# Utilizing Death Certificate Data for Health Services Planning: An Example Using Parkinson's Disease

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**CAHSPR May 11, 2011** 





## Introduction

- Administrative data sources have been used extensively for research purposes
- Vital Statistics Death Certificate data are particularly useful as the registration of all deaths is required by law
  - Population-based
  - Ongoing collection
- Cause of death information helps give insight into an individual's health condition at the end of life



# **Epidemiology PD**

- Usual onset between 50-70 years
  - infrequent before 30 years (Young onset)
- Male-to-Female ratio 3:2
- Incidence 20/100,000
- Prevalence 160/100,000
- Incidence is similar in all countries where records are kept



# **Symptoms of PD**

- Early stage
  - Loss of smell
  - Musculoskeletal Pain
  - **▶** Depression
- Motor symptoms
  - ▶ Tremor
  - ▶ Rigidity
  - Instability
- Later Manifestations
  - Freezing (causes falls)



# PD Background

- Service requirements are particularly acute as death approaches as symptoms become difficult to control with medications
- PD is characterized by frequent occurrences of comorbidities
- PD is a good example for examining disease interactions



# Research Objectives

- To measure the association between PD and a broad range of conditions
- To measure the strength that association
- To compare results with previous research such as basic biomedical and prospective studies on PD to help gain insights into the validity of using death certificate information



# **Data and Study Population**

- Nova Scotia Vital Statistics Death Certificate Data
- Residents of Nova Scotia who died between Jan 1, 1998 and Dec 31, 2005

Total observations: 63,431



## **Methods**

- All causes of death from death certificate utilized
  - ▶ Can be up to 13 causes of death listed
- Disease types were identified through ICD coding used on the death certificate
- Parkinson's disease was defined as ICD-10 codes G20-G21 (ICD-9 332) which includes secondary Parkinsonism
- Total observations with PD mentioned: 900



## **Methods**

- 14 conditions were analyzed
- Analysis also included:
  - A single category of diseases defined as "external causes of death"
  - Sub-grouping, skin cancer
- Examine measures of diseases coexisting with PD on the death certificate



## **Methods**

Percentage of decedents with study diseases appearing together with PD

- Observed/expected
  - ▶ Measure of strength of association
  - Control for chance occurrence of diseases appearing together



# **Observed/Expected Ratio Calculation**

Observed number of deaths with both PD and comparator disease

Expected number of deaths with both PD and comparator disease

Where expected number of deaths based on the assumption of independence is:

(deaths with PD) x (deaths with comparator)

Total deaths (all causes)



# Observed/Expected Ratio Interpretation

If ratio >1, then association is stronger than expected

If Ratio is < 1 then association is less than expected</p>

 Chi-squared calculation is calculated to test if causes are independent (95% confidence level)

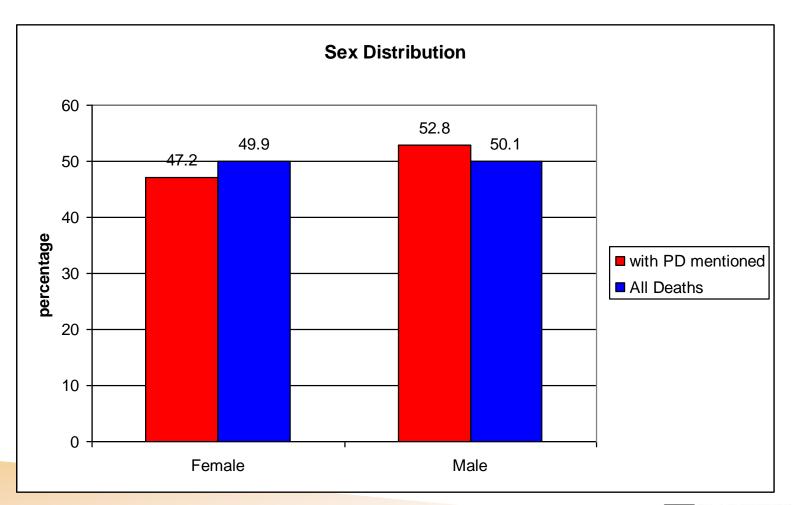


### **Control Factors**

- Age, Sex and Year of Death are potential confounding factors
  - e.g. certain diseases are more likely to be listed as a cause of death for older individuals so may occur together more often
- We constructed a cohort of matched to those with PD by age, sex and year of death

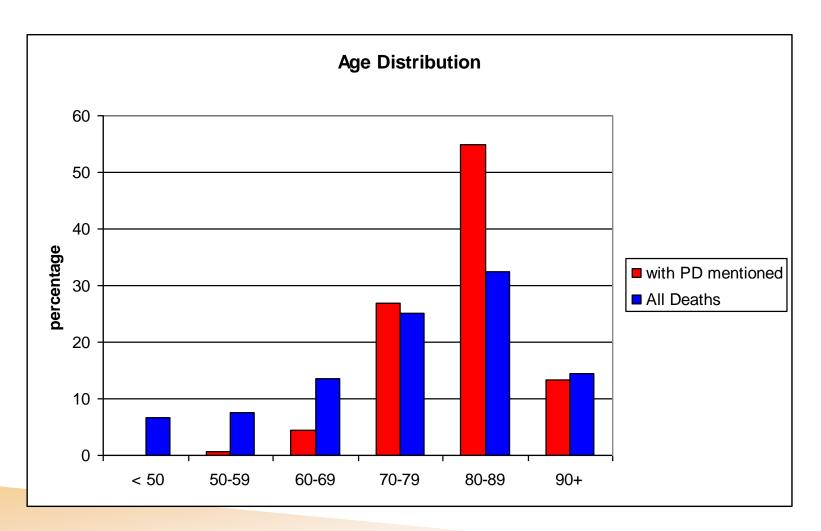


# **Sex Distribution**



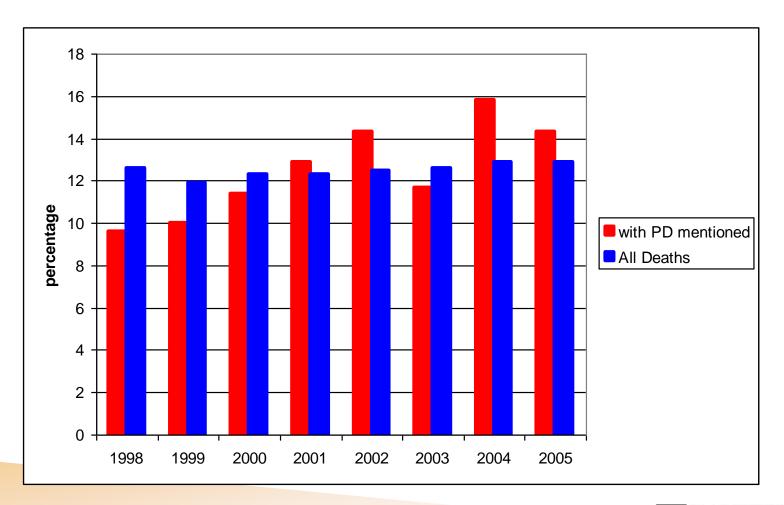


# **Age Distribution**



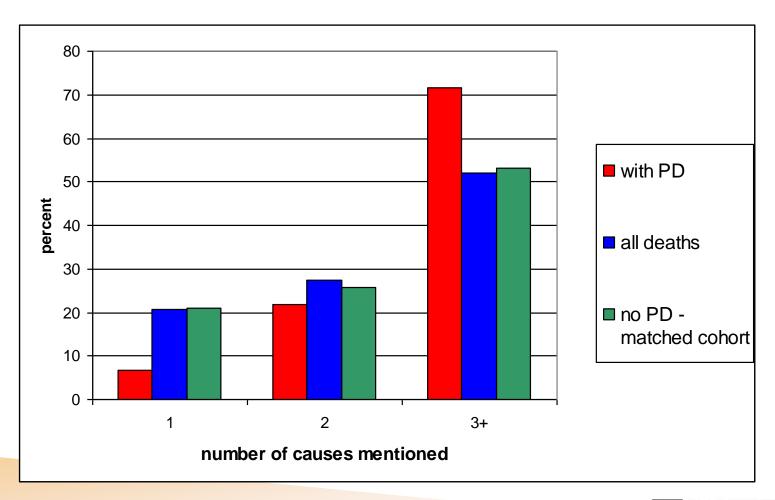


# **Distribution Across Study Years**





## **Number of Causes Mentioned**





# Percentage Mentions on Death Certificate

|                                  | Decedents with<br>Parkinson's<br>mentioned | All Decedents          | Matched Cohort of Decedents Parkinson's not mentioned |
|----------------------------------|--|------------------------|---|
| Alzheimer's disease /            | 26.2% ab                                   | 10.4%                  | 14.4%   |
| dementia                         | (23.3%-29.2%)                              | (10.1%-10.6%)          | (12.1%-16.8%)   |
| Pneumonia                        | 22.3% ab                                   | 12.2%                  | 12.8%   |
|                                  | (19.6%-25.1%)                              | (11.9%-12.4%)          | (10.5%-15.0%)   |
| Cerebrovascular disease (stroke) | 14.2%                                      | 12.1%                  | 11.4%   |
|                                  | (11.9%-16.6%)                              | (11.9%-12.4%)          | (9.3%-13.6%)  |
| Malignant neoplasms (cancer)     | 11.1% <sup>ab</sup> (9.0%-13.2%)           | 33.0%<br>(32.6%-33.4%) | 38.6%<br>(35.3%-41.8%)                                |
| Congestive heart failure         | 8.1% <sup>ab</sup>                         | 11.3%                  | 12.2%   |
|                                  | (6.3%-10.0%)                               | (11.0%-11.5%)          | (10.0%-14.4%)   |
| Diabetes                         | 8.0% ab                                    | 10.9%                  | 12.7%   |
|                                  | (6.2% - 9.8%)                              | (10.7%-11.1%)          | (10.4%-14.9%)   |
| observations                     | 900  | 63,431                 | 900   |

a statistically different from all deaths



b statistically different from those without Parkinson's

## Results

- Alzheimer's and Pneumonia are mentioned most frequently among those with PD
- Of note, only 11.1% of decedents with Parkinson's disease mentioned also has cancer mentioned
  - ▶ 33.3% for all
  - **▶** 38.6% for the matched cohort



# **Observed to Expected Ratios**

| Causes of Death<br>Associated with<br>Parkinson's | Ratio observed to expected deaths |                   |
|---|-----------------------------------|-------------------|
|   | Full Study<br>Population          | Matched<br>Cohort |
| Alzheimer's disease /<br>dementia                 | 2.53*                             | 1.29*             |
| Pneumonia   | 1.83*                             | 1.27*             |
| Cerebrovascular<br>disease (stroke)               | 1.17                              | 1.11              |
| Malignant neoplasms (cancer)                      | 0.34*                             | 0.45*             |
| Congestive heart failure                          | 0.72*                             | 0.80*             |
| Diabetes  | 0.73*                             | 0.77*             |
| observations                                      | 63,431                            | 1800              |

<sup>\*</sup>x<sup>2</sup> test for independence significant at p=.05.



## Results

- Observed/expected ratios differ for the matched cohort compared with the full population
- This difference is particularly apparent for both Alzheimer's and pneumonia
  - ► Like PD, positively associated with age



## Cancer

- Most frequently mentioned for all deaths
- Results suggest PD patients are less likely to have cancer
- Supported by biomedical studies
  - Genes predisposed to PD may be better protected from malignant growth
- Skin cancer is an exception
  - **▶** Small sample size here



## **Previous Evidence Other Associations**

- Pneumonia
  - Very often become bed-ridden and prone to infections
- Alzheimer's Disease
  - ► Like PD, characterized by dying brain cells
- Fractures
  - Increased risk due to the motor complications of PD
- Stroke
  - Same areas of the brain that are affected by PD can be affected by strokes Vascular Parkinsonism
  - No significant association in our study



## **Co-Morbidities and Health Services**

- Clinical Practice Guidelines (CPGs) generally focus on single diseases
- Treatments can be affected by the presence of comorbidities
- Patterns of functional decline can also be affected as they traditionally focus on a single condition



## Limitations

- Death certificate doesn't capture all PD patients
- Difficulties determining cause of death
  - ▶ Including all causes of death helps to mitigate this limitation
- Limited number of variables available as controls

No indication of date of disease occurrence



## **Future Work**

- Link to other data bases
  - Validity
  - Understand current patterns of service provision, including palliative care
- Code external causes more precisely
  - Fractures due to falls known to be common among those with PD



### **Conclusions**

- Examining cause of death information is an efficient, effective tool in understanding patterns of disease associations for those with PD
- As the population ages and co-morbidities increase, there's a shift away from a focus on individual diseases in patient care
- Supports a needs-based approach to Health Human Resource (HHR) planning

