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 the 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).

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 a 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 adult 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.

METHOD:

Since 2011 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-T8

1. The Short Form 36 (SF-36) (2007-2012w); 2. The Dementia Capable Group Homes for Adults with Intellectual Disability: Development Implications


Dr. Matthew Janicki, Ph.D.

Introduction

Mortality

Of legacy adults; 8/15 (53.9%) died over 7 years

- Xp: mean death = 63.2; DS: 58.8; ID: 71.5; M: 66.6; F: 61.0
- Average age at entry: 59.1 [ID: 66.2; DS: 53.5]
- Mean years from entry to death: 5.4 yrs
- 3 modal pattern of decline: 64, 56, 46 yrs
- Deaths began 2 years following admission
- Average death age 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 ID/D & COs.

Major comorbidities included: (incontinence (71.4%), depression (57.1%); back pain, constipation, foot pain, & heartburn (43.2%); arthritis & thyroid disorder (37.5%); high cholesterol & high blood pressure (28.6%); impaired vision or impaired vision (28.6%).

Admission age clusters

Admissions based on dementia and age showed a tri-modal pattern

Admit Age Group #1 entry: 1 age 50 [X=50.5] (range: 49-53)

Admit Age Group #2 entry: 1 age 57 [X=57.1] (range: 56-59)

Admit Age Group #3 entry: 1 age 67 [X=66.8] (range: 64-70)

Outliers were either much older (176, 78) or much younger (40, 44)

Dementia Behaviors

- Post-Ex is that the impact of aging will co-mingle with cognitive changes and behavioral changes stemming from dementia.

Trajectories showed increases in health factor challenges, diminishing behavioral capability, and dependence 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.

Dementia and Aging

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Dianbras, et al. 2013 (T1-T5)

T1: Community Living Research & Development Center on Intellectual Disability & Dementia Disablity

Diana Disorba, et al. 2013 (T1-T5)

T2: Community Living Research & Development Center on Intellectual Disability & Dementia Disablity

T3: Community Living Research & Development Center on Intellectual Disability & Dementia Disablity

T4: Community Living Research & Development Center on Intellectual Disability & Dementia Disablity

T5: Community Living Research & Development Center on Intellectual Disability & Dementia Disablity

T6: Community Living Research & Development Center on Intellectual Disability & Dementia Disablity

T7: Community Living Research & Development Center on Intellectual Disability & Dementia Disablity

T8: Community Living Research & Development Center on Intellectual Disability & Dementia Disablity

Darker shade is ID; Lighter shade is DS

Results – Legacy Cohort

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)

Staff time care patterns by home

GH1: 49.0 months (4.0 yr)

GH2: 45.6 months (3.8 yr)

GH3: 56.7 months (4.7 yr) (most stable)

Other Factors

Differences were attributed to more comorbidities in two older age admit groups (92,93) and more dementia-related behaviors in two younger age admit groups (#1, #2).

GH admissions were only in age group #1 and #2.

Costings

Annual pp cost per Home: GH1: $41,395

GH2: $48,196

GH3: $50,491

Xp: $46,693

Xm: $30,321

Results – Group Homes

Costings

Annual pp cost per Home: GH1: $41,395

GH2: $48,196

GH3: $50,491

Xp: $46,693

Xm: $30,321

Other Factors

Differences were attributed to more comorbidities in two older age admit groups (92,93) and more dementia-related behaviors in two younger age admit groups (#1, #2).

GH admissions were only in age group #1 and #2.

Home Specialization

Specialization trending over time was observed but was affected by deaths, transfers, and new admissions.

GH1 (1 death at 66) and GH2 (8 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 66).

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

Other Factors

Differences were attributed to more comorbidities in two older age admit groups (92,93) and more dementia-related behaviors in two younger age admit groups (#1, #2).

GH admissions were only in age group #1 and #2.

Conclusions

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, and patterns of care needs, dementia-related behaviors, aging-related issues, and probable trajectories for the character and needs 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 other 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.