What can big data do for public health palliative care research?

Joachim Cohen
Big data as the promise for health care?
Big data as the promise for health care?
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Big data as the promise for health care?

Assist in addressing various public health functions:

1. Population needs assessment and monitoring
2. Health care system & quality of care evaluations
3. Evaluation of policies, interventions, programs
4. Providing better evidence about effectiveness where this is difficult
5. More efficient RCTs
6. Algorithms for prediction and prospective decision support
What can big data do for end-of-life care?

Assist in addressing various public health functions:

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What big data?

**Health care use**
For every use:
- Nomenclature code
- Date
- By whom
- Cost,
- ...

**Medication dispensions:**
For every dispensation:

**End-of-Life Care dataset**
Cohort of deaths 2010-2015
For every death:
- Cause and place of death
- Cancer diagnosis
- All health care use last 24 months
- All medication use last 24 months
- Sociodemographics
- ...

**Cancer Registry**
For every new diagnosis:
- Type (ICD-O)
- Date
- TNM
- ...

**Death certificate data**

**Census data**
Housing information

**Population data**
For every resident:
- Sociodemographic information
  - Household situation

**Fiscal data**
Tax revenues and income
Function 1: population needs assessment and monitoring
Proportion of home-dwelling population in need of PC actually using home PC differs by age and region, 2015, N= 87,007

Function 1: population needs assessment and monitoring
Regional variation in receiving palliative home care

Adjusting for:
- Age
- Sex
- Diagnosis
- Household composition
- Income
- Educational level
- Urbanicity
- Care severity (hospitalizations in last 2 years)
- Care dependency
Function 2: Health care system & quality of care evaluations
How to read the region-variation in **risk-adjusted** QI scores

- Lowest scoring region
- median
- Highest scoring region

Name of indicator
Strong variation between regions in inappropriate EOLC for those with COPD, n= 4,231

During last 30 days of life:

- Late initiation of palliative care (last week) 2.9%
- Bloodtransfusion 6.6%
- Surgery
- New antidepressant
- Reanimation after intubation
- coronary/abdominal surgery
- repeated intubation
Strong variation between regions in inappropriate EOLC for those with COPD, n= 4,231

During last 30 days of life:

- Hospital death
- ICU admission from nursing home
- ICU admission
- Hospital admission
- ED Admission
### Strong variation between regions in appropriate EOLC for those with COPD, n= 4,231

<table>
<thead>
<tr>
<th>Service</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Increased contacts with GP</td>
<td></td>
</tr>
<tr>
<td>Home/nursing home of residence death</td>
<td></td>
</tr>
<tr>
<td>Home death</td>
<td></td>
</tr>
<tr>
<td>Palliative status</td>
<td></td>
</tr>
<tr>
<td>Specialist palliative care</td>
<td></td>
</tr>
<tr>
<td>Inhalation therapy</td>
<td></td>
</tr>
<tr>
<td>Opioids</td>
<td></td>
</tr>
</tbody>
</table>

![Graph showing variation in appropriate EOLC]
Function 3: Evaluation of policies, interventions, programs

Time trends to evaluate whether policies have intended effects
• Use of palliative care
• Timing of palliative care
Increase in use of palliative home care (PHC) measures 2010-2015

- Any PHC measure: +3.3 p.p.
- Palliative Lump sum: +2.3 p.p.
- Palliative home nursing of Physio: +3.4 p.p.
- Specialized PHC team: +2.7 p.p.
A slight shift towards earlier initiation

- Cancer: Earlier 47, Later 2015; Earlier 42, Later 2010
- Organ failure: Earlier 38, Later 2015; Earlier 29, Later 2010
- Dementia: Earlier 31.5, Later 2015; Earlier 29, Later 2010

Number of days before death
Function 4: Providing better evidence about effectiveness where this is difficult
What is the effect of using palliative home care on costs and appropriateness of end-of-life care?
Data used: All deaths in Belgium in 2012 (n=107,847)

- 8% Used palliative home care
- 92% Did not use palliative home care
Persons who used PHC (n=8,256)

- Hospitalised during last 14 days of life
  - 20% at least 1 hospitalisation
  - 80% no hospitalisation

Persons who did not use PHC (n=99,591)

- Hospitalised during last 14 days of life
  - 44% at least 1 hospitalisation
  - 56% no hospitalisation
Persons who used PHC (n=8,256)

Place of death

- In hospital: 24%
- Outside hospital: 76%

Persons who did not use PHC (n=99,591)

Place of death

- In hospital: 49%
- Outside hospital: 51%
Problem: important conditions for causal effect are missing

1. Covariance
   - Independent variables: HPC use
   - Dependent variables: quality and costs

2. Temporality
   - T0: Baseline
   - T1: Exposure
   - T2: Outcome

3. No confounding
   - HPC
   - Quality and costs of EOLC
   - Other factors
A classical RCT

1. Randomisation
2. Control over exposure
3. Evaluation effect (=intervention vs control)
A retrospective matched cohort design

1. Randomisation

Intervention

Matched for propensity to receive ‘intervention’

Outcomes

Matching the propensity score

Example data (fictional) N=9

<table>
<thead>
<tr>
<th>Obs</th>
<th>Outcome</th>
<th>Propensity score:</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Yes</td>
<td>0.77917</td>
</tr>
<tr>
<td>2</td>
<td>Yes</td>
<td>0.79674</td>
</tr>
<tr>
<td>3</td>
<td>No</td>
<td>0.17937</td>
</tr>
<tr>
<td>4</td>
<td>Yes</td>
<td>0.47309</td>
</tr>
<tr>
<td>5</td>
<td>No</td>
<td>0.83309</td>
</tr>
<tr>
<td>6</td>
<td>No</td>
<td>0.11415</td>
</tr>
<tr>
<td>7</td>
<td>No</td>
<td>0.47889</td>
</tr>
<tr>
<td>8</td>
<td>Yes</td>
<td>0.69812</td>
</tr>
<tr>
<td>9</td>
<td>No</td>
<td>0.74523</td>
</tr>
</tbody>
</table>

Calculated based on the confounders in the model
A retrospective matched cohort design

**Intervention**

1. Randomisation

2. Control over exposure

**Control**

**Outcomes**

Matched for propensity to receive ‘intervention’

T0 = before exposure

Exposure = HCT

T1 = final 2 weeks
A retrospective matched cohort design

1. Randomisation
   - Matched for propensity to receive ‘intervention’

2. Control over exposure
   - Control over exposure

3. Evaluation effect (=intervention vs control)

T0 = before exposure
Exposure = HCT
T1 = final 2 weeks
Use of palliative home care measures improves outcomes for quality EOLC in final 14 days

![Graph showing place of death and inappropriate EOLC]
... and reduces the costs of care in final 14 days
Study on **EFFECT of SPOUSAL LOSS on HEALTH OUTCOMES?**

Sweden
Function 5: More efficient RCTs

Big data provides data
- Fewer missings / drop-out problem
- Less burdening data-collection
- Less expensive

A classical RCT

Intervention

Outcomes

Control

Time
Function 6: Algorithms for prediction and prospective decision support

Improving Palliative Care with Deep Learning

Anand Avati*, Kenneth Jung†, Stephanie Harman‡, Lance Downing†, Andrew Ng‡ and Nigam H. Shah†

*Dept of Computer Science, Stanford University
Email: {avati,ang}@cs.stanford.edu
†Center for Biomedical Informatics Research, Stanford University
Email: {kjung,ldowning,nigam}@stanford.edu
‡Dept of Medicine, Stanford University School of Medicine
Email: {snharman}@stanford.edu

Abstract— Improving the quality of end-of-life care for hospitalized patients is a priority for healthcare organizations. Studies have shown that physicians tend to over-estimate prognoses, which in combination with treatment inertia results in a mismatch between patients' wishes and actual care at the end of life. We describe a method to address this problem using Deep Learning and Electronic Health Record (EHR) data, which is currently being piloted, with Institutional Review Board approval, at an academic medical center. The EHR data of admitted patients are automatically evaluated by an algorithm, which brings patients who are likely to benefit from palliative care services to the attention of the Palliative Care team. The algorithm is a Deep Neural Network trained on the EHR data from previous years, to predict all-cause 3-12 month mortality of patients as a proxy for patients that could benefit from palliative care. Our predictions enable the Palliative Care team to take a proactive approach in reaching out to such patients, rather than relying on referrals from treating physicians, or conduct time consuming chart reviews of all patients. We also present a novel interpretation technique which we use to provide explanations of the model’s predictions.

The criteria for deciding which patients benefit from palliative care can be hard to state explicitly. Our approach uses deep learning to screen patients admitted to the hospital to identify those who are most likely to have palliative care needs. The algorithm addresses a proxy problem - to predict the mortality of a given patient within the next 12 months - and use that prediction for making recommendations for palliative care referral. This feeds the palliative care team from manual chart review of every admission and helps counter the potential biases of treating physicians by providing an objective recommendation based on the patient's EHR. Currently existing tools to identify such patients have limitations, and they are discussed in the next section.

II. RELATED WORK
What can big data do for compassionate communities?

Assist in addressing various public health functions:

1. Population diagnosis
2. Outcome evaluation
# Evaluation framework for comcoms

<table>
<thead>
<tr>
<th>Structures</th>
<th>Process: activities</th>
<th>Output: Short-term achievements</th>
<th>Outcomes: Longer-term achievements</th>
</tr>
</thead>
<tbody>
<tr>
<td>Organizational capacity</td>
<td>policy development actions</td>
<td>Activities completed</td>
<td>individual, community or environmental health outcomes that are likely to take a longer period to achieve</td>
</tr>
<tr>
<td>Resources, funding</td>
<td>Actions to create supportive environments</td>
<td>Project objectives met?</td>
<td></td>
</tr>
<tr>
<td>Intersectoral partnerships</td>
<td>Education activities</td>
<td>Compare knowledge, attitude and practice change before and after activity</td>
<td></td>
</tr>
<tr>
<td>Community ownership</td>
<td>Community engagement activities</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Health services interactions</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Planning strategy</td>
<td></td>
<td></td>
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<td></td>
<td>Project evaluations</td>
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<tr>
<td>Examples of Indicators</td>
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<td>Examples of Indicators:</td>
</tr>
<tr>
<td>✓ Project office</td>
<td>✓ Community diagnosis</td>
<td>✓ Improvement in quality of EOLC</td>
<td>✓ Improvement in quality of EOLC</td>
</tr>
<tr>
<td>✓ Steering committee</td>
<td>✓ Activities implemented (eg nr of workshops, seminars)</td>
<td>✓ Improved bereavement experiences, support for family caregivers</td>
<td>✓ Improved bereavement experiences, support for family caregivers</td>
</tr>
<tr>
<td>✓ …</td>
<td>✓ Nr of target recipients involved in activities</td>
<td>✓ Increased death literacy</td>
<td></td>
</tr>
<tr>
<td></td>
<td>✓ Increased social capital</td>
<td>✓ Increased experiential learning</td>
<td></td>
</tr>
<tr>
<td></td>
<td>✓ Increased experiential learning</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Examples of Indicators**

- Project office
- Steering committee
- …
Candidate compassionate cities in Belgium

- Sint Niklaas
- Bruges
- Oostende
- Oudenaarde
- Herzele
1: community diagnosis

proportion with palliative status
- 13.0-14.8
- 14.8-16.2
- 16.2-16.9
- 16.9-17.8
- 17.8 or more

locations:
- Oostende
- Bruges
- Sint Niklaas
- Oudenaarde
- Herzele
Diagnosis of Bruges (quality EOLC QIs dementia)
2: outcome evaluation
Interrupted time series of EOLC outcomes (eg home death)
Improvement in risk-adjusted QI scores in [city] compared to all other cities

- Name of indicator
- QI2
- Lowest scoring region
- Highest scoring region
- Median
Conclusions

Big data can help the public health palliative care research agenda by:
1. assessing and monitoring need
2. quality of care evaluations
3. evaluation of policies, interventions, programs (including comcom!!)
4. providing evidence about effectiveness where this is difficult
5. enabling more efficient RCTs
6. working towards algorithms for prediction and prospective decision support

Limitations need to be acknowledged
Only provides one type of evidence