

Components of Dementia-Capable Group Home Care

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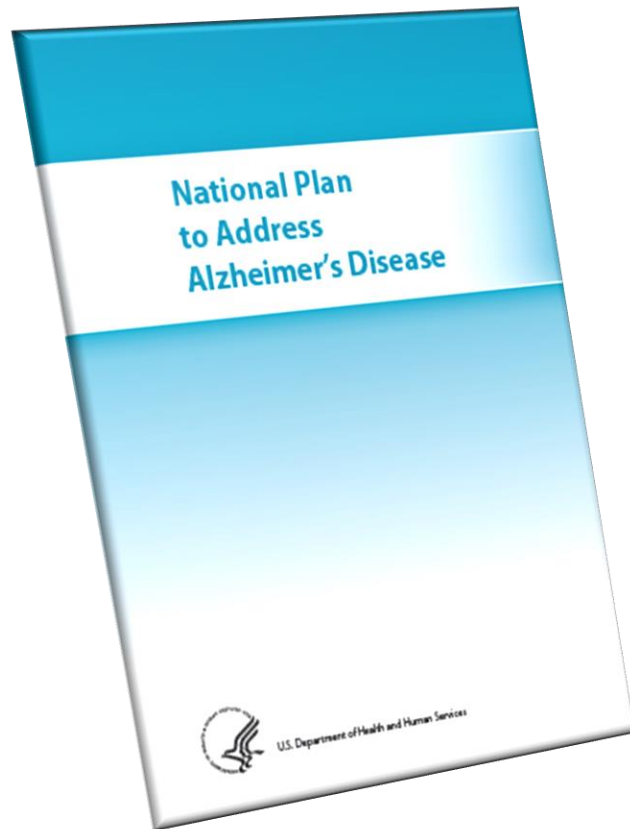
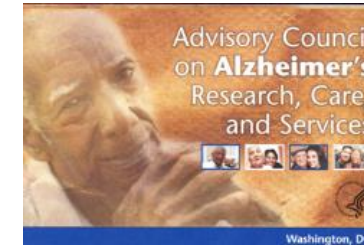
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U.S. National Plan to Address Alzheimer's Disease



- ✓ Issuance of practice guidelines for care and supports and expanded public education
- ✓ Promotion of assessment tool for detection of cognitive impairment as part of the annual wellness visit
- ✓ Enhanced supports for caregivers
- ✓ Community care supports and services
- ✓ Expanded research
- ✓ Special task groups on I/DD

Released on May 15, 2012

Updated annually until 2025!

Opportunistic study



- ID agency in mid-West decided to open three purpose-built group homes to provide in-community care for their clients with dementia.
- We came across the homes during a consult at the agency – providing training on ID and dementia.
- Homes were already built, but in final stages of finishing work.
- Agency agreed to participate in study focusing on the three homes
- Once methodology and instruments were identified, and IRB clearances were obtained, the agency began data collection.

Study Premise



Given the cluster model employed by an agency of three 'in-place progression' homes ...

- ◆ Our hypothesis is 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



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.**

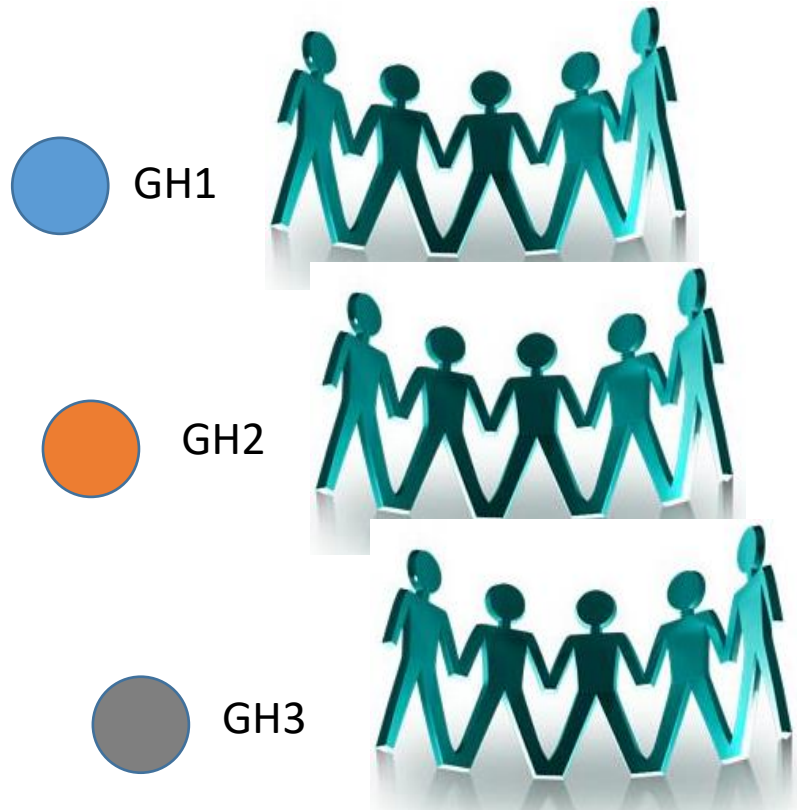




GH1 = Diana House; GH2 = WOW House; GH3 = Latimer House



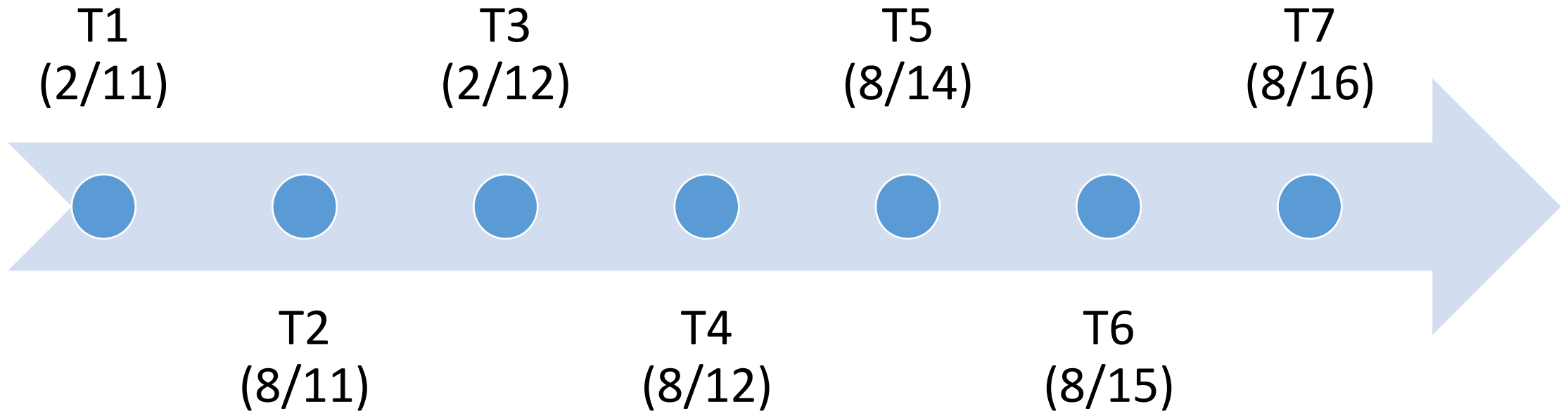
Study



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

- Residents compared on standard measures of health and function, co-incident conditions, and care needs
- Agency factors included costs, staffing and administrative decision-making

Timeline



Study Instruments



T1-T4

- ◆ 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)
- ◆ Administrative Factors (cost and staff data, interviews with administrative staff, environmental scans)

T5-T6

- ◆ NTG-Early Detection and Screening of Dementia (NTD-EDSD)

Key extracts from longitudinal data

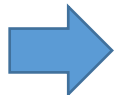
- Time patterns of staff care provision by GH
- Care activities key focus areas by GH
- Dementia symptoms by GH
- Most prevalent medical comorbidities
- Administrative factors
- Home specialization

Characteristics of Dementia GH Residents and Controls (T1 vs T5) [4.5yr]

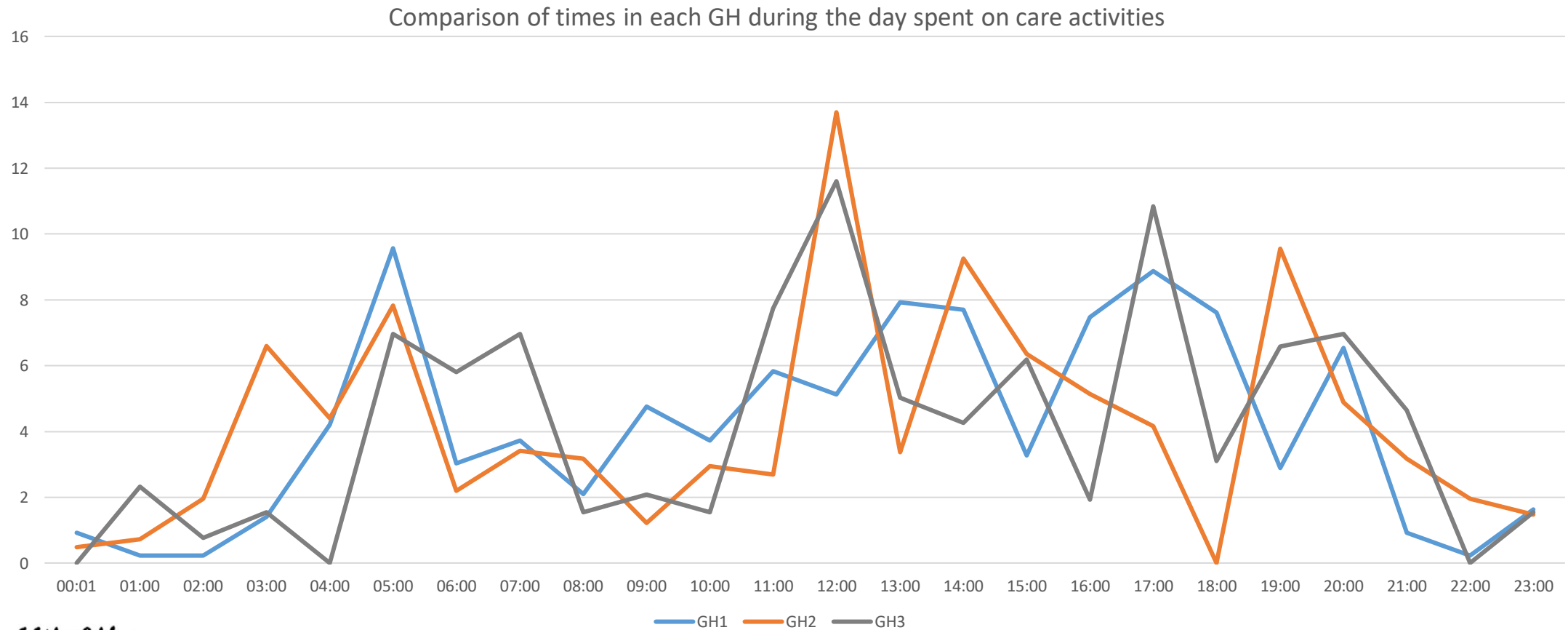
	○ GH#1		● GH#2*		● GH#3		Sum GH		Controls	
	T1	T5	T1	T5	T1	T5	T1	T5	T1	T5
Age (mean)	61.6	63.8	61.6	57.2	55.8	59.2	59.2	60.1	59.1	62.5
Age (range)	51-68	53-79	49-76	52-69	44-70	47-73	44-76	47-79	44-75	46-77
Sex ^a F/M	2/3	2/3	0/5	1/4	4/1	4/1	6/9	7/8	6/9	6/9
DS	2	2	2	3	1	1	5	6	1	1
IQ	Mod 5	Mod 5	Mod 3 Sev 2	Mild 1 Mod 2 Sev 2	Mild 1 Mod 2 Sev 2	Mild 1 Mod 2 Sev 2	Mild 1 Mod 9 Sev 4	Mild 2 Mod 9 Sev 4	Mild 3 Mod 8 Sev 4	Mild 3 Mod 7 Sev 3 Pro 1
BMI	30.0	32.2	26.6	30.6	32.9	29.9	29.8	30.9	34.8	n/a
Dem stage	Mod 5	Mod 5	Mod 3 Sev 2	Mod 3 Sev 2	Mod 3 Sev 2	Mod 3 Sev 2	Mod 11 Sev 4	Mod 11 Sev 4	-	-
Yrs since dementia Dx	1-3: 3 3-5: 2	3-5: 4 5+: 1	1-3: 3 3-5: 2	3-5: 4 5+: 1	1-3: 5	1-3: 1 3-5: 4	1-3: 3.6 3-5: 2	1-3: 1 3-5: 12 5+: 2	-	-
Co-morbidities	8.0	10.0	7.4	12.2	8.2	14.0	7.9	12.1	4.8	6.7
Health Now	2.6	2.2	2.2	2.6	2.2	2.2	2.2	2.3	3.2	3.1
Health yr ago	2.8	2.6	2.6	2.8	2.6	2.6	2.7	2.6	2.9	3.0

^a Females /Males

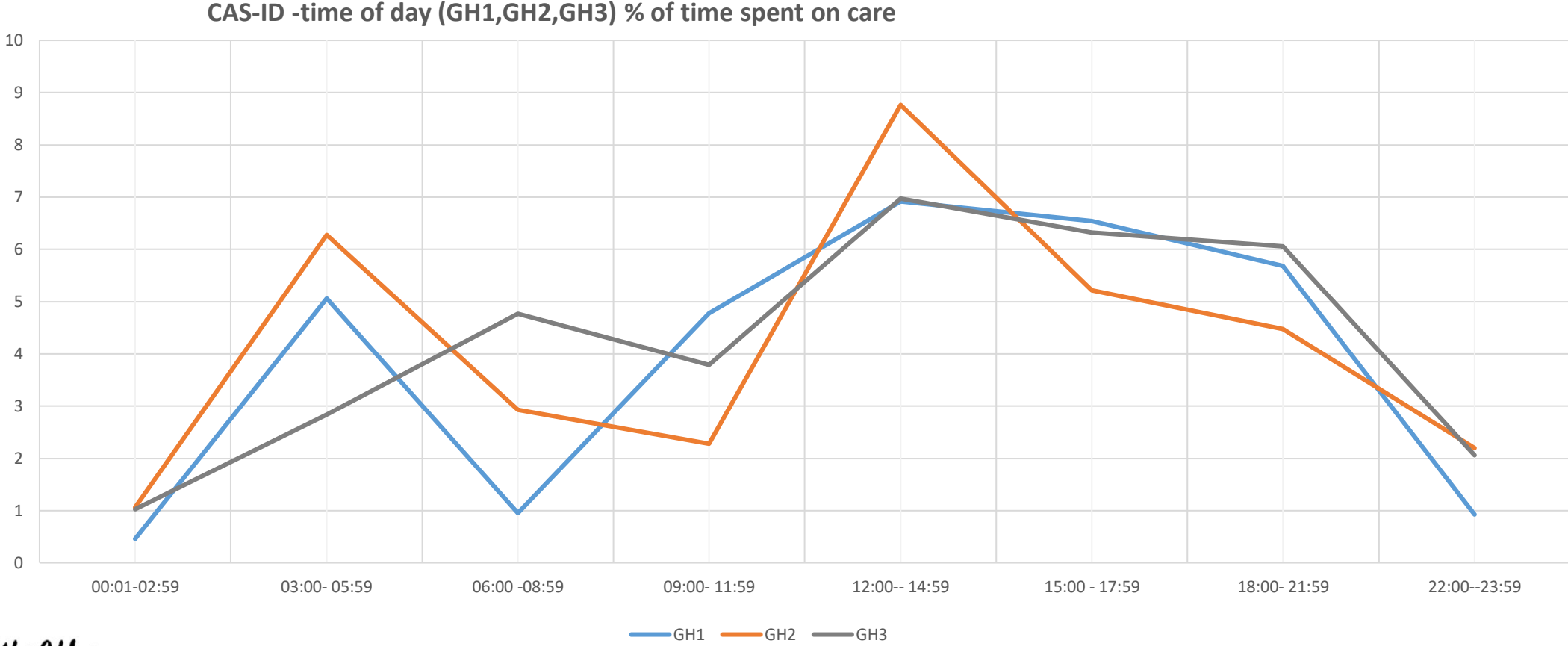
*Two original residents died since 2011 and were replaced with two others



Comparison of Time/Day in Each GH Spent on Care Activities (%)

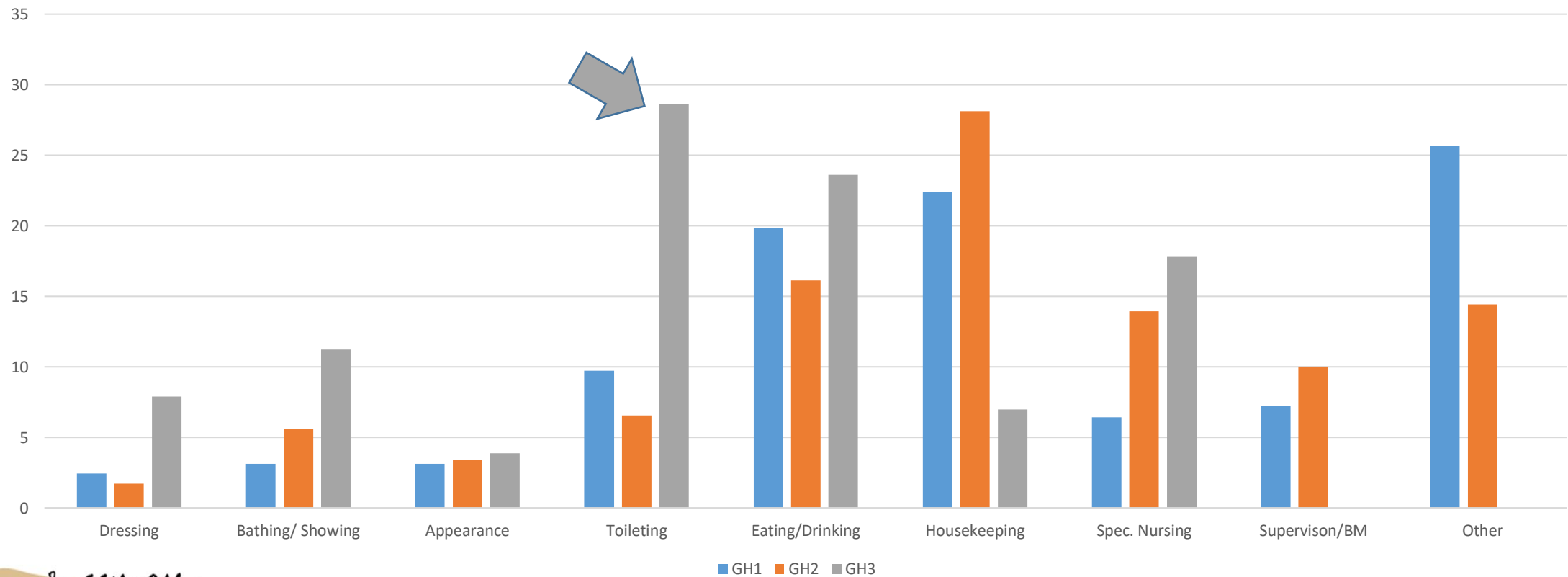


Times collapsed: by GH staff care patterns



%/Minutes by Home Spent on Care Activities

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



CAS-ID: mean minutes spent on care tasks in dementia group homes vs. controls

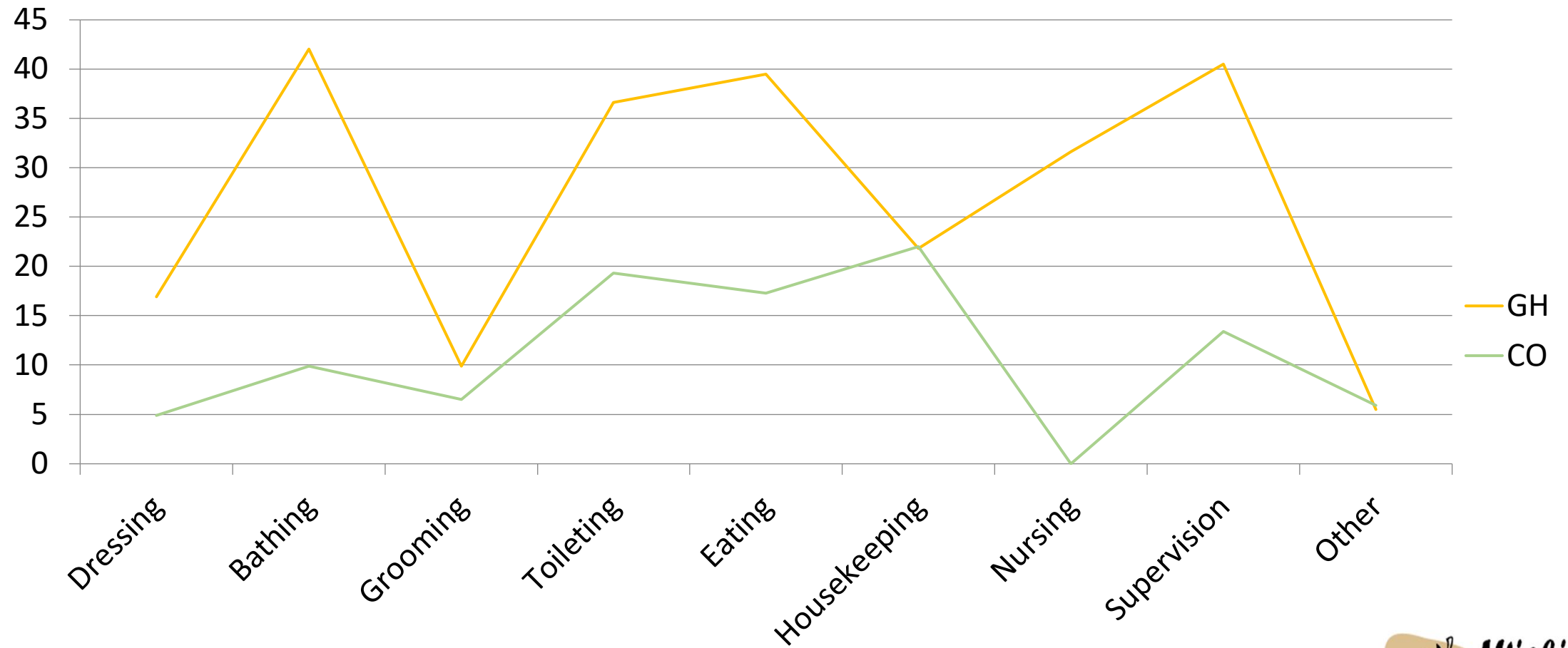
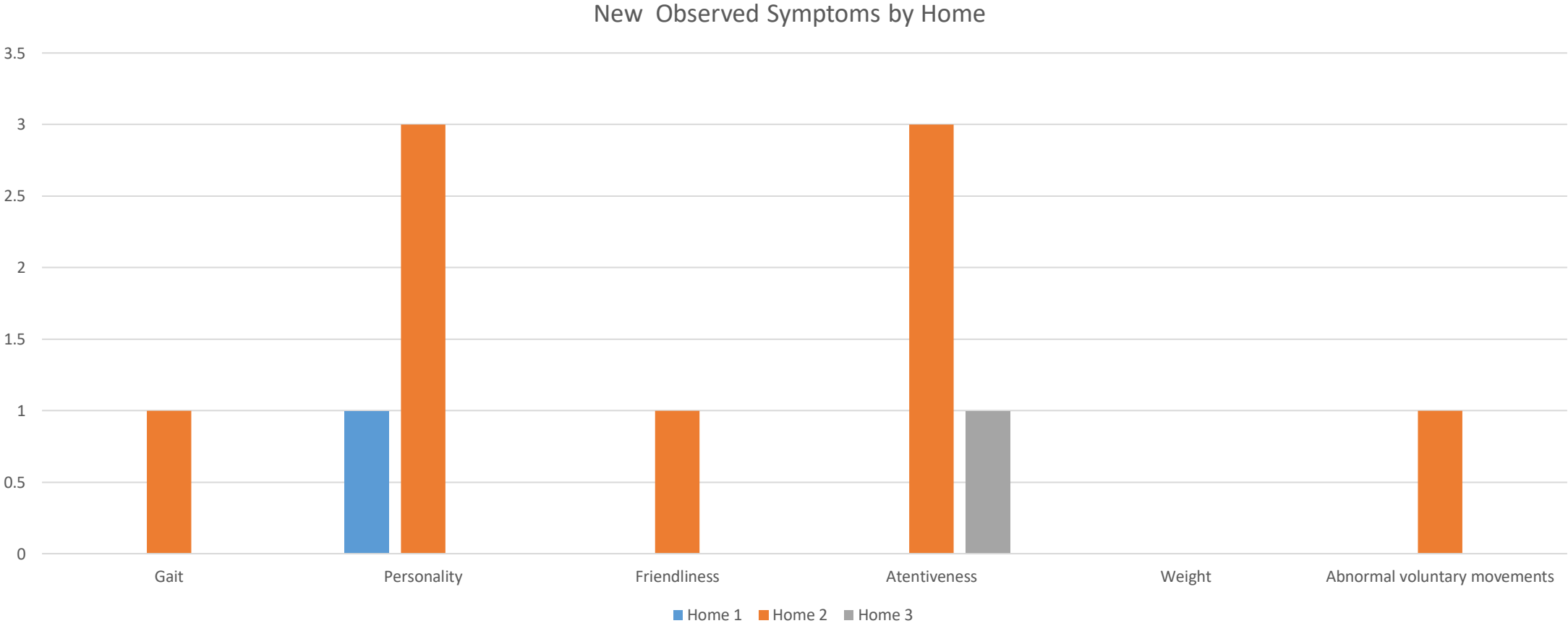


Table 3

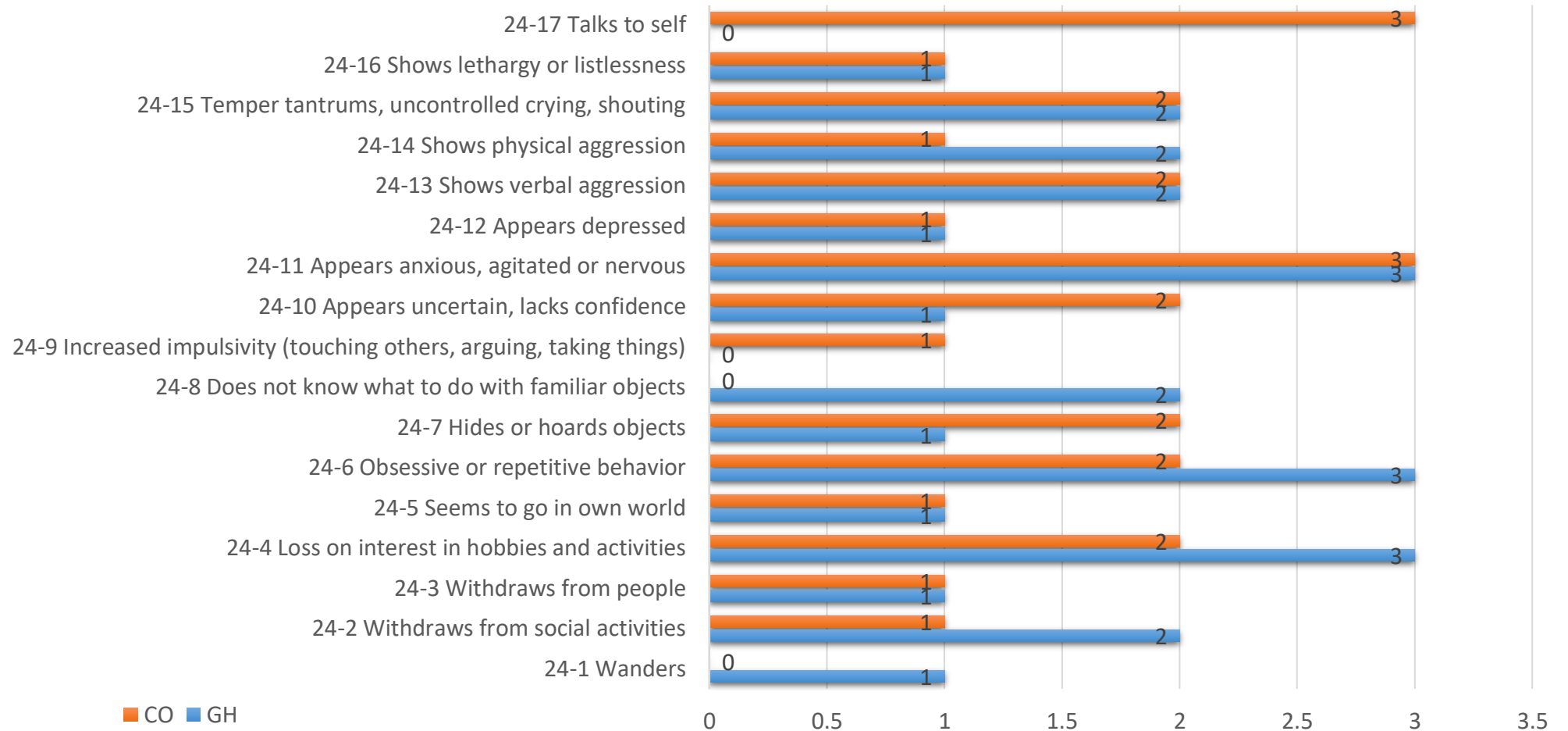
T5 – New observed symptoms by GH



Decline-associated behaviors - worsening

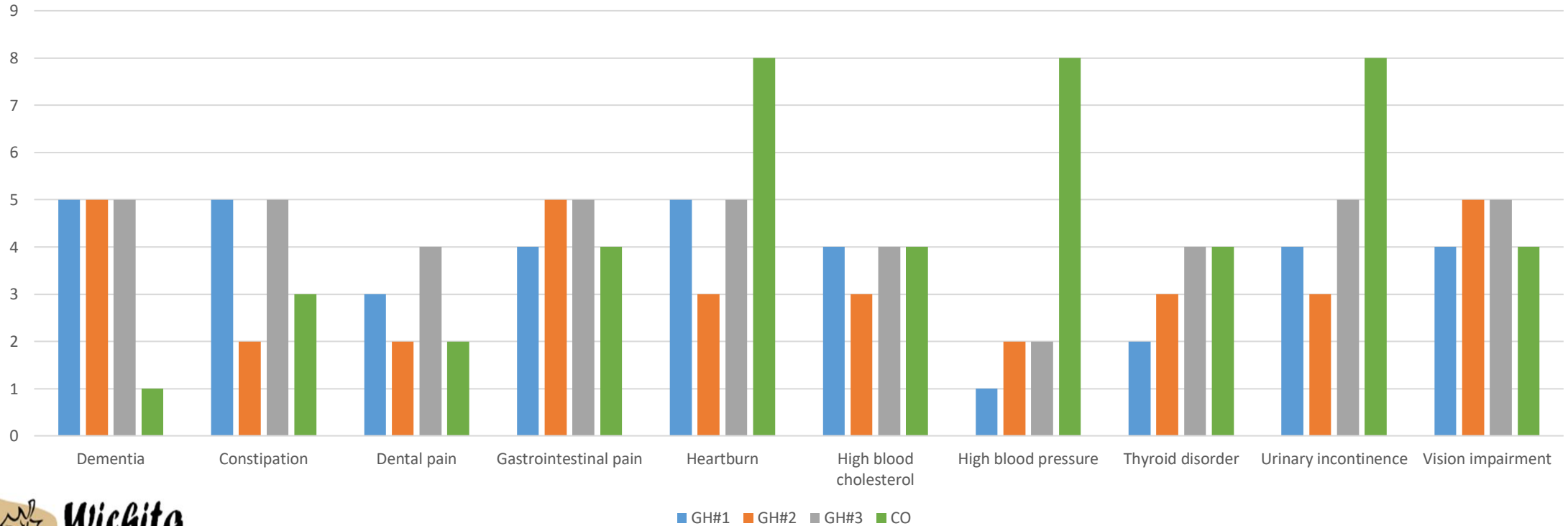


Behavior and Affect New Symptoms in Past Year






10 Most Prevalent Medical Conditions

Comparison of 10 most prevalent medical condition comorbidities of GH residents and controls (T5)



Administrative factors (T4)

Factor	GH1	GH2	GH3
			
Costs p.a. (Mean)	\$41,395	\$48,196	\$50,491
Staffing (Full, Part)	4, 2	4, 2	5, 3
Resident tenure	All still there	2 deaths, replaced	All still there
Focus of day activity	Off site	Off site / on site	On site

Summary 1

- Dementia affected adults in GHs are/have
 - More apt to have Down syndrome
 - Weigh less
 - Lower BMI
 - Greater number of co-morbidities
 - Demand/require 2x more staff time
 - Diminishing health over time

Advanced dementia

- More comorbidities
- Less activity
- Longer duration of dementia

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

Phase II: Longitudinal study [2014-2018] of agency experience with the three community based dementia care group homes



Findings

- **GH3** was identified as the home serving adults who were most impaired (i.e., advanced dementia) on a number of factors:
 - In aggregate, more staff time was devoted to *personal care* (5.18h per day vs. \bar{X} =3.52h for the other two homes) and more staff were assigned to the home.
 - Per resident annual costs were the highest (US\$50,491 vs \bar{X} =US\$44,795 for the other two homes).
 - Residents showed the least new dysfunction-related symptoms (6.3% vs. \bar{X} =46.9% for the other two homes).
 - Residents showed lesser number of present symptoms showing decline (27.8% vs. \bar{X} =36.2% for the other two homes).
 - Prevalent co-morbidities included high blood cholesterol, thyroid disorder, depression, constipation, gastrointestinal pain, vision impairment, heartburn/acid reflux, incontinence, & dental pain (Number of overall comorbidities: 70.0 vs. \bar{X} =55.5 for the other two homes).
 - Advanced-dementia related changes seen as worsening included gait, personality, sociability, attentiveness, weight, and abnormal voluntary movements.
 - Residents were least able to participate in out-of-home programs and activities.
- **GH2** was identified as the home with residents experiencing most active change and newly observed dysfunction – and emerging as the home mid-way between GH#1 and GH#3.
- **GH1** was identified as the home with residents least impaired by symptoms associated with dementia.

Conclusions

- Dementia care is affected by differences in complexity of impairments and co-incident conditions found in adults with dementia. When able, agencies will operate several dementia capable homes and will – over time – either administratively assign residents to home by degree of dementia-related impairment care needs or this will happen organically by virtue of how agencies replace adults who leave due to death or infirmity.
- While the study is still underway, the telling aspects of variations among the home are becoming evident.
 - Expectations are that such specialization will become even more evident with time.
- Recommendations include:
 - (a) planning should consider utility of matching incoming residents by stage of dementia impairment to maximize care outcomes;
 - (b) allocate greater number of staff to high demand care in mid-stage dementia; and
 - (c) track co-morbidities as dementia progresses.

Acknowledgements

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