Patterns of Aging in Adults with Intellectual Disabilities

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Intellectual Disability (ID)

• 1-3% affected depending on criteria used
• Many causes
• Some syndromes are associated with specific behavioural patterns
• Great variation in abilities and skills
Causes of ID

- Trauma
- Toxic
- Infectious (congenital and postnatal)
- Chromosomal Abnormalities
- Genetic and other inherited metabolic disorders
- Metabolic
- Environmental
- Nutritional
Vulnerability to Behavioural Challenges in People with ID

• Poor impulse control, impaired attention, disinhibition, irritability (especially in seizure disorders)
• Specific additional features in certain syndromes (ie hyperacusis in Williams’ syndrome, need for sameness in autism, obsessionality and rigidity in midlife DS, ADHD in Fragile X)
• Impaired communication skills
• Reduced coping skills with increased stress response
• Impaired learning of socially appropriate behaviours
• Social factors

## Features Associated With ID

<table>
<thead>
<tr>
<th>Feature</th>
<th>Mild</th>
<th>Moderate-severe</th>
</tr>
</thead>
<tbody>
<tr>
<td>Seizures</td>
<td>12%</td>
<td>35%</td>
</tr>
<tr>
<td>Cerebral Palsy</td>
<td>9%</td>
<td>20%</td>
</tr>
<tr>
<td>Blindness</td>
<td>1%</td>
<td>15%</td>
</tr>
<tr>
<td>Deafness</td>
<td>7%</td>
<td>10%</td>
</tr>
</tbody>
</table>

Bartley JA; Hall BD.. Orig Artic Ser 1978;14(6B):127-137
Life Expectancy/Demographics

• Although the percentage of people with ID who are old is smaller than that the general population due to increased mortality from pre-existing conditions:
  – The life expectancy of adults with ID has increased
  – Adults with Down Syndrome (DS) have increased their life expectancy to around 59 years (Glasson et al, 2002), but are particularly likely to get Alzheimer’s disease (AD) at an early age.
Survival Curve for DS in Western Australia, N=1332, 1953-2000

Survival by level of intellectual disability

Health of older people with ID

• Currently older people with ID are “healthy survivors” and may be the healthiest subgroup of their initial birth cohort.

• Some health risks are reduced in those with ID
  – motor vehicle accidents
  – substance abuse
  – sexually transmitted diseases
Aging changes in ID

– Aging changes are superimposed on pre-existing conditions
  • Physical ageing changes
  • Mental and cognitive ageing changes
    – Mental rigidity
    – Mild cognitive impairment
    – Dementia
Aging: Social support challenges

- Aging parents unable to continue to provide care (often sudden transitions)
- Lack of adult children or spouses
- Siblings frequently at a distance or unwilling to be involved
- Social networks dependent on others for maintenance (placements, transportation, care staff)
- Inadequate age and developmentally appropriate programming to replace sheltered workshops once too frail to attend these.
- Difficult “fit” in generic nursing homes/programs.
Adults with DS as prototypes for those developing dementia

• Pathological Brain Changes With Aging in People With DS
  – Almost 100% have plaques and tangles by age 35.
  – Changes are essentially identical to Alzheimer changes in those without DS

• A model for studying Alzheimer’s disease in the general population
  – Identifiable group
  – Generally low rate of behavioural comorbidities (smoking, drinking, head injuries)
“Why studying Alzheimer’s in people with Down Syndrome could help everyone”
(Washington Post, May 22, 2015)
Research development

• Caregiver initiation of the study

• Unclear needs for service adaptation to the demographic changes
  – Especially in those with DS because of the high rate of dementia and predicted increases in service needs with aging
Research questions: Health

- Epidemiology/Mortality
  - What are the determinants of mortality in adults with ID?

- Physical morbidity
  - What is the pattern and frequency of physical morbidity in adults with ID?

- Emotional, behavioural and psychiatric morbidity
  - What is the pattern and frequency of emotional, behavioural and psychiatric morbidity in adults with ID?
Study Questions: Functional-Cognitive Decline

• How do functional abilities vary across diagnostic and age groups?
• What determines change of functional abilities over time?
• How do specific functions associated with dementia vary across diagnostic and age groups?
• What determines change in specific neuropsychological functions associated with dementia in adults with ID?
Research Questions: Service Provision

• How do perceived deficits in service provision for physical, emotional, behavioural and psychiatric needs impact on participant re-institutionalization (for example, to a nursing home)?
• How does the use of specialized and generic aging programs vary across diagnostic and age groups?
• Is there a change over time in the use of aging services?
Research questions: Psychototropic Medication

• How does the use of psychototropic medication vary across diagnostic and age groups?
• Is there a change over time in the use of psychototropic medication?
Measured Health Outcomes

• Mortality
• Physical and mental health symptoms (caregiver report)
• Functional and cognitive measures
  – General caregiver rated functioning (DMR)
  – Dementia related specific abilities (visual working memory, dyspraxia)
• Service provision and perceived deficits
• Medication administration records
Potential Determinants of Health Outcomes

- Age
- Sex
- Cause of intellectual disability
- Baseline mental health
- Baseline medication use
- Premorbid intellectual functioning
Anticipated significance

- Provide information about longitudinal aging related changes in adults with ID
- Provide help with planning for service changes needed with the aging of the ID population
- Provide information on changes in health practices for people with ID
Methods

• General challenges
• Protocol development
• Inclusion criteria: community dwelling adults were considered by service ID care providers as having childhood onset ID
• Recruitment: from Community-living Division community service population
Methods continued

- Study assessments: two year intervals for a maximum of four full assessments.
- Phone follow-up contacts starting in spring 2003
- Last follow-up in summer, 2011
Methods: caregiver mail-out survey

- Demographics and general health
- Medication use
- Seizure disorders and epilepsy
- IQ and best level of intellectual functioning
- Dementia Questionnaire for Persons With Mental Retardation (DMR)
- Reiss screen for psychiatric disorders in ID
Methods continued: direct testing

- Dyspraxia scale
- Dalton/McMurray Visual Memory Test
- Quality of life interview
- Name-face recognition test
Methods continued: charts and medical record review

- IQ testing
- Chromosomal testing
- Additional health information
Data Set

• 360 participants entered the study
• 215 had four completed waves of caregiver data
• 262 people participated in individual testing
<table>
<thead>
<tr>
<th>Sex</th>
<th>Number</th>
<th>Mean Baseline Age</th>
<th>Mean follow-up time in years</th>
<th>Mean age of death in years</th>
</tr>
</thead>
<tbody>
<tr>
<td>Males</td>
<td>204</td>
<td>42.21</td>
<td>12.86</td>
<td>59.65</td>
</tr>
<tr>
<td>Females</td>
<td>156</td>
<td>42.18</td>
<td>13.03</td>
<td>58.58</td>
</tr>
<tr>
<td>All</td>
<td>360</td>
<td>42.20</td>
<td>12.93</td>
<td>59.23</td>
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<tr>
<td></td>
<td></td>
<td>Range: 17.79-83.65</td>
<td>Range: 0-16.10</td>
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</table>
## Study Participants by Diagnosis

<table>
<thead>
<tr>
<th>Sex</th>
<th>Number</th>
<th>Mean Baseline Age</th>
<th>Number deceased at last followup</th>
<th>Mean age of death in years</th>
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</thead>
<tbody>
<tr>
<td>Down Syndrome</td>
<td>116</td>
<td>40.16</td>
<td>42 (36.2%)</td>
<td>56.32</td>
</tr>
<tr>
<td>Non-Down Syndrome</td>
<td>244</td>
<td>43.17</td>
<td>66 (27.0%)</td>
<td>61.07</td>
</tr>
<tr>
<td>All</td>
<td>360</td>
<td>42.20</td>
<td>108 (30.0%)</td>
<td>59.23</td>
</tr>
<tr>
<td>Type of test</td>
<td>Test number</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>----------------------------------</td>
<td>----------------------</td>
<td>------</td>
<td>------</td>
<td>------</td>
</tr>
<tr>
<td>Caregiver mail-out survey</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>supplemented by chart review</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Demographics</td>
<td>360 (100)</td>
<td>348 (97)</td>
<td>309 (86)</td>
<td>222 (62)</td>
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<tr>
<td>Health problems</td>
<td>360 (100)</td>
<td>348 (97)</td>
<td>309 (86)</td>
<td>222 (62)</td>
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<tr>
<td>Medications</td>
<td>360 (100)</td>
<td>348 (97)</td>
<td>314 (87)</td>
<td>215 (60)</td>
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<tr>
<td>Dyspraxia Scale</td>
<td>360 (100)</td>
<td>349 (97)</td>
<td>310 (86)</td>
<td>220 (61)</td>
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<td>DMTS test</td>
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<tr>
<td>Shapes</td>
<td>264 (73)</td>
<td>236 (66)</td>
<td>166 (46)</td>
<td>*</td>
</tr>
<tr>
<td>Colours</td>
<td>266 (74)</td>
<td>243 (68)</td>
<td>1790 (50)</td>
<td>*</td>
</tr>
<tr>
<td>Nearest town</td>
<td>Number (%)</td>
<td>Nearest town</td>
<td>Number (%)</td>
<td>Nearest town</td>
</tr>
<tr>
<td>--------------</td>
<td>------------</td>
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<td>------------</td>
<td>--------------</td>
</tr>
<tr>
<td>Admiral</td>
<td>1 (0.3%)</td>
<td>Kinistino</td>
<td>6 (1.7%)</td>
<td>Regina</td>
</tr>
<tr>
<td>Battlefords</td>
<td>20 (5.6%)</td>
<td>Lloydminster</td>
<td>3 (0.8%)</td>
<td>Rosetown</td>
</tr>
<tr>
<td>Biggar</td>
<td>1 (0.3%)</td>
<td>Macklin</td>
<td>1 (0.3%)</td>
<td>Saskatoon</td>
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<tr>
<td>Carrot River</td>
<td>1 (0.3%)</td>
<td>Meadow Lake</td>
<td>1 (0.3%)</td>
<td>Shaunavon</td>
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<tr>
<td>Delisle</td>
<td>2 (0.6%)</td>
<td>Melfort</td>
<td>9 (2.5%)</td>
<td>Swift Current</td>
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<tr>
<td>Gravelbourg</td>
<td>4 (1.1%)</td>
<td>Melville</td>
<td>1 (0.3%)</td>
<td>Theodore</td>
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<tr>
<td>Gull Lake</td>
<td>1 (0.3%)</td>
<td>Moose Jaw</td>
<td>25 (6.9%)</td>
<td>Wadena</td>
</tr>
<tr>
<td>Hague</td>
<td>6 (1.7%)</td>
<td>Moosomin</td>
<td>1 (0.3%)</td>
<td>Waldheim</td>
</tr>
<tr>
<td>Hepburn</td>
<td>3 (0.8%)</td>
<td>Naicam</td>
<td>1 (0.3%)</td>
<td>Weyburn</td>
</tr>
<tr>
<td>Herbert</td>
<td>2 (0.6%)</td>
<td>Outlook</td>
<td>3 (0.8%)</td>
<td>Wilkie</td>
</tr>
<tr>
<td>Hudson Bay</td>
<td>1 (0.3%)</td>
<td>Porcupine Plain</td>
<td>8 (2.2%)</td>
<td>Yorkton</td>
</tr>
<tr>
<td>Humboldt</td>
<td>1 (0.3%)</td>
<td>Prince Albert</td>
<td>3 (0.8%)</td>
<td>Total</td>
</tr>
<tr>
<td>Kindersley</td>
<td>7 (1.9%)</td>
<td>Redvers</td>
<td>23 (6.4%)</td>
<td></td>
</tr>
</tbody>
</table>
Mortality by Sex (Adjusted for age)
Mortality by DS (Adjusted for age)

Cumulative Survival

Followup time in years

Down Syndrome

Non-Down Syndrome
Mortality by Sex and DS (Adjusted for age)
Mortality by Age Group and DS

Cumulative Survival

Followup time in years

Age categories
- <30
- 30-39
- 40-49
- 50+

Non-DS

DS
Mortality by Baseline DMR Mood Score

Cumulative Survival

Follow-up Years

DMR Mood 0-2
DMR Mood 3-4
DMR Mood 5-6
DMR Mood 7+
Mortality by Baseline DMR Mood Score: DS only
Mortality by Baseline DMR Practical Skills Deficits

![Graph showing cumulative survival over follow-up years for different levels of DMR practical skills deficits.](image)
Mortality by Baseline DMR Practical Skills Deficits: DS only, Adjusted for Age

Cumulative Survival

Followup Years

Down Syndrome only

DMR practical skills deficits 0-6

DMR practical skills deficits 7+
Mean predicted DMR-STM deficit scores at baseline

- Non-DS males
- Non-DS females
- DS males
- DS females

Age categories:
- Age <30
- Age 30-39
- Age 40-49
- Age 50+
Mean predicted DMR-PRA deficit scores at baseline

- Non-DS males
- Non-DS females
- DS males
- DS females

Age groups:
- Age <30
- Age 30-39
- Age 40-49
- Age 50+
Mean predicted DMR-MOOD deficit scores at baseline
Mean predicted yearly change in DMR-STM deficit scores (DMR-STM slope)

- Non-DS males
- Non-DS females
- DS males
- DS females

- Age <30
- Age 30-39
- Age 40-49
- Age 50-59
- Age 60+
Mean predicted Dyspraxia Overall percentage scores

- Non-DS males
- Non-DS females
- DS males
- DS females

Age groups:
- Age <30
- Age 30-39
- Age 40-49
- Age 50+
Mean predicted Dyspraxia
Overall yearly change scores
Percentage of participants at baseline with physical problems difficult to deal with using existing resources

- Age <30
- Age 30-39
- Age 40-49
- Age 50+
- All ages

Comparison between Non-DS and DS groups.
Percentage of participants at baseline with mental/emotional problems difficult to deal with using existing resources

![Bar chart showing the percentage of participants with mental/emotional problems by age group and diagnosis.](chart.png)
Number and percentage of participants with a psychiatric visit within 5 years of baseline.
Service Deficits Leading to Nursing Home Placement

• All participants who eventually transferred into a nursing home had perceived deficits in service provision for emotional, behavioral or psychiatric problems.

• This suggests that emotional, behavioral or psychiatric problems (especially aggression) pose a bigger challenge to care provision in small, community settings, and are more likely to result in institutionalization.

Percentage of 1429 Residents in 13 Saskatoon Nursing Homes With Mental Retardation
(Data as of August 2007)
Age of Admission of Person with Intellectual Disability to Saskatoon Nursing Home: Percentage in Each Age category. (Data as of August 2007)

Thorpe LU, unpublished data, 2008
Anticipated effect of increasing percentage of younger residents in LTC

- Longer LOS for younger residents in LTC
- Decreased bed turnover in LTC
- Lower LTC bed availability for seniors
- Different programming needs in LTC
  - Younger, more physically strong residents
  - Greater problems with aggression and other behavioural problems
Impact of LTC admission on adults with ID

• Care providers with less understanding of ID
• Decreased autonomy
  – Health model compared to social services model
• Increased use of psychotropic medications?
  – Overdiagnosis of mental disorders based on behaviours common in ID (Self-talk, misinterpretation etc)
• Decreased quality of life
Questions and comments