Dementia Capable Group Homes for Adults with Intellectual Disability: Development Implications

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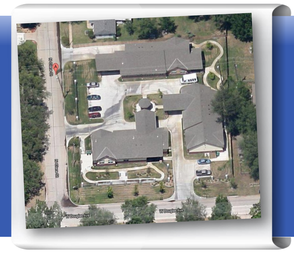


Abstract

STUDY: An opportunistic longitudinal study of three co-located dementia-care group homes (GHs) for adults with intellectual disability and dementia (ID/D) provided information on long-term care aspects of such GHs.
METHOD: Since 2011 a cohort of 15 legacy adults with ID/D (w/ 8 replacements) who lived in 3 purpose-built, 5-resident, dementia-capable GHs was followed annually, along with 15 community-dwelling (non-dementia) adults with ID as age-matched controls. Annual data collected included resident demographics, function, health, and other related information as well as staff/home administrative factors.
RESULTS: Of the 15 legacy residents 8 died and were replaced by 8 others (greater mortality was noted among legacy residents with ID compared to DS). All 23 residents (legacy and replacements – [All-ID/D]) exhibited features related to decline (increasing problems, more comorbidities with age, and lessened function with dementia progression). Over time there were inter-home transfers and new admissions, and the GHs trended toward stage/level specialty care. Observed was an ebb and flow of movement related to stage of dementia and changes in character among the 3 dementia GHs, as well as variations in staffing patterns and periods of focused staff care and intensity during the day. Costs and staffing patterns also varied among the homes.
CONCLUSION: These data can provide a basis for administrative guidance on GH development and maintenance, as well as identify markers for tracking health and function, planning for morbidity, mortality, and home transitions, and enable agencies to provide in-community group housing and quality care in accord with stage-defined functional changes and aging-related needs for older persons with ID (and for older persons without ID).

Introduction

Specialized housing for adults with intellectual disability and dementia has become more prevalent as agencies set up such housing for when families exhaust their physical and financial capital for continued home-based care. One agency employing an 'in-place progression' model in 3 new purpose-build small dementia care group homes provided an opportunity for a longitudinal study of such homes. We posited that as homes are established for dementia care, their character will eventually change due to the nature of dementia and that home specialization will be an organic outcome of multiple dementia care group home availability.

Our hypothesis was that eventually, as changes affect adults with dementia, agencies will specialize group homes based on function and stage.

The study also allowed us to follow a cohort of new admissions and detail their progression over time.

Instruments & Methods

- **SUBJECTS** were a cohort of 15 legacy adults with ID/D, and 15 community-dwelling matched controls (CO) over a period of 7 years (including 8 ID/D replacements)
- **DATA** were collected semi-annually in 2011-2013 (T1-T4) and then annually in 2015-2018 (T5-T8). Subjects were compared on standard measures of health and function, co-incident conditions, and care needs/provision. Agency factors included care time patterns, costs, staffing, and administrative decision-making.
- **STUDY INSTRUMENTS** T1-T4 & T5-T8

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, and environmental scans); NTG-Early Detection and Screening of Dementia (NTD-EDSD) – added in T5-T9

- **ANALYSES** examined the trajectories and condition factors of the legacy 15 ID/D, compared to controls, all 23 ID/D as to 3 GH factor variations, groupings by age of admission, and Down vs non-Down. Administrative factors were examined as to staffing, costs, and time care patterns in each home.

Results – Legacy Cohort

Mortality

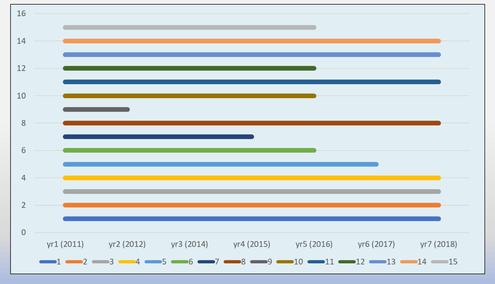
Of legacy adults, 8/15 (53%) died over 7 years
- X_{age} death = 65.2 [DS: 58.8; ID: 71.5; M: 66.6; F: 65.0]

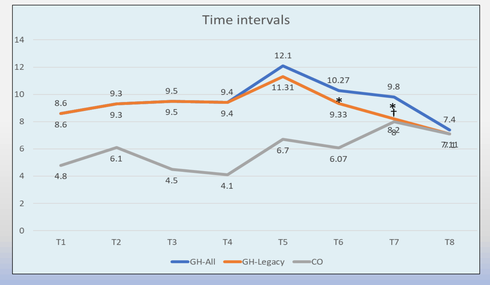
Average age at entry: 59.1 [ID: 66.2; DS: 53.5]
Mean years from entry to death: 5.4yrs
Deaths began 2 years following admission
Average age of death for COs: 78.5 yrs

Comorbidities

Over time all adults had greater drop off of comorbidities due to deaths. COs showed an upward trend with increasing age. There was a significant difference in the N/comorbidities between LID/D & COs.

Major comorbidities included: incontinence (71.4%); depression (57.1%); back pain, constipation, foot pain, & heartburn (42.9%); arthritis & thyroid disorder (37.5%); high cholesterol & high blood pressure (28.6%); impaired vision or impaired vision (28.6%).

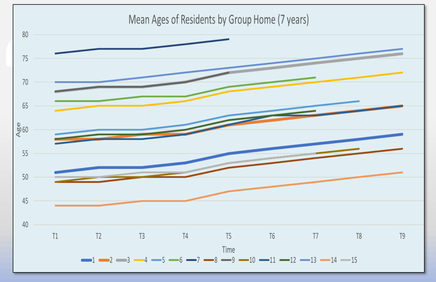




Admission patterns

Admission age clusters

Admissions based on dementia and age showed a *tri-modal pattern*
Admit Age Group #1 entry: ± age 50 [X=50.5] [range: 49-53]
Admit Age Group #2 entry: ± age 57 [X=57.1] [range: 56-59]
Admit Age Group #3 entry: ± age 67 [X=66.8] [range: 64-70]
Outliers were either much older [76, 79] or much younger [40, 44]



Differences were attributed to more **comorbidities** in two older age admit groups (#2,#3) and more **dementia-related behaviors** in two younger age admit groups (#1,#2). DS admissions were only in age admit group #1 and #2.

Other Factors

Dementia Behaviors

Category		DGH	COs
Function changes			
Activities of daily living		7	2
Language & Communication		10	3
Sleep-wake change patterns		3	5
Ambulation		1	1
Memory		7	3
Behavior & affect		5	7
	Sums	33	20
	Mean	5.5	3.5
How changes noted			
Self-reported problems		5	2
Notable changes observed by others		11	5
	Sums	16	7
	Mean	8.0	3.5

- **Behaviors observed were typically associated with dementia**. Most adults showed increased challenges with ADLs, communication skills, behavior, and memory when compared to controls.
- Some adults reported these challenges themselves; most were observed to have them by staff or others.
- Newly observed behaviors included: cognitive isolation, loss of interest, social withdrawal, and anxiety and agitation.

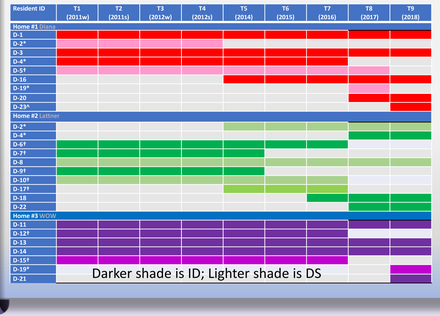
Dementia and Aging

- Post-Dx expectation is that the **impact of aging will co-mingle with cognitive losses and behavioral changes stemming from dementia**. Age trajectories showed increases in health factor challenges, diminishing behavioral competence, and debilitation due to dementia.
- Admission trends showed that **adults with Down syndrome were admitted to homes earlier**, but had more life-years in the homes than elderly adults admitted at later age but who succumb earlier to disease complications.

Results – Group Homes

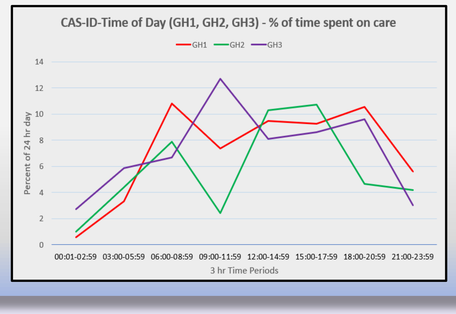
Length of stay patterns by home

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) (*most stable*)
Overall mean LOS for all was 49.4 months (4.12 yr)



Staff time care patterns by home

Staff care time patterns varied by homes as well as the caregiving focus. Most time was spent on – toileting aid (GH1/GH3), food(eating/drinking) assistance (GH1/GH2), behavior management (GH2).
Chart shows 3hr block pattern variations by home (averaged over 3 times – T1, T5 & T8).



Home Specialization

Specialization trending over time was observed but was affected by deaths, transfers, and new admissions.
GH1 (1 death at 66) and GH2 (3 deaths at 57, 72, 79) were somewhat similar with mid-stage residents with varying needs; GH3 was adapted to late stage or advanced dementia with 2 deaths (at 64 and 56).
Specific home issues:
GH1: MH issues, body physical issues; less stable LOS; Mean oldest age
GH2: GI-Issues, High cholesterol, depression; less stable LOS; transfers from GH1
GH3: Incontinence; most stable LOS; most dementia behaviors; most staff

Staff assignments by home

More staff were assigned to GH3, the advanced dementia home.
Mean staffing: 4.3 full-time and 2.3 part-time

Costings

Annual pp cost per home & Controls:
GH1: $41,395
GH2: $48,196
GH3: $50,491
X_{GH}: $46,693
X_{CO}: $30,321

Conclusion

- *Home specialization can evolve* from the needs of adults with ID and dementia and be contingent on resource availability and the agencies' administrative policies *when* agencies have multiple homes.
- *Small group home community-based dementia-capable care can be viable* if it is based on knowing key variables, such as dementia-stage, mortality expectations, health status, daily patterns of care needs, dementia-related behaviors, aging-related issues, and probable trajectories of decline of the residents.
- GH administrators *should expect* varied trajectories of decline, mortality linked to complexity of pre-existing conditions and progression of dementia, changes in the focus of care needs in GH cohorts over time (including end-of-life care), and *plan for* differential staffing patterns and cost demands due to stage of dementia.
- *Dementia care GHs can enable agencies to provide in-community group housing* and quality care in accord with stage-defined functional changes and needs if structured in a planful way.

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Additional data reports can be sourced at ***www.aadmd.org/ntg/resources/wichita-project***

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