LONGITUDINAL STUDY OF THREE DEMENTIA CARE GROUP HOMES FOR ADULTS WITH INTELLECTUAL DISABILITIES

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*Study*
- The Wichita Project: A naturalistic examination of the evolution of three specialty group homes for dementia-related care of adults with intellectual disabilities

*Funding*
- University of Illinois at Chicago - Rehabilitation Research and Training Center on Developmental Disabilities and Health (US National Institute of Rehabilitation and Disability Research) & Starkey, Inc. (Wichita, KS) and logistical support from the University at Albany

Background
- More local agencies are taking responsibility for the later-life care of aging adults with intellectual disabilities and are developing small dementia-care group homes.
- The homes are designed to be ‘dementia-capable’ and provide extended older age care.
- As dementia affects adults differentially, both with respect to symptoms and decline, it might be that individual dementia care homes will eventually be defined by their residents in terms of residual functional skills and degree of personal care needs.

Aim of Study
- Given that stage-specific changes eventually occur, it was of scientific interest to conduct a longitudinal study of three such dementia-care community-based group homes to observe progression of decline, resident needs, and adaptations to care practices.

The ‘Wichita Study’

Dementia-Changes Over Time

- Hypothetical test scores on series of performance measures over 5 years
- Although all generally begin at about same level, different outcomes and rates of decline occur over time
Starkey's Goebel LIGHTHouse Project consists of three specialized homes for 15 people with intellectual disabilities and dementia. The three 3,700 square foot (343.7 sq m) homes have five bedrooms each, bathrooms, and shared dining and living spaces. The homes were designed to provide a supportive community living experience for people with disabilities and dementia with specialized staff support until skilled nursing care is required.

Study tracked the 15 residents and 15 controls (who lived in other settings) over three years, as well as examined staff and administrative factors.

GH1 = Diana House; GH2 = WOW House; GH3 = Latimer House

Dementia Group home residents N=15, 5 per home

Controls – same age and general functioning N=15, from various places

Compared on standard measures of health and function, co-incident conditions, and care needs.
**Study method**

- Data were collected 4 times – at approximately 6 month intervals
  - T1: February 2011
  - T2: August 2011
  - T3: February 2012
  - T4: August 2012
- Dementia group home residents (n=15)
- Controls (same age and general features) (n=15)

**Study Instruments**

- The Longitudinal Health and Intellectual Disability Survey (LHIDS)*
- Caregiver Activity Survey-Intellectual Disabilities (CASID)*
- 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) †

* T1, T2, T3, T4; † T1
First Year – ‘T1’

What were the residents of the three homes like in the first year?

| Age (mean) | 58.0 |
| Sex (males) | 2:♀ 3:♂ |
| Down syndrome present | Yes: 2 |
| Mean Weight (lbs/kg) | 32.04 |
| Mean BMI | 30.04 |
| IQ | 5:Mod |
| Dementia stage | 5:Mod |
| Dementia years | 3-5yr: 2 |
| Co-morbidities | 3-5yr: 2 |
| Co-morbidities Average (number/person) | 3-5yr: 2 |

| Age (mean) | 61.6 |
| Sex (males) | 5:♂ |
| Down syndrome present | Yes: 2 |
| Mean Weight (lbs/kg) | 26.56 |
| Mean BMI | 26.56 |
| IQ – Moderate/Severe | 2:Sev |
| Co-morbidities | 2:Sev |
| Co-morbidities (Average #) | 2 |
| Mean CAS-ID (min/day)/(hr/day) | 87.5m/4.6h |
| Mean Health Now Score | 2.3 (F-G) |
| Health year ago (About same or Better) | 53.0% |

| Age (mean) | 55.8 |
| Sex (males) | 4:♀ 1:♂ |
| Down syndrome present | Yes: 1 |
| Mean Weight (lbs/kg) | 32.86 |
| Mean BMI | 32.86 |
| IQ – Moderate/Severe | 1:Mod 2:Sev |
| Co-morbidities | 1:Mod 2:Sev |
| Co-morbidities (Average #) | 2:Sev |
| Mean CAS-ID (min/day)/(hr/day) | 167.2m/2.8h |
| Mean Health Now Score | 3.2 (V-VG) |
| Health year ago (About same or Better) | 86.7% |

Comparison: T1 Dem GH vs. Control

| Dementia Group Homes (n=15) | Control Adults w/ID (n=15) |
| Age (mean) | 59.1 | 59.1 |
| Sex (males) | 60% | 60% |
| Down syndrome present | 33.4% | 33.4% |
| Mean Weight (lbs/kg) | 166.37/4.4 | 166.37/4.4 |
| Mean BMI | 29.82 | 29.82 |
| IQ – Moderate/Severe | 66.7/27.7% | 66.7/27.7% |
| Co-morbidities (Average #) | 6.6 | 6.6 |
| Mean CAS-ID (min/day)/(hr/day) | 275.9m/4.6h | 275.9m/4.6h |
| Mean Health Now Score | 2.3 (F-G) | 2.3 (F-G) |
| Health year ago (About same or Better) | 53.0% | 53.0% |

Group Home Residents (Yr 1)

Co-incident conditions Mental Health (T1)

- Sleep
- Anxiety
- Depression

Age: mean age; Down Syndr: Down Syndrome; BMI: Body mass index; Dem stage: Stage of dementia; Dem years: Years since onset; Co-morbid: Co-morbidities ( Average number/person)
### Co-incident conditions

#### Cardiovascular (T2)
- Heart disease
- High Cholesterol
- Blood Pressure

#### G-I/U (T2)
- Constipation
- Gastro-intestinal
- Heartburn
- Incontinence

#### Miscellaneous (T2)
- Diabetes
- Osteoporosis
- Thyroid

### Care challenges

<table>
<thead>
<tr>
<th></th>
<th>Dementia Home</th>
<th>Control Settings</th>
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<tbody>
<tr>
<td>Mean CAS-ID (min/day)</td>
<td>267.47 (4.4h)*</td>
<td>161.47 (2.7h)*</td>
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<tr>
<td>Mean day to day care burden</td>
<td>17.4*</td>
<td>20.67*</td>
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<td>Mean Care Challenges Score</td>
<td>3.6</td>
<td>3.2</td>
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<tr>
<td>Mean Quality of Life Score</td>
<td>11.33</td>
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</tbody>
</table>

* Statistically significant difference
The 15 residents...

- In their late 50s
- About 1/3 with Down syndrome
- 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

Two years ‘T1-T4’

[T1 – 2011, T4 – 2013]
What were the residents like after two years and what had changed?
**Comparison of #Co-morbidities, Dementia Care Group Home Residents vs. Controls**

![Comparison of #Co-morbidities, Dementia Care Group Home Residents vs. Controls](image)

**Co-incident conditions**

**Mental Health (T4)**

- Sleep
- Anxiety
- Depression

**Co-incident conditions**

**Cardiovascular (T4)**

- Heart disease
- High cholesterol
- Blood pressure

**Co-incident conditions**

**GI/U (T4)**

- Constipation
- Gastro-intestinal
- Heartburn
- Incontinence
Co-incident conditions
Miscellaneous (T4)

Comparison of Dementia Symptoms (AADD 'How Often' Select Items) among Group Home Residents by Home (T4)

Comparison of dementia symptoms (AADD 'How Often' Select Items) between group home residents with Down syndrome and non-Down others (T4)
The 15 residents...two years later
- Older and there is some evidence of change in function and increasing health problems or less ‘wellness’
- Residents in homes 2 & 3 show the greatest impact of dementia over the two years
- Staff time spent on caregiving varies by home and is much more than that for ‘the controls’
- Fluctuations of staff times by time of day indicated periods when most staff-resident interactions occur

Findings
What can we say from the data?

Two years later ...
- Evidence of change in function and increasing health problems or less ‘wellness’
- Residents in homes 2 & 3 showed the greatest impact of dementia over the two years
- Higher number of co-morbidities among dementia residents compared to controls
- Staff time spent on caregiving much more than that for ‘the controls’
- Trending toward individual home specialization as to level of care

Findings
- With respect to dementia homes – The adults with dementia had more care needs, overtime were changing with respect to their function and abilities, had more physical and mental health needs, and were in declining health
- With respect to staff – there were times of the day when staff time with the residents was more intensive and focused
- With respect to specialization -- over two years a trend toward specialization among the homes was observed
- With respect to the controls – generally remained ‘as is’, but two were showing early signs of dementia
Summary 1

One aim was to see what differences there were between adults with dementia and without dementia.

- It was found that dementia care was affected by differences in complexity of impairments and co-incident conditions found in adults with ID and dementia.
  - Specifically, there were significant differences in the number of comorbidities, staff time devoted to specialized care, and frequency of occurrence of dementia-associated behaviors between dementia-care group home residents and controls.
  - Also, residents with Down syndrome were younger and had significantly less comorbidities.
- It was found that dementia affected adults in GHs are/have
  - Weigh less and have lower BMI
  - Greater number of co-morbidities
  - Demand/require 2x more staff time
  - Diminishing health over time

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Save the date!

2014 Princeton Conference on Intellectual Disabilities and Dementia

June 17-18, 2014
Princeton, New Jersey USA

For information:
www.aadmd.org/ntg