Death Registration in the 21st Century: Challenges and Opportunities

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Why am I here?

- Licensed in 3 states to certify cause of death
- Graduate, Cause of Death ‘short course’ (2am, July, 1992, 9200 nurses station, Barnes Hospital, St. Louis, MO)
- ‘Discovered’ the central importance of vital statistics: October, 2009
- It’s mid-August in DC!!
Why do vital statistics matter?

- Public policy
  - Assist in allocation of public health resources
  - Inform design of public health interventions
  - Guide funding for research and development
- Knowledge advancement
  - Measurement of population health status
  - Early detection of epidemics
  - Research
- Impact clinical practice
Considerations affecting the integrity of the US Death Registration System

- Data quality
- Timeliness of analyses and reporting
- Recognition of importance by healthcare providers and partners
- Greater understanding of the value by policy makers and the public
Quality of Cause of Death Data

• Numerous studies exist assessing quality of cause of death data
• Error rate varies from 20%-60% depending on the study
  • Differing gold standard
    • Autopsy diagnosis
    • Chart-substantiated diagnosis
  • Variable definitions of error
Physician-generated Errors

- Listing a mechanism as a cause
- Inadequate detail or specificity
- Improper causal sequence
- Competing causes
- Failure to include time intervals
- Incorrect use of Part II
NYC among highest reported heart disease (HD) death rates in US
- US 2006: 199/100,000 Population
- NYC 2006: 255/100,000 Population

Yet rates of HD risk factors (hypertension, cholesterol, smoking, obesity) largely comparable or better in NYC than nationally.

2003 NYC validation study: death certificates overestimated HD mortality >50% for decedents 35–74 yrs
- 94% overestimated for decedents 75–84 years
- 137% overestimated for decedents >85 years

### NYC/US Leading Causes of Death with Dissimilar Age-Adjusted Rates (per 100,000)

<table>
<thead>
<tr>
<th>Cause of Death</th>
<th>NYC</th>
<th>US</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diseases of heart I00-I09, I11, I13, I20-I51</td>
<td>254.7</td>
<td>199.4</td>
</tr>
<tr>
<td>Influenza and pneumonia J10-J18</td>
<td>29.9</td>
<td>17.7</td>
</tr>
<tr>
<td>Cerebrovascular diseases I60-I69</td>
<td>19.8</td>
<td>43.6</td>
</tr>
<tr>
<td>Chronic lower respiratory diseases J40-J47</td>
<td>16.5</td>
<td>40.4</td>
</tr>
<tr>
<td>Septicemia A40-A41</td>
<td>4.5</td>
<td>10.9</td>
</tr>
<tr>
<td>Alzheimer's disease G30</td>
<td>2.8</td>
<td>22.7</td>
</tr>
</tbody>
</table>
Randomly sampled 50 Death Certificates with Heart Disease as underlying cause:

- 64% documented only Heart Disease in Part I and Part II
- 36% documented other contributing causes with an underlying cause of Heart Disease
Deaths Due to Heart Disease by Reporting Institution, 2008

- % of Heart Disease Deaths per Hospital
- Cumulative % of NYC Total Deaths
- Cumulative % of NYC Heart Disease Deaths
Proportion of Heart Disease Deaths reported at Intervention and Non-intervention Hospitals reporting >50 deaths, NYC 2009–2010

Jan - Mar 2009: 0.633
Apr - Jun 2009: 0.627
Jul - Sept 2009: 0.494
Oct - Dec 2009: 0.401
Jan - Mar 2010: 0.309, 0.307
Sources of Physician Error

• Incorrect antemortem diagnosis
  • May be as high as 30%
  • Low autopsy rate makes improvement difficult

• Intentional errors
  • “Protect” family members
  • Poor guidance from associated staff
  • System design flaws

• Unintentional errors
NYC Physician Survey (2009)

- Random sample of 1200 physicians with primary practice site in NYC.
- Questionnaire examining knowledge and use of DOHMH services and resources
  - Only 34% agreed that instructions for recording cause of death were clear
  - Only 36% agreed that the process for electronically certifying cause of death was straightforward
Unintentional Errors: Why is this so hard for clinicians to get?

- No formal training consistently provided in medical school or residency
  - Importance of accurately recording cause of death poorly understood
  - Training usually *ad hoc* and of poor quality
- Resources for accurate guidance limited
- Instructions inconsistent or confusing
- Terminology and format not necessarily intuitive to the clinician
Describe as clearly as possible the events that led to the scene depicted.
Would this be your first attempt?

- 155 passengers and crew were safely evacuated onto the wings awaiting rescue
- The pilots skillfully ditched the aircraft in the Hudson River abeam 50th ST
- Seeing no other option, the captain chose to bring the plane down in the river
- The plane hit a flock of birds and lost all power
- US Airways Flight 1549 took off from LGA bound for CLT at 15:24 on January 15, 2009
How do we improve the system??

• Training
• Real time or near real time support
• Audit programs
• Electronic registration systems
• Electronic health records
Training content

• Medical science related to determining cause of death
• Principles of certifying cause of death
• Rules for specific causes of death
• Legal/ethical issues
• General and Specific uses of cause of death data

CDC Core Curriculum or Certifiers of Underlying Cause of Death. 2006 (www.cdc.gov/nchs)
Teaching physicians how to record cause of death

- Monthly publication
- Clinician-friendly guidance on public health topics
- Distributed free to 30,000 NYC physicians
- CME Credit offered

Training format

• Many studies show training leads to significant improvement in accuracy of cause of death statements
• Degree of improvement varies with type of training
  • Printed materials least helpful
  • Interactive approaches associated with the greatest change (>7 published studies)
• Audit programs helpful, but labor intensive and of questionable sustainability
Teaching physicians how to record cause of death

E-learning Module
• Launched 2008
• Self-paced
• Interactive
• CME credits

Evaluation of the NYC Cause of Death E-learning Module

- 114 PGY1 residents (internal medicine; general surgery) sent email with invitation to complete online:
  - Pretest
  - Training module
  - Evaluation of module
  - Posttest (same as pretest)

- 113 PGY2 residents (internal medicine; general surgery; emergency medicine) sent email with invitation to complete online:
  - Test (same as PGY1 pre/posttest)
  - Survey describing their experience completing death certificates
Experience with Death Certificates

# of Death Certificates Completed by Residency Year

0% 20% 40% 60% 80%

PGY 1 PGY 2

68% 64%

0-2 3+

36% 32%
Comparison of Knowledge Test Scores

• Prior to course, average knowledge test score was comparable for PGY1 and PGY2 residents (59% vs. 61%, p=0.89)

• Post-course, average knowledge test score among PGY1 residents improved significantly (59% to 72%, p<0.001)
Perceived Expertise Completing Death Certificates

PGY1 Pre-course
- Very knowledgeable: 14%
- Somewhat knowledgeable: 71%
- Slightly knowledgeable: 55%

PGY1 Post-course
- Very knowledgeable: 71%
- Somewhat knowledgeable: 14%
- Slightly knowledgeable: 55%

PGY2
- Very knowledgeable: 14%
- Somewhat knowledgeable: 71%
- Slightly knowledgeable: 55%
Improving the e-learning module: Lessons learned

• Clearer, more detailed coverage of frequently misunderstood concepts
  • Mechanisms vs. causes of death
  • Specific vs. non-specific diagnoses

• More sample cases for additional practice

• Cases that cover a broader spectrum of diseases and specialties

• Integrated post-course evaluation
Electronic Death Registration

- Ongoing initiative for development and implementation of EDR across the US
- Once in place could offer a number of benefits:
  - Improved timeliness of death registration
  - Potential for user-friendly data entry
  - Potential for on-line instructions and help
  - Facilitation of real-time q/a review
  - Increased accuracy and timeliness of cause of death analysis and reporting
respiratory failure

aspiration pneumonia

Parkinson’s disease
Now for the fun part…

"For crying out loud, Douglas, try and think outside the box."
EDR Wish List

• Instant sequence analysis and coding
• “Smart” search capability for disease terms
• Smart form for cause of death entry
### Smart Form

#### Review of Systems

If a system is entirely Negative, check "All Normal"; otherwise, check each Positive Exception below.

<table>
<thead>
<tr>
<th>Constitutional:</th>
<th>change in appetite</th>
<th>cold intolerance</th>
<th>fatigue</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>heat intolerance</td>
<td>polydipsia</td>
<td>polyphagia</td>
</tr>
<tr>
<td></td>
<td>weakness</td>
<td>weight gain</td>
<td>weight loss</td>
</tr>
<tr>
<td></td>
<td>All Normal</td>
<td></td>
<td>fever</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>polyuria</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Eyes:</th>
<th>blurred vision</th>
<th>cataracts</th>
<th>dimness</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>excess tearing</td>
<td>flashing lights</td>
<td>glaucoma</td>
</tr>
<tr>
<td></td>
<td>pain</td>
<td>redness</td>
<td>itching</td>
</tr>
<tr>
<td>All Normal</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Ears, Nose, Mouth and Throat:</th>
<th>bleeding gums</th>
<th>ear discharge</th>
<th>earaches</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>hearing loss</td>
<td>hoarseness</td>
<td>nasal discharge</td>
</tr>
<tr>
<td></td>
<td>tinnitus</td>
<td>vertigo</td>
<td>sinus problems</td>
</tr>
<tr>
<td>All Normal</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Cardiovascular:</th>
<th>chest pain</th>
<th>chest pressure</th>
<th>diaphoresis</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>edema</td>
<td>history of hypertension</td>
<td>history of rheumatic fever</td>
</tr>
<tr>
<td></td>
<td>palpitations</td>
<td>paroxysmal nocturnal dyspnea</td>
<td>prior abnormal EKG</td>
</tr>
<tr>
<td>All Normal</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Respiratory:</th>
<th>cough</th>
<th>hemoptysis</th>
<th>history of asthma</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>history of tuberculosis</td>
<td>night sweats</td>
<td>pleuritic chest pain</td>
</tr>
<tr>
<td></td>
<td>sputum</td>
<td>wheezing</td>
<td>shortness of breath</td>
</tr>
<tr>
<td>All Normal</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Gastrointestinal:</th>
<th>abdominal pain</th>
<th>blood in stool</th>
<th>change in bowel frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>constipation</td>
<td>diarrhea</td>
<td>change in stool size</td>
</tr>
<tr>
<td></td>
<td>hearburn</td>
<td>hematochezia</td>
<td>food intolerance</td>
</tr>
<tr>
<td>All Normal</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

| Genitourinary: | decreased stream | dysmenorrheal | dyspareaunia |
|                | fever            | flank pain    | dysuria |
|                | incontinence     | malodorous urine | hesitancy |
| All Normal     |                 |                | nocturia |

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SAFER • HEALTHIER • PEOPLE
Constitutional: Denies weight changes, appetite changes, weakness, fatigue, fever, heat or cold intolerance, polyuria, polydipsia and polyphagia.

Eyes: Denies all except: Claims cataracts

Ears, Nose, Mouth and Throat: Denies all except: Claims vertigo

Cardiovascular: Denies chest pain or pressure, palpitations, disphoresis, dyspnea on exertion, orthopnea, paroxysmal nocturnal dyspnea, edema, history of hypertension, history of rheumatic fever, or past abnormal EKG.

Respiratory: Denies cough, sputum, hemoptysis, wheezing, pleuritic chest pain, shortness of breath, night sweats, history of tuberculosis, asthma or pneumonia.

Gastrointestinal: Denies heartburn, dysphagia, nausea, vomiting, hematochezia, change in bowel frequency, change in stool size, rectal bleeding, abdominal pain, diarrhea, constipation, or food intolerance.

Genitourinary: Denies polyuria, nocturia, dysuria, hematuria, frequency, hesitancy, decreased stream, incontinence, stress incontinence, flank pain, fever, or malodorous urine. Denies dysmenorrhea, premenstrual symptoms, unprotected intercourse, pelvic pain, dyspareunia, vaginal discharge, or vaginal itching.

Musculoskeletal: Denies all except: Claims arthritis

Skin: Denies all except: Claims nail brittleness, claims nail ridging

Neurological: Denies all except: Claims vertigo

Psychiatric: Denies all except: Claims anxiety, claims insomnia

Endocrine System: Denies heat or cold intolerance, neck swelling, changes in hair, changes in skin, weakness, fatigue, polydipsia, or polyuria.

Hematologic / Lymphatic: Denies anemia, easy bruising, easy bleeding or swollen lymph nodes.

Allergic / Immunologic: Denies all except: Claims hay fever.
EDR Wish List

• Instant sequence analysis and coding
• “Smart” search capability for disease terms
• Smart form for cause of death entry
• Seamless integration with the electronic medical record
Summary and Conclusions

• Quality of cause of death data is one of several challenges faced by the vital statistics system
• Interactive training is helpful in improving cause of death data quality
• Electronic death registration and electronic medical records have potential in improving the system
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