Opportunistic longitudinal study

• In 2010, ID agency in the US mid-West decided to open three purpose-built group homes to provide in-community care for their clients with dementia.
• In 2011, agency agreed to participate in study focusing on the three homes.
• The study followed a cohort of 15 adults with intellectual disability (ID) and dementia, along with 15 community-dwelling matched controls over a period of 7 years (including 8 dementia replacements).
• The study gave us an opportunity to longitudinally observe changes in the cohort.

Given the cluster model employed by an agency of three ‘in-place progression’ homes … our hypothesis was that eventually, as changes affect the residents, the agency will begin to specialize the homes based on function and stage.

• If this happens, it will show that as homes are established for dementia care, their character will eventually change due to the nature of dementia and that home specialization is an organic outcome of multiple group home availability.

“Wichita Project”

• ID agency in mid-West USA opened three purpose-built group homes in 2010 to provide in-community care for adults with ID and dementia.

Dementia Group home residents N=15, 5 per home

Controls – same age and function level (N=15)

GH1

GH2

GH3

Residents compared on standard measures of health and function, co-incident conditions, and care needs/provision

• Agency factors included costs, staffing, and administrative decision making.

AIM: Given that stage-specific changes eventually occur, it was of scientific interest to conduct a longitudinal study of three dementia-care community-based group homes to observe progression of decline, resident needs, and adaptations of care practices over time.
Characteristics of Dementia GH Residents and Controls (T1 vs T8) [Pyr]

<table>
<thead>
<tr>
<th>GH#1</th>
<th>GH#2</th>
<th>GH#3</th>
<th>Sum GH</th>
</tr>
</thead>
<tbody>
<tr>
<td>T1</td>
<td>T8</td>
<td>T1</td>
<td>T8</td>
</tr>
<tr>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>Age (mean)</td>
<td>61.6</td>
<td>65.5</td>
<td>61.6</td>
</tr>
<tr>
<td>Age (range)</td>
<td>51-68</td>
<td>56-79</td>
<td>49-76</td>
</tr>
<tr>
<td>Sex</td>
<td>2/3</td>
<td>2/3</td>
<td>0/5</td>
</tr>
<tr>
<td>DS</td>
<td>2</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>IQ#</td>
<td>3.0</td>
<td>3.0</td>
<td>2.8</td>
</tr>
<tr>
<td>BMI</td>
<td>30.0</td>
<td>34.5</td>
<td>26.6</td>
</tr>
<tr>
<td>Dem stage</td>
<td>Mod 5 - Mod 3</td>
<td>-</td>
<td>Sev 2</td>
</tr>
<tr>
<td>Yrs since dementia Dx</td>
<td>1-3: 3</td>
<td>3-5: 2</td>
<td>1-3: 5</td>
</tr>
<tr>
<td>Co-morbidities</td>
<td>8.0</td>
<td>5.6</td>
<td>7.4</td>
</tr>
<tr>
<td>Health Now</td>
<td>2.6</td>
<td>3.3</td>
<td>2.2</td>
</tr>
<tr>
<td>Health yr ago</td>
<td>2.6</td>
<td>3.3</td>
<td>2.2</td>
</tr>
</tbody>
</table>

Characterization of legacy residents

- In their late 50s
- About 1/3 with DS
- Most were obese or overweight
- Generally had multiplicity of health problems
- Had dementia for about 3 years
- Generally were in mid-stage dementia
- Had diminishing health

- In their mid-60s
- About 1/3 with DS
- Most were obese or overweight
- Showed an increase in number of health problems
- Had dementia for about 5+ years
- Generally were in mid-stage dementia
- Had diminishing health

- In their 60s
- Now 9 survivors (6 deaths)
- About 1/3 with DS
- Most were obese or overweight
- Showed an increase in number of health problems
- Had dementia for about 8+ years
- Generally were in mid-stage to advanced dementia
- Had mixed health

Study Instruments

- T1-T4
  - The Longitudinal Health and Intellectual Disability Survey (LHIDS)
  - Caregiver Activity Survey-Intellectual Disabilities (CAS-ID)
  - Assessment for Adults with Developmental Disabilities Scale (AADS)
  - Dementia Status Questionnaire (DSQ)
  - Group Home Site Questionnaire (GHSQ)
  - Kane Quality of Life Scale (KQoL)
  - Caregiving Difficulty Scale (CDS)
  - Administrative Factors (cost and staff data, interviews with administrative staff, environmental scans)
- T5-T9 (added)
  - NTG-Early Detection and Screening of Dementia (NTD-EDSD)
Mean ages of GH residents – ID vs DS

Mean ages of GH residents over time (T1-T8)

- DS adults: Xage at entry was 53.5 for males and 57.5 for females
- ID adults: Xage at entry was 64.4 for males and 58.0 for females

Mean ages of DGH by home

LOS - Deaths and new admissions T1-T8 – ID vs DS

Study began with 15 GH residents ("legacy")

- Since 2011, there have been 23 GH residents
- Resident length of stay (LOS)
  - At T1, homes began with 5 residents each
  - Deaths began by T4 (2 yrs)
  - At T8 (Aug 2017), 6 of the original residents had died;
    - 2 died afterward
  - At T8 (Jan 2018), there was one vacancy; new filled
    - Arrow means still resident in home
    - Diamond means changed homes
- At T8+ (Jan 2018), there was one vacancy; now filled
- Dashes are DS; Solids are ID
- Timeframe: 2011-2018

LOS – Dementia Home Residents

Mortality patterns ID vs DS

- Original (legacy) cohort n=15
- Survival (legacy) cohort n=8 (53%)
- Mean years from entry to death – DS: 6.5y
- Average age at entry for ID: 66.2; DS: 53.5

- 8 GH died since homes opened (2011)
- 2 CO died since beginning (2011)
- Range of years as resident before death: 2-7y
- Mean years in residence before death: 5y

- Average age at death (GH): 65.2 (4); 58.8 (DS); 73.5 (ID)
- Males age at death: 65.6
- Female age at death: 65.0

- Average age at death (CO): 78.5

- Deaths
  - 8 GH died since homes opened (2011)
  - 2 CO died since beginning (2011)
- Range of years as resident before death: 2-7y
- Mean years in residence before death: 5y

- Sinai et al. (2017)*: in a UK study of ~250 adults with DS and dementia, noted a survival difference between men and women, with shorter survival in men compared to women
  - Median survival in men: 3.10 years, women: 4.40 years
  - Age at diagnosis was a strong predictor of survival
    - Those diagnosed before age 50 had a median survival of 4.94 years
    - Those diagnosed between 50-60 had a median survival of 4.06 years
    - Those diagnosed after 60 had a median survival of 2.56 years
  - Level of ID is also a significant predictor of survival; median survival was
    - 9.08 years for mild ID
    - 6.15 years for moderate ID
    - 2.60 years for severe ID

Comparative comorbidities

5 most prevalent comorbidities among all GH residents:
- Depression
- Urinary incontinence
- Constipation
- Foot pain
- Heartburn/acid reflux

5 most prevalent comorbidities among Controls:
- Impaired vision
- G-I pain
- Depression
- High blood pressure
- Constipation

### Primary comorbidities in study subjects

<table>
<thead>
<tr>
<th>Mean N comorbidities</th>
<th>ID: 7.67</th>
<th>DS: 5.83</th>
</tr>
</thead>
<tbody>
<tr>
<td>GH = 8.6</td>
<td>CO = 6.8</td>
<td></td>
</tr>
<tr>
<td>GH = 7.40</td>
<td>CO = 7.10</td>
<td></td>
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### 5 most prevalent comorbidities among all GH residents

- Depression
- Urinary incontinence
- Constipation
- Foot pain
- Heartburn/acid reflux

### 5 most prevalent comorbidities among Controls

- Impaired vision
- G-I pain
- Depression
- High blood pressure
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Comparative frequencies of comorbidities of GH residents – ID vs DS (base: 3 or more for ID)

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### Comparative frequencies of comorbidities ID vs DS – GH residents & Controls (3 or more for ID)

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5 most prevalent comorbidities among ID residents:
- Depression
- Urinary incontinence
- Constipation
- Foot pain
- Heartburn/acid reflux

5 most prevalent comorbidities among DS residents:
- Impaired vision
- G-I pain
- Depression
- Heartburn/acid reflux

### Progression:

<table>
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<tr>
<td>(GH vs CO) T1-T8</td>
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Due to deaths in the homes, younger new residents were added at T6 and T7, thus affecting the trending of comorbidity increases over time.

An uptick in comorbidities in the controls was noticed over the same period.

*Resident replacements due to deaths
†Death of control
Progression:
# of Comorbidities (GH-All, GH Legacy vs CO) T1 - T8

Due to deaths in the homes, younger new residents were added at T6 and T7, thus affecting the trending of comorbidity increases over time.

An uptick in comorbidities in the controls was noticed over the same period.

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Changes in frequency of comorbidities by home of legacy residents

Survivor effect - deaths have changed the dynamics of frequency of comorbidities among legacy residents over time in GH1 (no deaths, but 2 resident moved to GH2) and GH3 (2 deaths).

GH2 had 4 deaths and movement from GH1, leaving those with more comorbidities with age (and time).

Changes in frequency of comorbidities by home residents (all)

Update data to reflect all.

AADS dementia symptom related Items – ID vs DS

Behaviors occurring at minimum 2-3 times in past 2 weeks.
CAS-ID - %/Minutes Spent on Care Activities

Comparison of CAS-ID Minutes (%) - Mean/Care Activities by GH

- Staff spent an average of 222.5 min/day providing care to GH residents (or about 9.27 m/hr over a 24-hour period)
- Staff spent an average of 215.8 min/day with Controls (8.99 m/hr)
- Staff spent 220.4 min/day with residents with ID (9.18 m/hr)
- Staff spent 228.1 min/day with residents with DS (9.50 m/hr)

GH staff care patterns (T4,T5,T8 combined)

- Staff spent an average of 222.5 min/day providing care to GH residents (or about 9.27 m/hr over a 24-hour period)
- Staff spent an average of 215.8 min/day with Controls (8.99 m/hr)
- Staff spent 220.4 min/day with residents with ID (9.18 m/hr)
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LOS – by GH (ID vs DS)

- Home #2 has had the most change/movement
  - Some residents from D/GH1 moved to D/GH2
- Home #3 is the 'advanced dementia' home
- Down Syndrome
  - Number: 1/3 (n=5) from T1 to T4
  - Increased to 1/3+ (n=6) from T5 to T7
  - Decreased to 1/3- (n=4) in T8

Group Home and LOS* and Transitions

Average LOS over 7 years for each home was:
GH1: 49.0 months (4.0 yr)
GH2: 45.6 months (3.8 yr)
GH3: 56.7 months (4.7 yr)
Overall LOS was 49.4 months (4.12 yr)

Most movement/resident changes were observed in GH1 and GH2; GH3 had the most stability and highest LOS

Lighter shade = residents with Down syndrome

LOS = Length of Stay
Commentary

Community-based dementia-capable care is based on knowing key variables, such as dementia-stage, mortality, health status, daily patterns of care, dementia-related behaviors, and probable trajectories of decline.

Onset patterns for DS in early 50s and relative shorter duration of progressive dementia point to need for earlier surveillance for functional and behavior changes signaling MCI or AD.

Information on progression timelines can aid agencies with residence resource planning and assignment of staff and clinical resources.

• Using a GH model of in-community dementia-capable care can enable adults with Down syndrome and other intellectual disabilities receive dementia care in a specialized setting.

• As dementia begins to affect an increasing number of adults with ID (due to aging) more attention needs to be given to viable models for in-community long-term advanced dementia capable care.
By tracking the health and function longitudinally, outcome information can pinpoint markers that are associated with premorbid dementia and can help health providers maintain surveillance over select functions and health conditions of those adults already affected.

Screening instruments, incorporating these markers, can more precisely be used to identify at-risk adults for ADRD and aid providers in designing remediation programs earlier.

Knowing about probabilities of occurrence of co-conditions can help with medical management and with providing accommodations for non-dementia related effects.

Conclusions

Further research is needed to obtain more reliable data and identify trajectories of co-conditions associated or disassociated with dementia.

Care should be taken when generalizing from limited N studies.

Acknowledgements

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Matthew P. Janicki, Ph.D. University of Illinois at Chicago
mjanicki@uic.edu