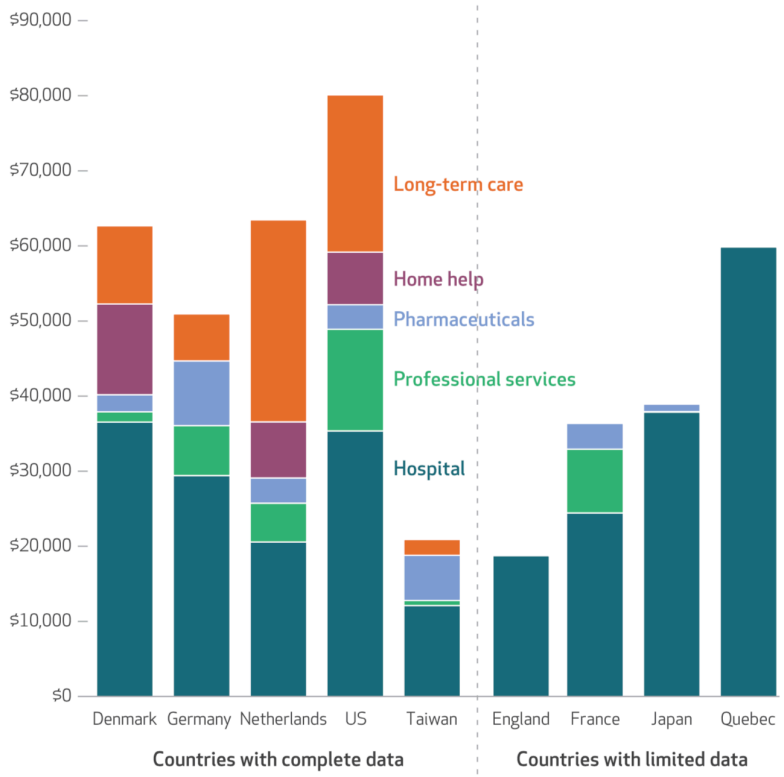
End-Of-Life Medical Spending In Last Twelve Months Of Life Is Lower Than Previously Reported

ABSTRACT **Although end-of-life medical spending is often viewed as a major component of aggregate medical expenditure, accurate measures of this type of medical spending are scarce. We used detailed health care data for the period 2009–11 from Denmark, England, France, Germany, Japan, the Netherlands, Taiwan, the United States, and the Canadian province of Quebec to measure the composition and magnitude of medical spending in the three years before death. In all nine countries, medical spending at the end of life was high relative to spending at other ages. Spending during the last twelve months of life made up a modest share of aggregate spending, ranging from 8.5 percent in the United States to 11.2 percent in Taiwan, but spending in the last three calendar years of life reached 24.5 percent in Taiwan. This suggests that high aggregate medical spending is due not to last-ditch efforts to save lives but to spending on people with chronic conditions, which are associated with shorter life expectancies.**

The high medical expenses that people incur close to death have attracted considerable interest from academics and policy makers over the past thirty years, particularly in the United States. Many consider unnecessary end-of-life care to be a major source of wasteful medical spending.[1] Despite this interest, evidence on medical spending shortly before death is relatively scarce and often based on incomplete measures of expenditure. More than two decades ago Ezekiel Emanuel and Linda Emanuel calculated that only about 10–12 percent of total US medical spending occurred during the year of death.[1] Not much follow-up evidence has emerged since then. Melissa Aldridge and Amy Kelley estimated a slightly higher end-of-life spending fraction, 13 percent, but relied extensively on imputations.[2] Gerald Riley and James Lubitz found that Medicare spending during the last year of life was one-quarter of total Medicare spending, a fraction essentially unchanged from thirty years before.[3] However, because Medicare covers the expenses only of the elderly and disabled and does not pay for long-term care and other services, Riley and Lubitz's results might not be representative of health spending as a whole.

Cross-country comparison of end-of-life medical spending has been difficult because most studies examine just one country, and each of those studies uses a different measure of medical spending. This is unfortunate; there is much to be learned by comparing end-of-life spending across countries with different mechanisms for the funding and provision of health care. Johan Polder and coauthors estimate that medical spending at the end of life constitutes 11 percent of total medical spending in the Netherlands, and they speculate that it may be higher in the

Mean per capita medical spending (in 2014 US dollars) in 9 countries in the last 12 months of life, by category of spending



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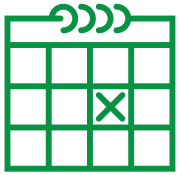

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BACK
TO THE FUTURE

JAMA

Resurrecting Treatment Histories of Dead Patients

A Study Design That Should Be Laid to Rest

Peter B. Bach, MD, MAPP
Deborah Schrag, MD, MPH
Colin B. Begg, PhD

In this article we address whether studies of care rendered to patients prior to their death ("studies of decedents") produce an accurate portrait of care provided to patients who are dying. Studies of decedents typically analyze the care provided to patients over a defined interval antecedent to death. Studies of dying patients analyze care provided to patients subsequent to the time that their terminal status is perceived. We address whether 2 fundamental differences between studies of decedents and studies of the dying—the ways that subjects are identified and the time periods that are examined—lead to differences in interpretation of study results. Using examples from population-based cohorts of individuals with cancer, we show that both the differences in subject selection and time period introduce very substantial biases into studies of decedents. We conclude that studying care received prior to death can lead to invalid conclusions about the quality or type of care provided to dying patients.

JAMA. 2004;292:2765-2770 www.jama.com

SEVERAL GROUPS, INCLUDING THE National Cancer Policy Board of the Institute of Medicine, have recommended that researchers study the care received by patients over a period of time prior to their death to characterize and ultimately improve the quality of care that is provided to dying patients.[1,2] To date, a large number of investigators have done so and, consistent with the National Cancer Policy Board's recommendations, have interpreted their results as being indicative of the care received by individuals who are perceived to be "dying" or who are "terminally ill."[3-22]

For instance, variations in hospice use prior to death between patients with different characteristics (eg, patients with and without a living will) have been interpreted as showing that access to comfort care is not uniform.[20,21,23] The finding that a large fraction of patients with cancer who died received chemotherapy prior to their death has been similarly interpreted as suggesting that cancer care is inadequately focused on comfort.[3,12,24]

At the heart of these studies is the laudable objective of identifying and addressing inadequacies in the quality of terminal care in the United States. Underlying them is the assumption that studying care received by individuals prior to their death is equivalent to studying care received by individuals who are dying. If this assumption is incorrect, then these analyses may be misrepresenting the care received by terminally ill patients, and thus motivating misguided quality improvement initiatives. In this article, we assess the underlying assumption in these studies. We show that due to design differences, studying care received by patients who have died may produce a biased portrait of terminal care when compared with study care received by dying patients.

Differences in Study Design

The Type of Study. Studies that observe care provided to dying patients are conceptually similar to studies that observe care rendered to patients prior to death. But the 2 types of studies follow different designs, have different underlying characteristics, and are typically used to study different types of research questions.

To study the dying, investigators traditionally identify a group of subjects who are known to be "dying," as evidenced by a sentinel event—for instance, subjects diagnosed with amyotrophic lateral sclerosis or metastatic cancer, transferred to a long-term acute care facility, or admitted to a hospice.[25-28] Investigators then observe the

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Le monde qui nous entoure aurait-il pu être différent?

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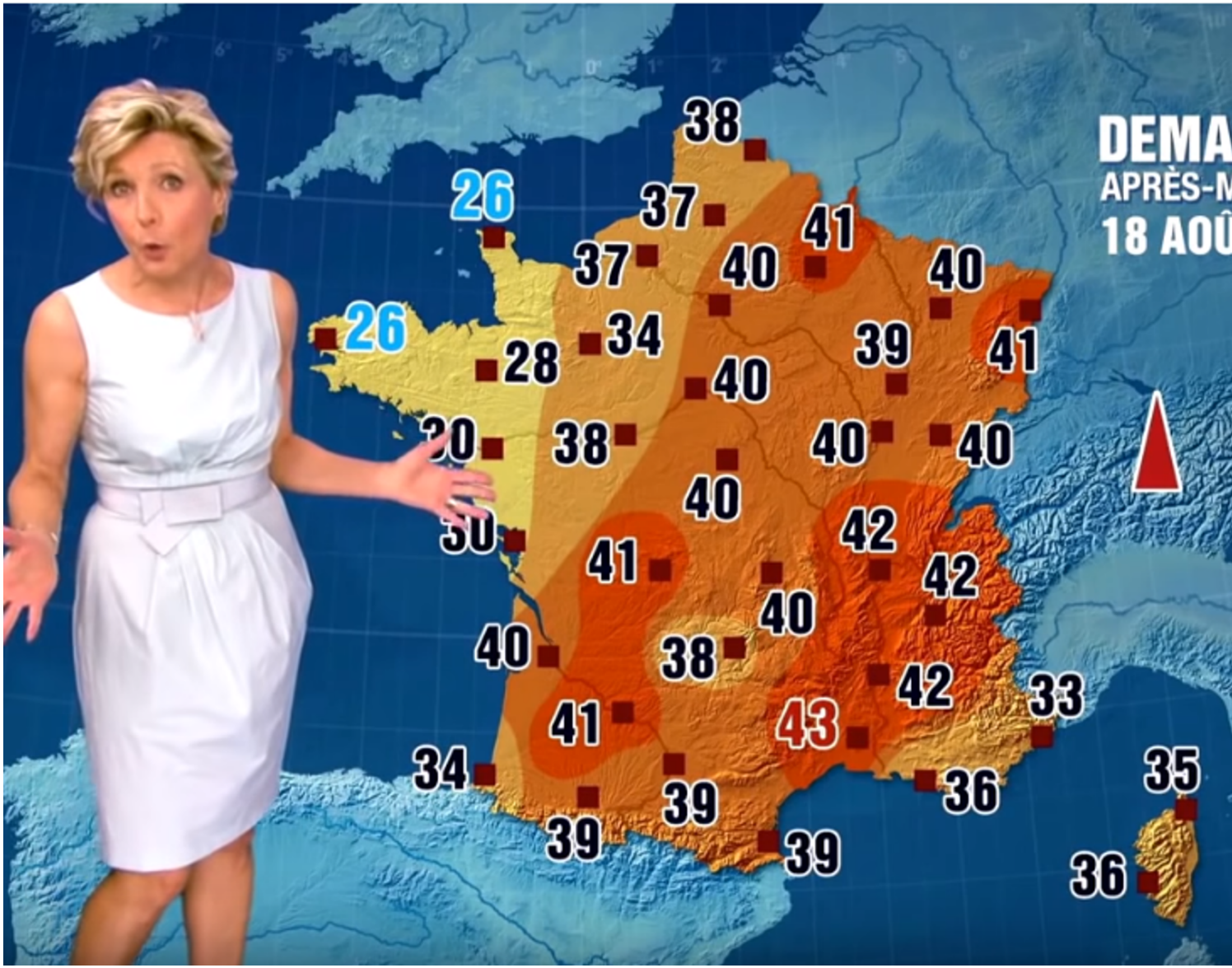

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A quoi ressemblera le monde de demain?

JAMA

Prognostic Indices for Older Adults
A Systematic Review

Lindsey C. Yourman, MD
Sei J. Lee, MD, MAS
Mara A. Schonberg, MD, MPH
Eric W. Widera, MD
Alexander K. Smith, MD, MS, MPH

Context To better target services to those who may benefit, many guidelines recommend incorporating life expectancy into clinical decisions.

Objective To assess the quality and limitations of prognostic indices for mortality in older adults through systematic review.

Data Sources We searched MEDLINE, EMBASE, Cochrane, and Google Scholar from their inception through November 2011.

Study Selection We included indices if they were validated and predicted absolute risk of mortality in patients whose average age was 60 years or older. We excluded indices that estimated intensive care unit, disease-specific, or in-hospital mortality.

Data Extraction For each prognostic index, we extracted data on clinical setting, potential for bias, generalizability, and accuracy.

Results We reviewed 21 593 titles to identify 16 indices that predict risk of mortality from 6 months to 5 years for older adults in a variety of clinical settings: the community (6 indices), nursing home (2 indices), and hospital (8 indices). At least 1 measure of transportability (the index is accurate in more than 1 population) was tested for all but 3 indices. By our measures, no study was free from potential bias. Although 13 indices had *C* statistics of 0.70 or greater, none of the indices had *C* statistics of 0.90 or greater. Only 2 indices were independently validated by investigators who were not involved in the index's development.

Conclusion We identified several indices for predicting overall mortality in different patient groups; future studies need to independently test their accuracy in heterogeneous populations and their ability to improve clinical outcomes before their widespread use can be recommended.

JAMA. 2012;307(2):182-192 www.jama.com

Failure to consider prognosis in the context of clinical decision making can lead to poor care. Hospice is underutilized for patients with nonmalignant yet life-threatening diseases.[1] Healthy older patients with good prognosis have low rates of cancer screening.[2] Older adults with advanced dementia or metastatic cancer are screened for slow-growing cancers that are unlikely to ever cause them symptoms but may lead to distress from false-positive results, invasive workups, and treatments.[3,4] In recognition of these phenomena, guidelines increasingly incorporate life expectancy as a central factor in weighing the benefits and the burdens of tests and treatments (Table 1). Prognostic indices offer a potential role for moving beyond arbitrary age-based cutoffs in clinical decision making for older adults.[2] However, little is known about the quality of prognostic indices for older adults, limiting their clinical use.

We performed a systematic review to describe the quality and limitations of validated non–disease-specific prognostic indices that predict absolute risk of all-cause mortality in older adults. Recognizing that older adults are more likely to have more than 1 chronic illness than younger adults, we focused on non–disease-specific indices.

For editorial comment see p 199.

CME available online at www.jamaarchivescme.com and questions on p 205.

METHODS

We used broad Medical Subject Heading terms (eg, *mortality*, *prognosis*, *aged*) to search MEDLINE, EMBASE, Cochrane, and Google Scholar from their inception through November 2011 for English-language–validated prognostic indices that predicted absolute risk of all-cause mortality in patients whose average age was 60 years or older. Authors of included studies and experts in the field were contacted and asked for additional

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A quoi ressemblera le monde de demain?

nature medicine

The Artificial Intelligence Clinician learns optimal treatment strategies for sepsis in intensive care

Matthieu Komorowski[1,2,3], Leo A. Celi[3,4], Omar Badawi[3,5,6], Anthony C. Gordon[1*] and A. Aldo Faisal[2,7,8,9*]

Sepsis is the third leading cause of death worldwide and the main cause of mortality in hospitals[1–3], but the best treatment strategy remains uncertain. In particular, evidence suggests that current practices in the administration of intravenous fluids and vasopressors are suboptimal and likely induce harm in a proportion of patients[1,4–6]. To tackle this sequential decision-making problem, we developed a reinforcement learning agent, the Artificial Intelligence (AI) Clinician, which extracted implicit knowledge from an amount of patient data that exceeds by many-fold the life-time experience of human clinicians and learned optimal treatment by analyzing a myriad of (mostly suboptimal) treatment decisions. We demonstrate that the value of the AI Clinician's selected treatment is on average reliably higher than human clinicians. In a large validation cohort independent of the training data, mortality was lowest in patients for whom clinicians' actual doses matched the AI decisions. Our model provides individualized and clinically interpretable treatment decisions for sepsis that could improve patient outcomes.

Sepsis is defined as severe infection leading to life-threatening acute organ dysfunction[7]. The management of intravenous fluids and vasopressors in sepsis is a key clinical challenge and a top research priority[1,4]. Besides general guidelines, such as the Surviving Sepsis Campaign, no tool currently exists to personalize treatment of sepsis and assist clinicians in making decisions in real-time and at the patient level[4–6]. As a consequence, clinical variability in sepsis treatment is extreme, with consistent evidence that suboptimal decisions lead to poorer outcomes[8–10].

We developed the AI Clinician, a computational model using reinforcement learning, which is able to dynamically suggest optimal treatments for adult patients with sepsis in the intensive care unit (ICU). Reinforcement learning is a category of AI tools in which a virtual agent learns from trial-and-error an optimized set of rules—a policy—that maximizes an expected return[11,12]. Similarly, a clinician's goal is to make therapeutic decisions in order to maximize a patient's probability of a good outcome[12,13]. Reinforcement learning has many desirable properties that may help medical decision-making. The intrinsic design of models using reinforcement learning can handle sparse reward signals, which makes them well-suited to overcome the complexity related to the heterogeneity of patient responses to medical interventions and the delayed indications of the efficacy of treatments[11]. Importantly, these algorithms are able to infer optimal decisions from suboptimal training examples. Reinforcement learning has been successfully applied in the past to medical problems, such as diabetes and mechanical ventilation in the ICU[14–17].

Our AI Clinician was built and validated on two large nonoverlapping ICU databases containing data routinely collected from adult patients in the United States. The Medical Information Mart for Intensive Care version III (MIMIC-III)[18] was used for model development, and the eICU Research Institute Database (eRI) for model testing. In both datasets, we included adult patients fulfilling the international consensus sepsis-3 criteria[7]. After exclusion of ineligible cases, we included 17,083 admissions (88.4% of eligible patients with sepsis) from five separate ICUs in one tertiary teaching hospital and 79,073 admissions (73.6% of eligible patients with sepsis) from 128 different hospitals from MIMIC-III and eRI, respectively (Supplementary Fig. 1). Patient demographics and clinical characteristics are shown in Table 1 and Supplementary Table 1.

In both datasets, we extracted a set of 48 variables, including demographics, Elixhauser premorbid status[19], vital signs, laboratory values, fluids and vasopressors received (Supplementary Table 2). Patients' data were coded as multidimensional discrete time series with 4-h time steps, and for each patient, we included up to 72 h of measurements taken around the estimated time of onset of sepsis. The total volume of intravenous fluids and maximum dose of vasopressors administered over each 4-h period defined the medical treatments of interest. The model aims at optimizing patient mortality, so a reward was associated to survival and a penalty to death.

A Markov decision process (MDP) was used to model the patient environment and trajectories[20,21]. The various elements of the model were defined using patient data time series from the training set (a random sample of 80% of MIMIC-III; Fig. 1). We deployed the AI Clinician to solve the MDP and predict outcomes of treatment strategies. First, we evaluated the actual treatments of clinicians by analyzing all the prescriptions and computing the average return of each treatment option, which can take values from −100 to +100 in our model. Then, the MDP was solved using policy iteration, which identified the treatments that maximized return, that is, the expected 90-d survival of patients in the MIMIC-III cohort[11]. The resultant policy is referred to hereafter as the 'AI policy'.

Evaluating the performance of this new AI policy using the trajectories of patients generated by another policy (the clinicians' policy)

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A quoi ressemblera le monde de demain?

THE LANCET
Respiratory Medicine

Machine learning for real-time prediction of complications in critical care: a retrospective study

Alexander Meyer, Dina Zverinski, Boris Pfahringer, Jörg Kempfert, Titus Kuehne, Simon H Sündermann, Christof Stamm, Thomas Hofmann, Volkmar Falk, Carsten Eickhoff

Summary

Background The large amount of clinical signals in intensive care units can easily overwhelm health-care personnel and can lead to treatment delays, suboptimal care, or clinical errors. The aim of this study was to apply deep machine learning methods to predict severe complications during critical care in real time after cardiothoracic surgery.

Methods We used deep learning methods (recurrent neural networks) to predict several severe complications (mortality, renal failure with a need for renal replacement therapy, and postoperative bleeding leading to operative revision) in post cardiosurgical care in real time. Adult patients who underwent major open heart surgery from Jan 1, 2000, to Dec 31, 2016, in a German tertiary care centre for cardiovascular diseases formed the main derivation dataset. We measured the accuracy and timeliness of the deep learning model's forecasts and compared predictive quality to that of established standard-of-care clinical reference tools (clinical rule for postoperative bleeding, Simplified Acute Physiology Score II for mortality, and the Kidney Disease: Improving Global Outcomes staging criteria for acute renal failure) using positive predictive value (PPV), negative predictive value, sensitivity, specificity, area under the curve (AUC), and the F_1 measure (which computes a harmonic mean of sensitivity and PPV). Results were externally retrospectively validated with 5898 cases from the published MIMIC-III dataset.

Findings Of 47 559 intensive care admissions (corresponding to 42 007 patients), we included 11 492 (corresponding to 9269 patients). The deep learning models yielded accurate predictions with the following PPV and sensitivity scores: PPV 0·90 and sensitivity 0·85 for mortality, 0·87 and 0·94 for renal failure, and 0·84 and 0·74 for bleeding. The predictions significantly outperformed the standard clinical reference tools, improving the absolute complication prediction AUC by 0·29 (95% CI 0·23–0·35) for bleeding, by 0·24 (0·19–0·29) for mortality, and by 0·24 (0·13–0·35) for renal failure ($p<0·0001$ for all three analyses). The deep learning methods showed accurate predictions immediately after patient admission to the intensive care unit. We also observed an increase in performance in our validation cohort when the machine learning approach was tested against clinical reference tools, with absolute improvements in AUC of 0·09 (95% CI 0·03–0·15; p=0·0026) for bleeding, of 0·18 (0·07–0·29; p=0·0013) for mortality, and of 0·25 (0·18–0·32; $p<0·0001$) for renal failure.

Interpretation The observed improvements in prediction for all three investigated clinical outcomes have the potential to improve critical care. These findings are noteworthy in that they use routinely collected clinical data exclusively, without the need for any manual processing. The deep machine learning method showed AUC scores that significantly surpass those of clinical reference tools, especially soon after admission. Taken together, these properties are encouraging for prospective deployment in critical care settings to direct the staff's attention towards patients who are most at risk.

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BMC Medical Informatics and Decision Making

RESEARCH Open Access

Improving palliative care with deep learning

Anand Avati[1*], Kenneth Jung[2], Stephanie Harman[3], Lance Downing[2], Andrew Ng[1] and Nigam H. Shah[2]

Abstract

Background: Access to palliative care is a key quality metric which most healthcare organizations strive to improve. The primary challenges to increasing palliative care access are a combination of physicians over-estimating patient prognoses, and a shortage of palliative staff in general. This, in combination with treatment inertia can result in a mismatch between patient wishes, and their actual care towards the end of life.

Methods: In this work, we address this problem, with Institutional Review Board approval, using machine learning and Electronic Health Record (EHR) data of patients. We train a Deep Neural Network model on the EHR data of patients from previous years, to predict mortality of patients within the next 3-12 month period. This prediction is used as a proxy decision for identifying patients who could benefit from palliative care.

Results: The EHR data of all admitted patients are evaluated every night by this algorithm, and the palliative care team is automatically notified of the list of patients with a positive prediction. In addition, we present a novel technique for decision interpretation, using which we provide explanations for the model's predictions.

Conclusion: The automatic screening and notification saves the palliative care team the burden of time consuming chart reviews of all patients, and allows them to take a proactive approach in reaching out to such patients rather then relying on referrals from the treating physicians.

Keywords: Deep learning, Palliative care, Electronic health records, Interpretation

Background

The gap between the desires of patients of how they wish to spend their final days, versus how they actually spend, is well studied and documented. While approximately 80% of Americans would like to spend their final days at home if possible, only 20% do [1]. Of all the deaths that happen in the United States, up to 60% of them happen in an acute care hospital while the patient was receiving aggressive care. Over the past decade access to palliative care resources has been on the rise in the United States. In 2008, Of all hospitals with fifty or more beds, 53% of them reported having palliative care teams; which rose to 67% in 2015 [2]. However, data from the National Palliative Care registry estimates that, despite increasing access, less than half of the 7-8% of all hospital admissions that need palliative care actually receive it [3]. A major contributor for this gap is the shortage of palliative care workforce [4]. Yet, technology can still play a crucial role by efficiently identifying patients who may benefit most from palliative care, but might otherwise slip through the cracks under current care models.

We address two aspects of this problem in our study. First, physicians tend to be overoptimistic, work under extreme time pressures, and as a result may not fail to refer patients to palliative care even when they may benefit [5]. This leads to patients often failing to have their wishes carried out at their end of life [6] and overuse of aggressive care. Second, the shortage of professionals in palliative care makes it expensive and time-consuming for them to proactive identify candidate patients via manual chart review of all admissions.

Another challenge is that the criteria for deciding which patients benefit from palliative care may be impossible to state explicitly and accurately. In our approach, we use deep learning to automatically screen all patients admitted to the hospital, and identify those who are most likely

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THE LINDVALL LAB

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DANA-FARBER CANCER INSTITUTE

HARVARD T.H. CHAN SCHOOL OF PUBLIC HEALTH

Massachusetts Institute of Technology

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Needle in a Haystack: Natural Language Processing to Identify Serious Illness

Brooks Udelsman, MD, MHS,[1] Isabel Chien, BS,[2,3] Kei Ouchi, MD,[4] Kate Brizzi, MD,[5,6] James A. Tulsky, MD,[2,7] and Charlotta Lindvall, MD, PhD[2,7]

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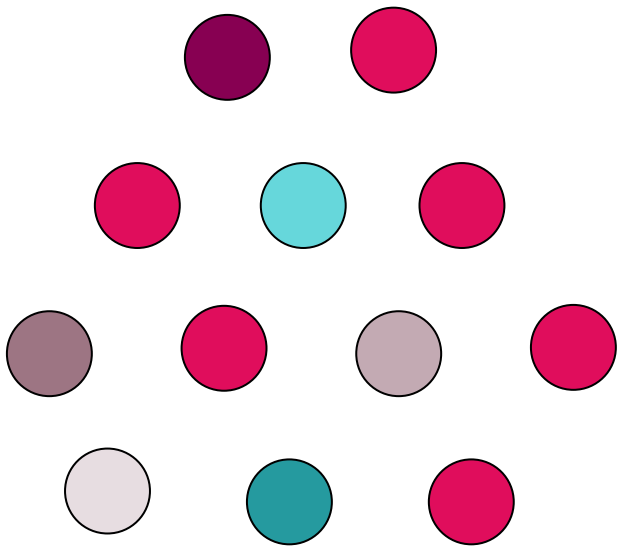

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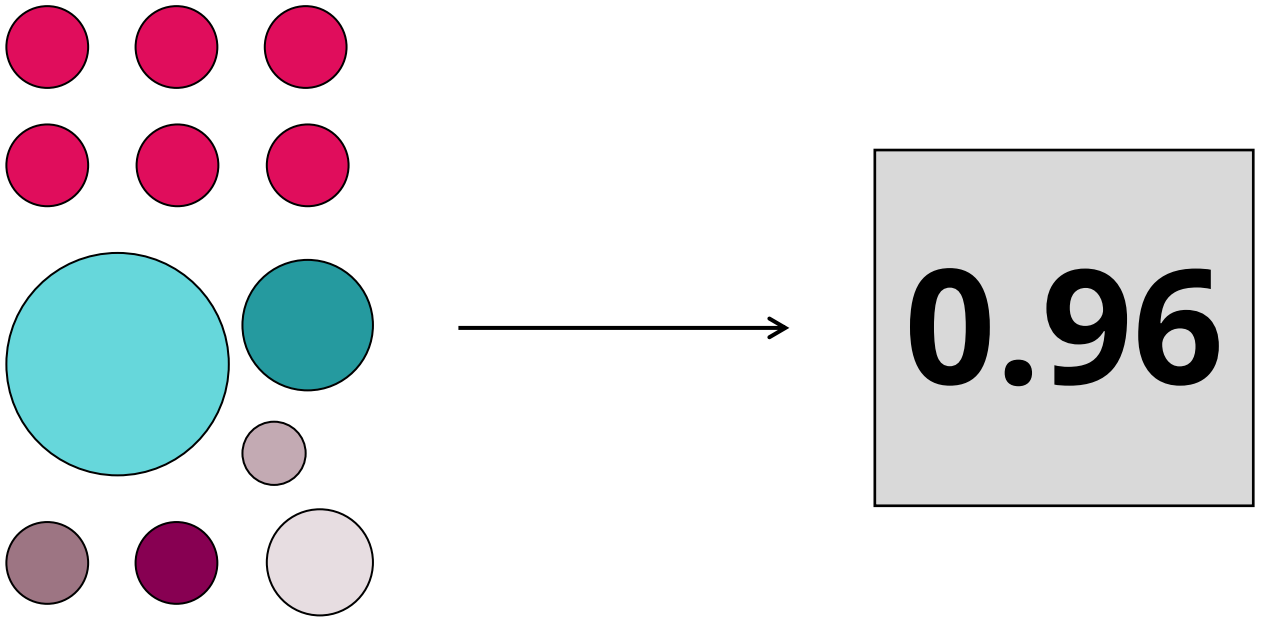

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Anticipation des complications

Précision diagnostique/prognostique

Identification des patients-cibles

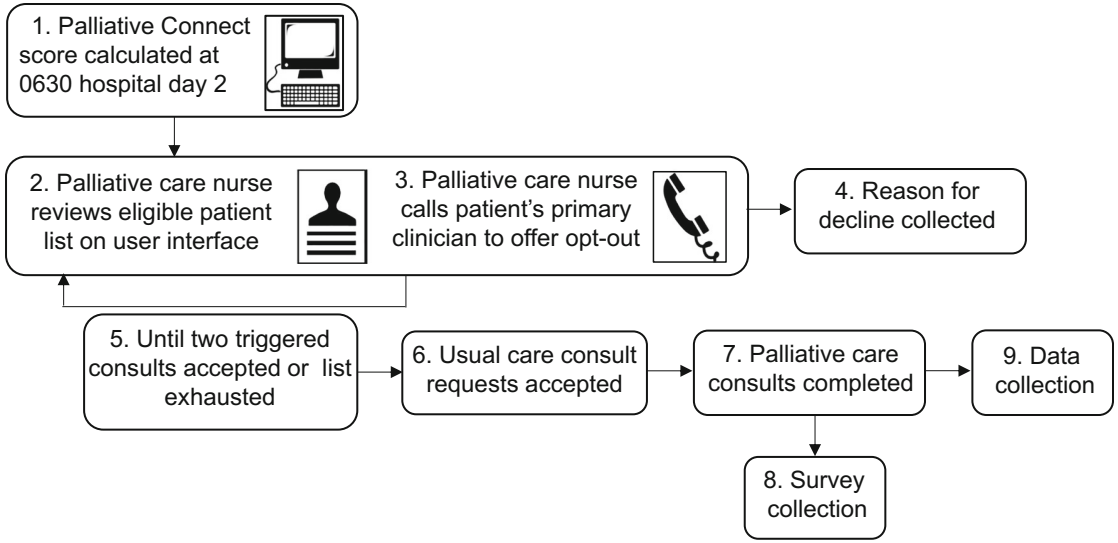
Katherine Courtright

University of Pennsylvania

JGIM
Journal of General Internal Medicine

Electronic Health Record Mortality Prediction Model for Targeted Palliative Care Among Hospitalized Medical Patients: a Pilot Quasi-experimental Study

Katherine R. Courtright, MD, MS[1,2], Corey Chivers, PhD[3], Michael Becker, BSc[3], Susan H. Regli, PhD[4], Linnea C. Pepper, MD[1], Michael E. Draugelis, BSc[3], and Nina R. O'Connor, MD[1,2]



Daniel Stow

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Stow *et al. BMC Medicine* (2018) 16:171
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BMC Medicine

RESEARCH ARTICLE Open Access

Frailty trajectories to identify end of life: a longitudinal population-based study

Daniel Stow, Fiona E. Matthews and Barbara Hanratty*

Abstract

Background: Timely recognition of the end of life allows patients to discuss preferences and make advance plans, and clinicians to introduce appropriate care. We examined changes in frailty over 1 year, with the aim of identifying trajectories that could indicate where an individual is at increased risk of all-cause mortality and may require palliative care.

Methods: Electronic health records from 13,149 adults (cases) age 75 and over who died during a 1-year period (1 January 2015 to 1 January 2016) were age, sex and general practice matched to 13,149 individuals with no record of death over the same period (controls). Monthly frailty scores were obtained for 1 year prior to death for cases, and from 1 January 2015 to 1 January 2016 for controls using the electronic frailty index (eFI; a cumulative deficit measure of frailty, available in most English primary care electronic health records, and ranging in value from 0 to 1). Latent growth mixture models were used to investigate longitudinal patterns of change and associated impact on mortality. Cases were reweighted to the population level for tests of diagnostic accuracy.

Results: Three distinct frailty trajectories were identified. Rapidly rising frailty (initial increase of 0.022 eFI per month before slowing from a baseline eFI of 0.21) was associated with a 180% increase in mortality (OR 2.84, 95% CI 2.34–3.45) for 2.2% of the sample. Moderately increasing frailty (eFI increase of 0.007 per month, with baseline of 0.26) was associated with a 65% increase in mortality (OR 1.65, 95% CI 1.54–1.76) for 21.2% of the sample. The largest (76.6%) class was stable frailty (eFI increase of 0.001 from a baseline of 0.26). When cases were reweighted to population level, rapidly rising frailty had 99.1% specificity and 3.2% sensitivity (positive predictive value 19.8%, negative predictive value 93.3%) for predicting individual risk of mortality.

Conclusions: People aged over 75 with frailty who are at highest risk of death have a distinctive frailty trajectory in the last 12 months of life, with a rapid initial rise from a low baseline, followed by a plateau. Routine measurement of frailty can be useful to support clinicians to identify people with frailty who are potential candidates for palliative care, and allow time for intervention.

Keywords: Frailty, Geriatrics, Palliative care, Primary care, End of life

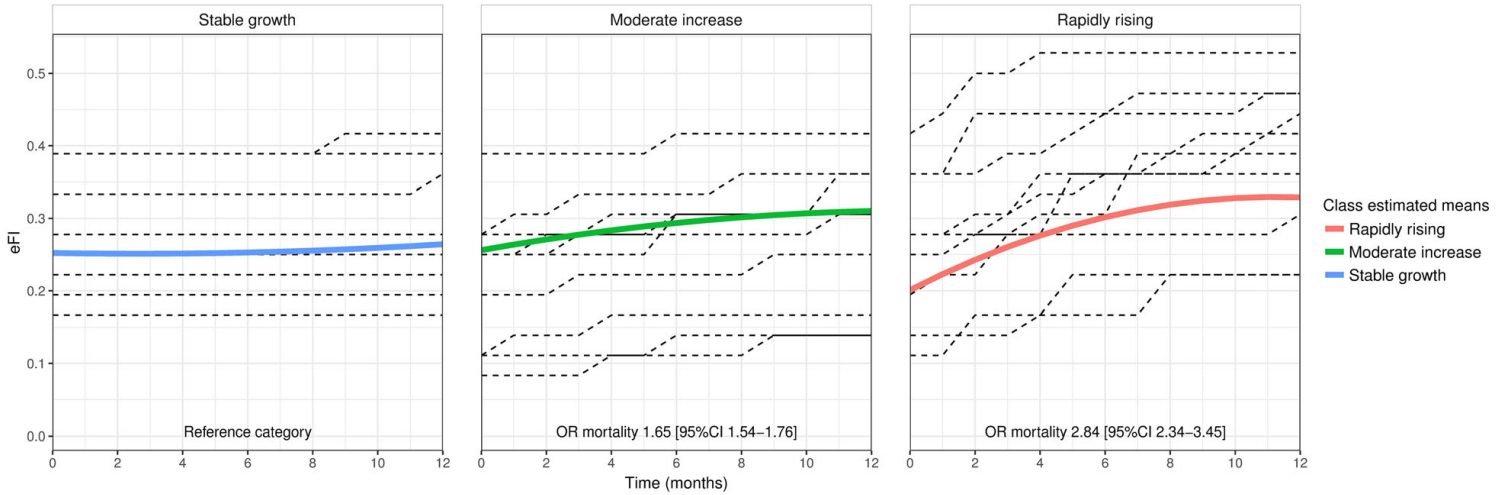

Fig. 1 Estimated mean trajectories of eFI over 1 year for each of the three latent classes with a random sample of observed individual trajectories for each class

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WESTWORLD

Etablir un lien de cause à effet

En quoi le monde qui nous observons diffère-t-il du monde que nous *aurions observé* si un élément très précis avait été modifé?

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Z = 0

Z = 1

?

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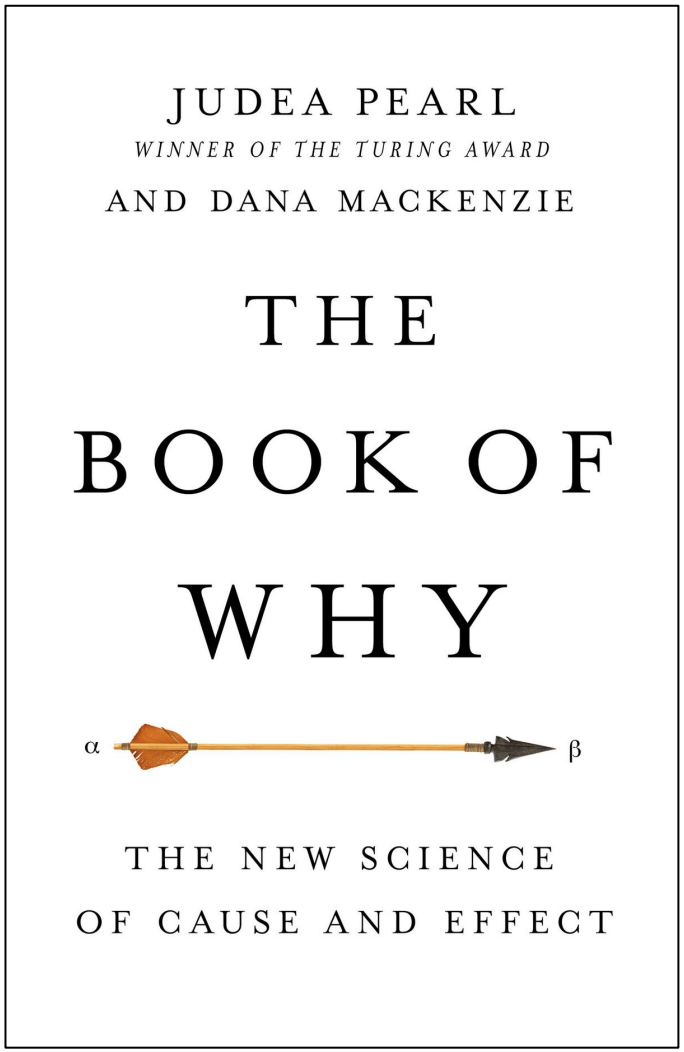

En moyenne, l'intervention Z améliore-t-elle la qualité de vie des personnes malades ?

Etablir un lien de cause à effet

- Traitements
- Parcours de soins
- Politiques de santé
- Modalités de tarification

03

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The NEW ENGLAND JOURNAL of MEDICINE

SPECIAL ARTICLE

Changes in Medicare Costs with the Growth of Hospice Care in Nursing Homes

Pedro Gozalo, Ph.D., Michael Plotzke, Ph.D., Vincent Mor, Ph.D., Susan C. Miller, Ph.D., and Joan M. Teno, M.D.

ABSTRACT

BACKGROUND

Nursing home residents' use of hospice has substantially increased. Whether this increase in hospice use reduces end-of-life expenditures is unknown.

METHODS

The expansion of hospice between 2004 and 2009 created a natural experiment, allowing us to conduct a difference-in-differences matched analysis to examine changes in Medicare expenditures in the last year of life that were associated with this expansion. We also assessed intensive care unit (ICU) use in the last 30 days of life and, for patients with advanced dementia, feeding-tube use and hospital transfers within the last 90 days of life. We compared a subset of hospice users from 2009, whose use of hospice was attributed to hospice expansion, with a matched subset of non–hospice users from 2004, who were considered likely to have used hospice had they died in 2009.

RESULTS

Of 786,328 nursing home decedents, 27.6% in 2004 and 39.8% in 2009 elected to use hospice. The 2004 and 2009 matched hospice and nonhospice cohorts were similar (mean age, 85 years; 35% male; 25% with cancer). The increase in hospice use was associated with significant decreases in the rates of hospital transfers (2.4 percentage-point reduction), feeding-tube use (1.2 percentage-point reduction), and ICU use (7.1 percentage-point reduction). The mean length of stay in hospice increased from 72.1 days in 2004 to 92.6 days in 2009. Between 2004 and 2009, the expansion of hospice was associated with a mean net increase in Medicare expenditures of $6,761 (95% confidence interval, 6,335 to 7,186), reflecting greater additional spending on hospice care ($10,191) than reduced spending on hospital and other care ($3,430).

03

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Open access Research

BMJ Open

Impact of palliative home care support on the quality and costs of care at the end of life: a population-level matched cohort study

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► Prepublication history and additional material for this paper are available online. To view these files, please visit the journal online (http://dx.doi.org/10.1136/bmjopen-2018-025180).

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ABSTRACT

Objectives To evaluate the impact of palliative home care support on the quality of care and costs in the last 14 days of life.

Design Matched cohort study using linked administrative databases.

Setting All people who died in Belgium in 2012 (n=107 847).

Participants 8837 people who received palliative home care support in the last 720 to 15 days of life matched 1:1 by propensity score to 8837 people who received usual care.

Intervention Receiving the allowance for palliative home patients, multidisciplinary palliative home care team visit or palliative nurse or physiotherapist visit at home.

Main outcome measures Home death, number of family physician contacts, number of primary caregiver contacts, hospital death, hospital admission, intensive care unit (ICU) admission, emergency department (ED) admission, diagnostic testing, blood transfusion and surgery. Total inpatient and outpatient costs. All outcomes were measured in the last 14 days of life.

Results In the unmatched cohort, 11 149 (13.5%) people received palliative home care support in the last 720 to 15 days of life. After matching, those using palliative home care support had, compared with those who did not, more family physician contacts (mean 3.1 [SD=6.5] vs 0.8 [SD=1.2]), more chance of home death (56.2%vs13.8%; relative risk [RR]=4.08, 95% CI 3.86 to 4.31), lower risk of hospital admission (27.4%vs60.8%; RR=0.45, 95% CI 0.43 to 0.46), ICU admission (18.3%vs40.4%; RR=0.45, 95% CI 0.43 to 0.48) or ED admission (15.2%vs28.1%; RR=0.54, 95% CI 0.51 to 0.57). Mean total costs of care were lower for those using palliative home care support (€3081 [95% CI €3025 to €3136] vs €4698 [95% CI €4610 to €4787]; incremental cost: −€1617 [p<0.001]).

Conclusions Palliative home care support use positively impacts quality of care and reduces total costs of care at the end of life in Belgium. Policy makers and healthcare practitioners should increasingly focus on communicating the existing options for palliative home care support to patients and their caregivers.

Strengths and limitations of this study

- By using nationwide administrative data on every death over one whole year, our findings are generalisable to the full population, whereas experimental studies, surveys or sample-based observational studies often have difficulties in reaching certain under-represented subgroups and lack the strength necessary for generalisability.
- A matched cohort study design with a high-quality matching is the best possible technique to evaluate the impact of policy on quality and costs of care, given ethical and practical concerns.
- No previous work has evaluated the impact of all palliative home care support available in one country for the full population.
- Our operationalisation of palliative home care support as the use of any of available policy measure increases the reproducibility of our study in other countries and allows comparison studies that focus on the impact of other existing types of palliative home care support, especially in countries with similar health care service delivery models and funding.
- Important aspects of quality end-of-life care are not visible in administrative data, such as quality of communication, existential or psychological care. Qualitative research can complement our findings.

BACKGROUND

A majority of the growing population encountered with chronic and life-limiting illnesses prefers to receive high-quality care and to die at home.[1 2] Palliative home care support aims to meet the needs of these people by managing symptoms, improving quality of life and preventing avoidable healthcare interventions such as hospitalisations at the end of life.[3] It is estimated that palliative care could be beneficial in 38%–74% of all deaths worldwide.[4] In recent years, policy makers internationally have focused on promoting the integration of palliative care services into the community and on developing supportive

Validité externe (généralisabilité)

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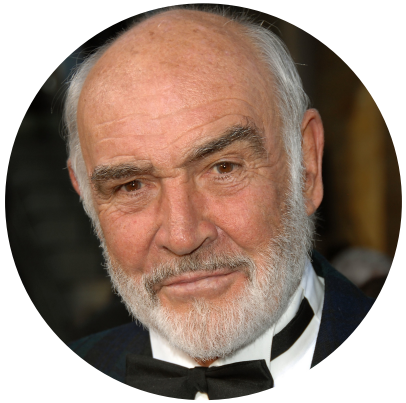
Essai clinique



Cohorte

Monde réel

Les données collectées en routine (e.g. SNDS, CPRD, SEER, Medicare) sont aveugles aux préférences des patients.

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JAMA Internal Medicine

Association of β-Blockers With Functional Outcomes, Death, and Rehospitalization in Older Nursing Home Residents After Acute Myocardial Infarction

Michael A. Steinman, MD; Andrew R. Zullo, PharmD, ScM; Yoojin Lee, MS, MPH; Lori A. Daiello, PharmD, ScM; W. John Boscardin, PhD; David D. Dore, PharmD, PhD; Siqi Gan, MPH; Kathy Fung, MS; Sei J. Lee, MD, MAS; Kiya D. R. Komaiko, BA; Vincent Mor, PhD

Table 3. Effect of β-Blockers on Main Outcomes

Outcome	β-Blocker Users vs Nonusers, OR/HR (95% CI)[a]	NNH or NNT, Point Estimate (95% CI)[b]
Functional decline	1.14 (1.02-1.28)	NNH 52 (32-141)
Death, HR (95% CI)	0.74 (0.67-0.83)	NNT 26 (19-39)
Rehospitalization, HR (95% CI)	1.06 (0.98-1.14)	NNH 82 (NNH 250 to ∞ to NNT 36)[c]

Abbreviations: HR, hazard ratio; NNH, number needed to harm; NNT, number needed to treat; OR, odds ratio.

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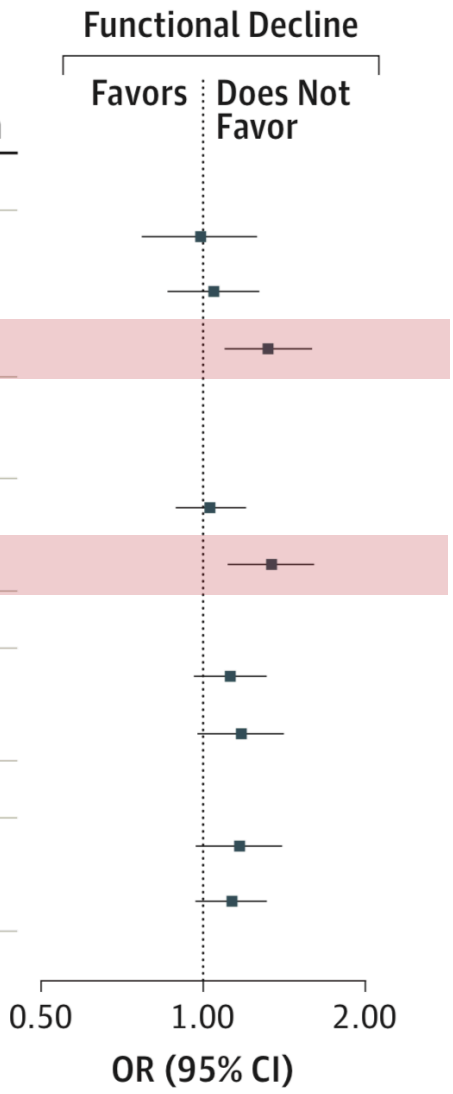
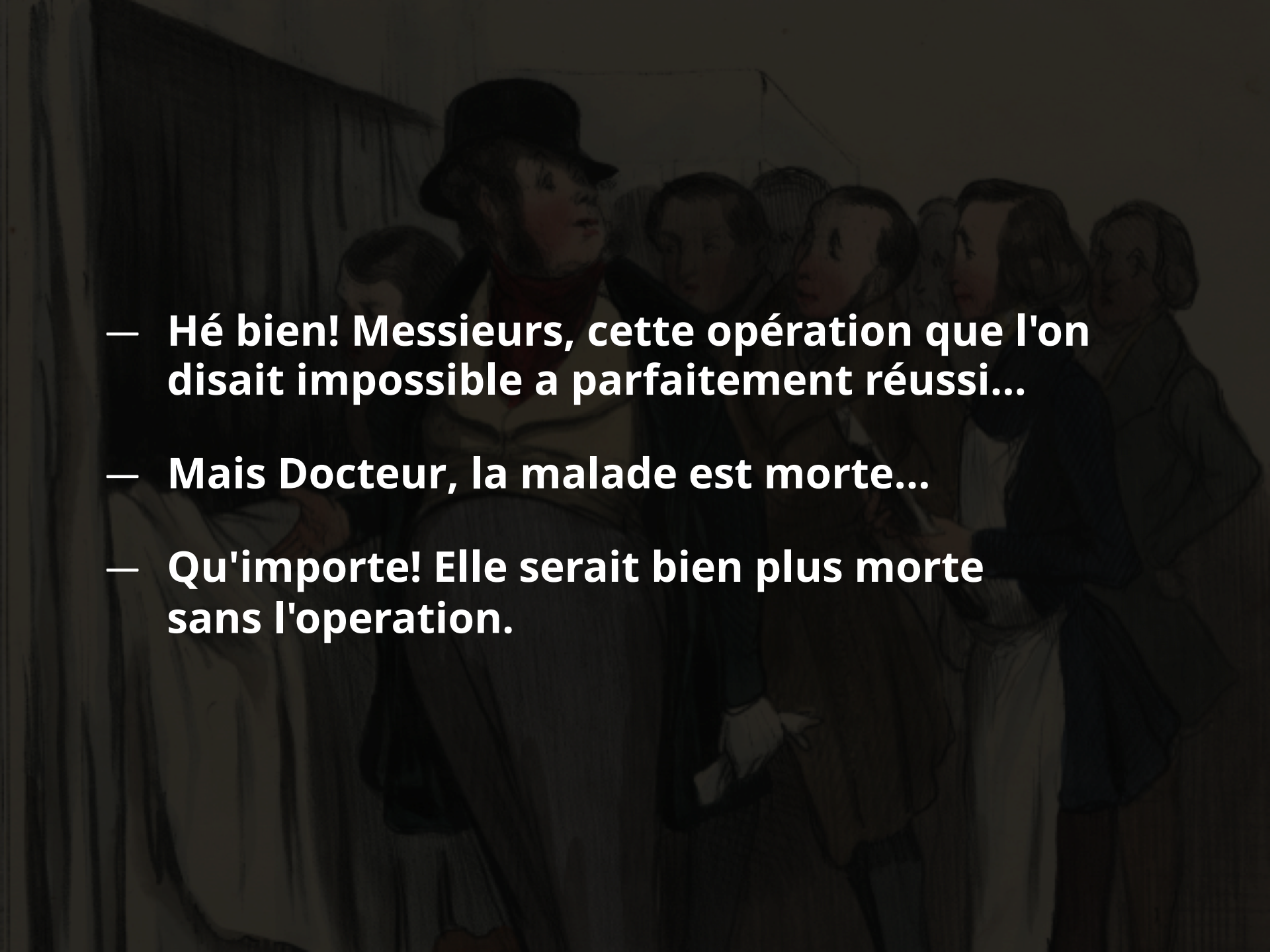
Subgroup	OR (95% CI)	*P* Value for Effect Modification
ADL score[a]		
<14	0.99 (0.77-1.26)	
14-19	1.05 (0.86-1.27)	.06
>20	1.32 (1.10-1.59)	
Cognitive performance score[b]		
0-2	1.03 (0.89-1.20)	.03
3-6	1.34 (1.11-1.61)	
Age, y		
<85	1.12 (0.96-1.31)	.68
≥85	1.18 (0.98-1.41)	
CCU/ICU stay		
None	1.17 (0.97-1.40)	.78
≥1 d	1.13 (0.97-1.31)	



Au delà des difficultés méthodologiques et statistiques, les *big data* présentent un problème conceptuel important: elles ne permettent pas de mesurer ce qui a du sens pour les personnes malades.

Poser des **questions pertinentes**
pour apporter des **réponses utiles**


— Hé bien! Messieurs, cette opération que l'on disait impossible a parfaitement réussi...
— Mais Docteur, la malade est morte...
— Qu'importe! Elle serait bien plus morte sans l'operation.

Patient-Reported Outcome Measures (PROMs)

EAPC VZW

Call for papers for a special issue of *Palliative Medicine*: "Big Data in Palliative and End-of-Life Care"

Guest Editors: Bregje Onwuteaka-Philipsen and Lucas Morin

We are delighted to announce a call for papers for a special issue of *Palliative Medicine* about big data in palliative and end-of-life care. Deadline for submissions is Friday 17 April 2020.

Read more: https://journals.sagepub.com/home/pmj

Date limite pour soumettre vos manuscrits: 17 avril 2020

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