Longevity and Causes of Death in Persons with Intellectual Disabilities Resident at Rideau Regional Centre (1979 – 2008): Implications for Community Care

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Aerial Photograph of Rideau Regional Centre

Health Care at Rideau Regional Centre

Role of Unit Staff:
- Observation
- Administration of Interventions

Role of Area Nurses:
- Screening
- Coordinating
- Preventing
- Treating

Role of Primary Care Physicians:
- Annual Health checks
- Regular clinics
- Inpatient care
- Transfers for specialized care

Two Questions Often Raised About a Death

1. What was it?
2. What was the cause?

Deaths in Persons with Intellectual Disabilities vs Members of the General Population

- Premature: 20 years decrease in longevity
- Particularly frequent deaths before age 50

A Further Concern Regarding Deaths in ID Population

- 70 – 80% Increase in death rates in those moving from institutions to the community

<table>
<thead>
<tr>
<th>Occurred</th>
<th>ID Population</th>
<th>Non-ID Population</th>
</tr>
</thead>
<tbody>
<tr>
<td>Heart Attack</td>
<td>Heart attack</td>
<td>Kidney infections</td>
</tr>
<tr>
<td>Stroke</td>
<td>Stroke</td>
<td>&quot;Respiratory&quot;</td>
</tr>
<tr>
<td>Cancer</td>
<td>Cancer</td>
<td>Cancer</td>
</tr>
</tbody>
</table>
The Present Study

Characterize mortality patterns with Rideau Regional Centre in relation to implications for community-based care.

In The Event of a Death

- Primary care physician:
- Contact next of kin
- Contact Coroner
- Complete a Mortality Summary

Coroner:
- Complete report; arrange for postmortem examination

Pathologist:
- Conduct postmortem examination and Pathology Report

Sources of Data 1979 – 2008

- 275 MORTALITY SUMMARIES
  - Age, gender
  - Level of MR
  - Other problems: CP, Epilepsy, Down’s
  - Cause of death (clinical impression)

- 48 PATHOLOGY REPORTS
  - Cause of death (pathology impression)
  - Significant contributing factors

Table 1: INHERITED DEATHS BY EACH GROUPING AT DIAL INSTITUTE

<table>
<thead>
<tr>
<th>Group</th>
<th>All Subjects</th>
<th>Profound</th>
<th>Severe</th>
<th>Moderate</th>
<th>Mild</th>
<th>Unspecified</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dial Foundation</td>
<td>164 (59.6%)</td>
<td>52 (58.4%)</td>
<td>59 (67.6%)</td>
<td>19 (22.7%)</td>
<td>11 (13.5%)</td>
<td></td>
</tr>
<tr>
<td>Cerebral Palsy</td>
<td>126 (33.5%)</td>
<td>26 (21.1%)</td>
<td>24 (25.5%)</td>
<td>10 (12.4%)</td>
<td>8 (6.7%)</td>
<td></td>
</tr>
<tr>
<td>Epilepsy</td>
<td>145 (46.9%)</td>
<td>34 (23.8%)</td>
<td>56 (38.1%)</td>
<td>24 (16.4%)</td>
<td>11 (7.6%)</td>
<td></td>
</tr>
<tr>
<td>Cerebral Palsy and Epilepsy</td>
<td>94 (29.2%)</td>
<td>19 (20.2%)</td>
<td>41 (43.6%)</td>
<td>16 (17.0%)</td>
<td>8 (8.5%)</td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>71 (20.3%)</td>
<td>13 (18.3%)</td>
<td>18 (25.4%)</td>
<td>15 (21.1%)</td>
<td>10 (14.1%)</td>
<td></td>
</tr>
</tbody>
</table>

Age at death in years
- 1979 - 88: 31.8
- 1989 - 98: 48.0
- 1999 - 2008: 55.0

<table>
<thead>
<tr>
<th>Interval</th>
<th>Age Range</th>
<th>Mean Age</th>
<th>Total Subjects</th>
<th>Profound</th>
<th>Severe</th>
<th>Moderate</th>
<th>Mild</th>
<th>Unspecified</th>
</tr>
</thead>
<tbody>
<tr>
<td>1979 – 88</td>
<td>9 - 63</td>
<td>31.8</td>
<td>32.6</td>
<td>30.0</td>
<td>26.3</td>
<td>24.0</td>
<td>28.3</td>
<td></td>
</tr>
<tr>
<td>1989 – 98</td>
<td>18 - 80</td>
<td>46.3</td>
<td>50.5</td>
<td>55.0</td>
<td>61.0</td>
<td>61.0</td>
<td>60.0</td>
<td>62.4</td>
</tr>
<tr>
<td>1999 – 2008</td>
<td>24 - 74</td>
<td>55.0</td>
<td>57.6</td>
<td>56.0</td>
<td>56.0</td>
<td>56.0</td>
<td>56.0</td>
<td>56.0</td>
</tr>
</tbody>
</table>

Table 2: GENDER AND MEAN AGE AT DEATH (YEARS) BY INTERVAL

<table>
<thead>
<tr>
<th>Interval</th>
<th>Male</th>
<th>Female</th>
<th>Male</th>
<th>Female</th>
</tr>
</thead>
<tbody>
<tr>
<td>1979 – 88</td>
<td>9</td>
<td>63</td>
<td>11</td>
<td>78</td>
</tr>
<tr>
<td>1989 – 98</td>
<td>18</td>
<td>80</td>
<td>20</td>
<td>80</td>
</tr>
<tr>
<td>1999 – 2008</td>
<td>24</td>
<td>74</td>
<td>28</td>
<td>86</td>
</tr>
</tbody>
</table>

164 males, 111 females
### Table 4: Clinical Group* and Mean Age at Death (Years) by Interval

<table>
<thead>
<tr>
<th>Interval</th>
<th>All Subjects</th>
<th>Down Syndrome</th>
<th>Epilepsy</th>
<th>Cerebral Palsy</th>
<th>Epilepsy and Cerebral Palsy</th>
<th>Cerebral Palsy and Other Conditions</th>
<th>Cause of Death</th>
</tr>
</thead>
<tbody>
<tr>
<td>1979 - 86</td>
<td>31.8</td>
<td>29.6</td>
<td>31.6</td>
<td>26.5</td>
<td>26.4</td>
<td>22.5</td>
<td>Hypothermia 29, Sudden Death 23, Other Causes 4</td>
</tr>
<tr>
<td>1980 - 86</td>
<td>48.0</td>
<td>49.0</td>
<td>45.9</td>
<td>51.1</td>
<td>43.1</td>
<td>37.3</td>
<td>Hypothermia 18, Other Causes 32, Other Causes 22</td>
</tr>
<tr>
<td>1987 - 98</td>
<td>56.5</td>
<td>56.9</td>
<td>57.2</td>
<td>54.9</td>
<td>49.8</td>
<td></td>
<td>Hypothermia 2</td>
</tr>
</tbody>
</table>

* Down Syndrome 29, Epilepsy 74, Cerebral Palsy 50, Epilepsy and Cerebral Palsy 4 (Individuals may have more than one diagnosis)

### Table 5: Number of Deaths by Cause by Interval

- Other 1979 - 86: Hypothermia, Osteogenesis imperfecta, Generalized arteriosclerosis, Endocarditis, Hepatitis, Diabetic acidosis, Acute asthma
- Other 1980 - 86: Hypothermia, Osteogenesis imperfecta, Generalized arteriosclerosis, Endocarditis, Hepatitis, Diabetic acidosis, Acute asthma
- Other 1987 - 98: Hypothermia, Osteogenesis imperfecta, Generalized arteriosclerosis, Endocarditis, Hepatitis, Diabetic acidosis, Acute asthma

### Post-mortem Observations

<table>
<thead>
<tr>
<th>Age/ Gender</th>
<th>Disability Profile</th>
<th>Medical Profile</th>
<th>Cause of Death</th>
<th>Neuroradiolucre Findings</th>
<th>Brain Weight</th>
</tr>
</thead>
<tbody>
<tr>
<td>28 M</td>
<td>Profound ID epinephrine</td>
<td>Pica, Anorexia</td>
<td>Mass effect of cerebral hemisphere</td>
<td>None specific</td>
<td>1660 gms</td>
</tr>
<tr>
<td>29 M</td>
<td>Profound ID epinephrine at 6 months</td>
<td>Seizure, Epilepsy</td>
<td>Sudden death of epilepsy</td>
<td>Cortical retraction and gliosis in hippocampus</td>
<td>1790 gms</td>
</tr>
<tr>
<td>32 M</td>
<td>Profound ID Down Syndrome</td>
<td>Epilepsy</td>
<td>Brainstem necrosis</td>
<td>Microhemorrhages in periventricular region</td>
<td>1237 gms</td>
</tr>
</tbody>
</table>

### Implications for Community-Based Care

- Awareness of health issues
- Training - First aid, use of medication
- Note and report incidence of Ill health
- Vigilance regarding "High risk" situations
- Contribution to "Hospital Passports"
IMPLICATIONS FOR COMMUNITY-BASED CARE

**HEALTH CARE PROVIDERS**
- Include developmental disabilities in curricula for nurses, physicians, etc.
- Positive relationships with caregivers
- Awareness of Clinical Practice Guidelines
- Judicial use of consultants (neurology, psychiatry) etc.

**SYSTEMS**
- Careful manner of death
- Public health observatory

**SYSTEMS**
- Impacts of rules with "suicide deaths"
- Community nursing services (Ontario vs UK)
- Waiting list issues, ambulance response times
- Funding for "mental health checks", regional issues
- Changes in death certificates

QUESTIONS?