Longitudinal Outcomes of Dementia-capable Group Home Use by Adults with Down Syndrome

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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*

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

GH1

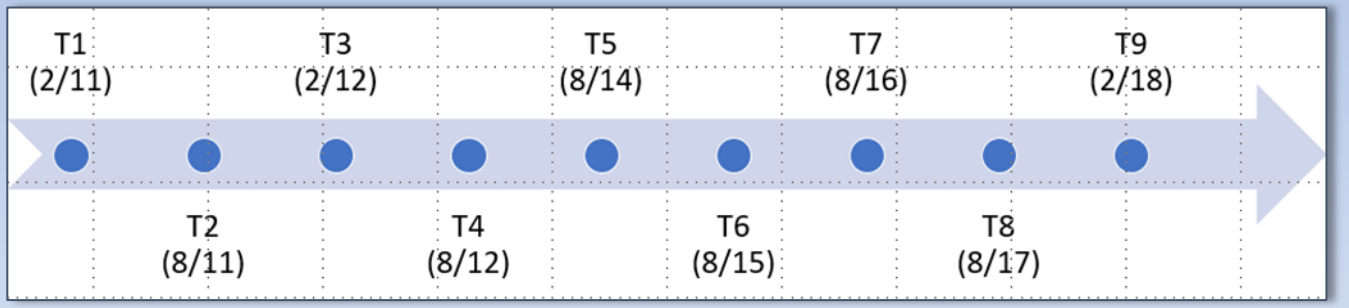
GH2

GH3

Dementia Group
N=15, 5 per hom

"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**



- 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

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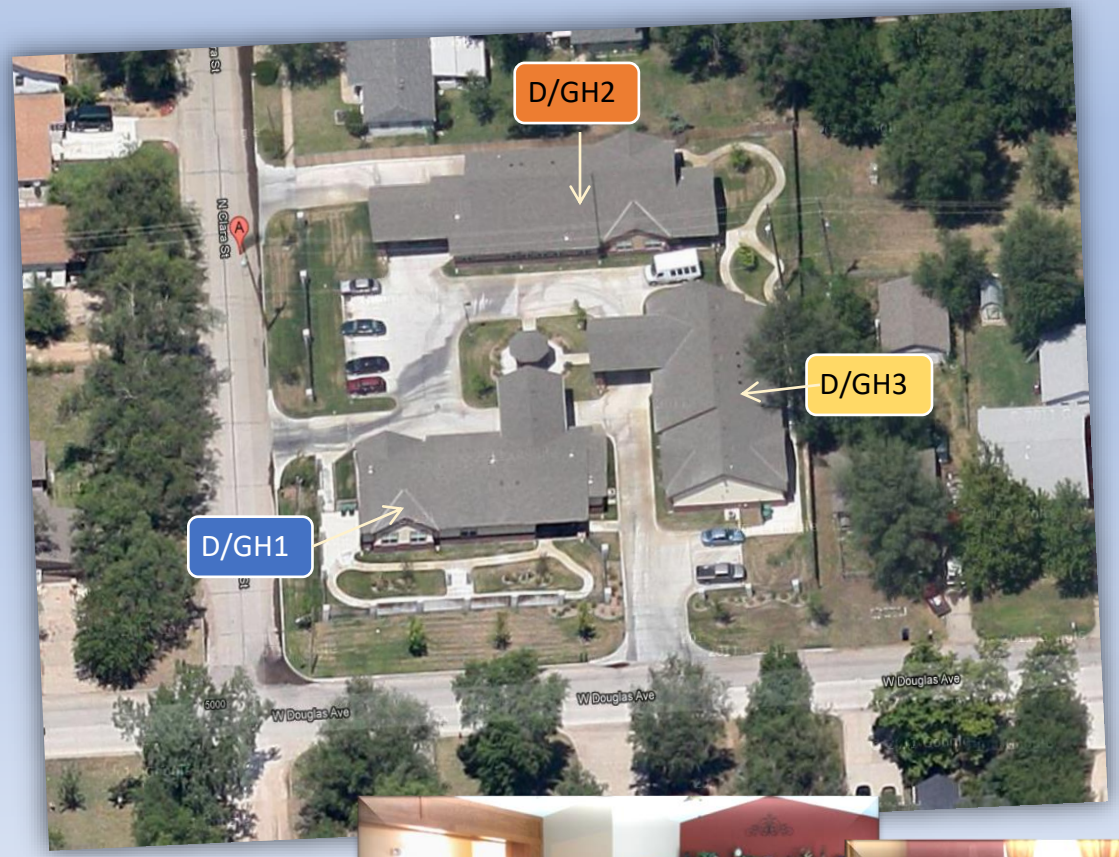

D/GH1 = Diana House; D/GH2 = WOW House; D/GH3 = Latimer House

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

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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)

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Characteristics of Dementia GH Residents and Controls (T1 vs T8) *[7yr]*

	GH#1[b]		GH#2[c]		GH#3[d]		Sum GH		Controls	
	T1	T8	T1	T8	T1	T8	T1	T8	T1	T8
Age (mean)	61.6	65.5	61.6	61.5	55.8	60.8	59.2	60.1	59.1	62.5
Age (range)	51-68	56-79	49-76	52-71	44-70	53-71	44-76	47-79	44-75	46-77
Sex[a] F/M	2/3	2/3	0/5	3/2	4/1	2/2	6/9	7/8	6/9	6/9
DS	2	2	2	2	1	1	5	6	1	1
IQ#	3.0	2.8	2.6	2.6	2.8	2.5	2.6	2.6	2.9	3.2
BMI	30.0	34.5	26.6	29.4	32.9	36.3	29.8	33.4	34.8	n/a
Dem stage	Mod 5	-	Mod 3 Sev 2	-	Mod 3 Sev 2	-	Mod 1 Sev 4	-	-	Mod 2
Yrs since dementia Dx	1-3: 3 3-5: 2	-	1-3: 3 3-5: 2	-	1-3: 5		1-3: 3.6 3-5: 2	-	n/a	n/a
Co-morbidities	8.0	5.6	7.4	7.4	8.2	5.6	7.9	6.2	4.8	6.7
Health Now	2.6	3.3	2.2	3.0	2.2	2.5	2.2	2.9	3.2	3.1
Health yr ago	2.8	3.0	2.6	3.0	2.6	3.0	2.7	3.0	2.9	3.0

IQ - borderline: 5; mild: 4; moderate: 3; severe: 2; profound: 1

[a] Females /Males
[b] Two original residents in GH#1 were moved to GH#2 and were replaced with two new residents
[c] Three original residents in GH#2 died since 2011 and were replaced with three others
[c] Two original residents in GH#3 died since 2011 and were replaced with two new residents

Underweight: BMI is less than 18.5
Normal weight: BMI is 18.5 to 24.9
Overweight: BMI is 25 to 29.9
Obese: BMI is 30 or more

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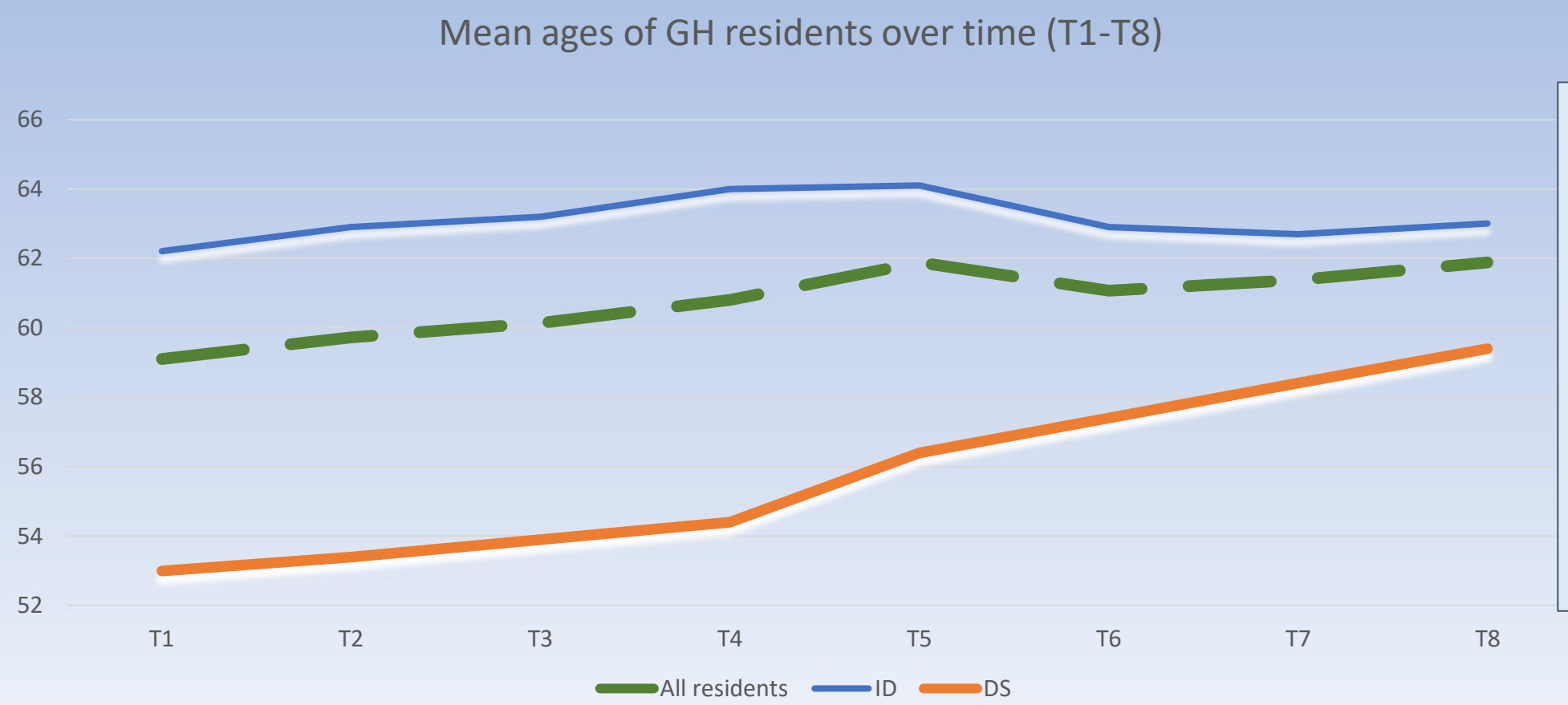
Characterization of original residents

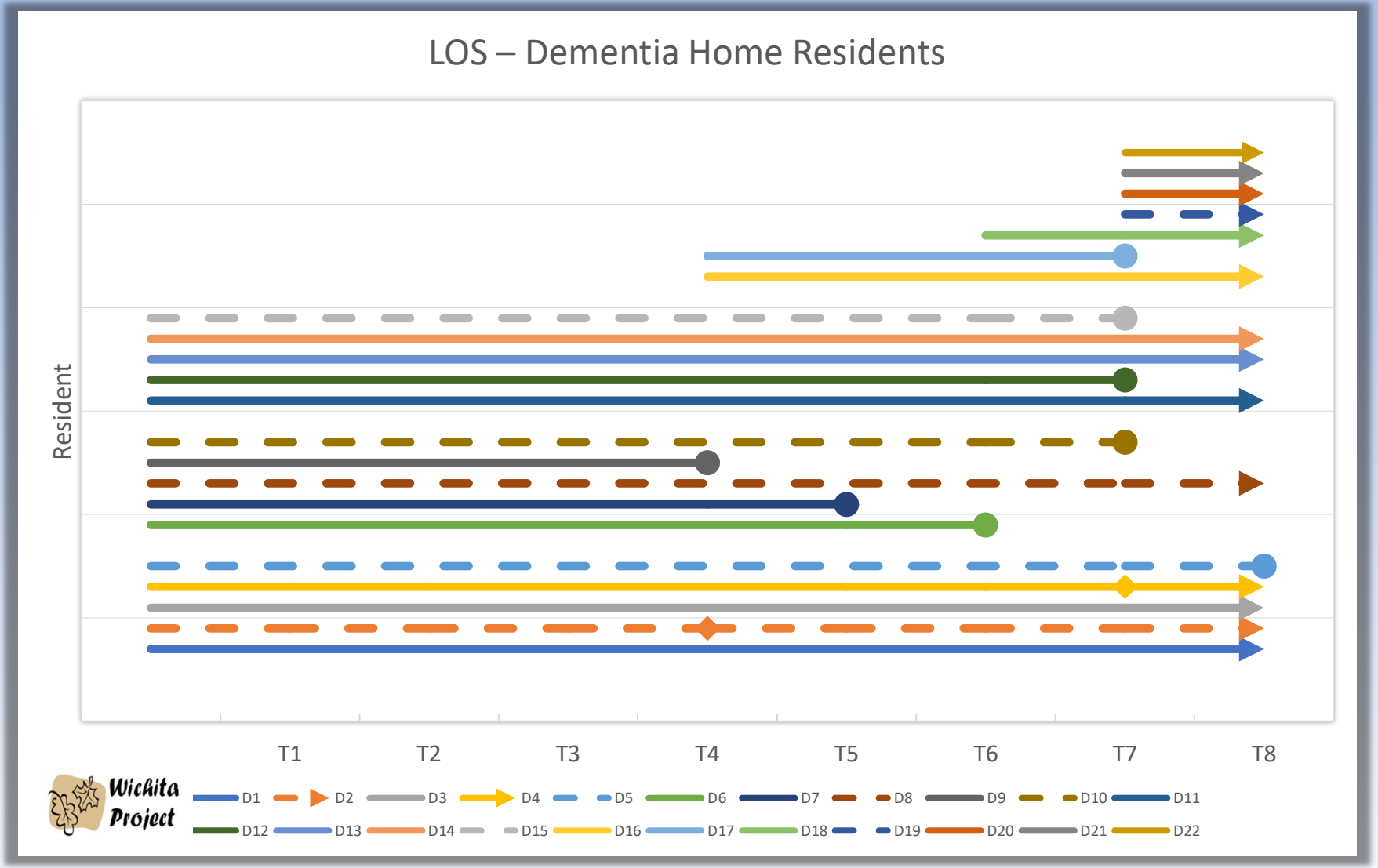
Original 15 GH residents	Original 15 GH residents 4+ years later	Original 15 GH residents 7+ years later
• In their late 50s • About 1/3 with DS • Most were obese or overweight • Generally had multiplicity of health problems • Had dementia for about 3 years • Generally were in mid-stage dementia • Had 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

Mean ages of GH residents – ID vs DS



- ✓ 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

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



Study began with 15 GH residents

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 afterwards
- ✓ At T8+ (Jan 2018), there was one vacancy; now filled
  - **Arrow** means still resident in home
  - **Circle** means deceased
  - **Diamond** means changed homes
- ✓ **Dashes are DS; Solids are ID**
- ✓ Timeframe: 2011-2018

Mortality patterns ID vs DS

Average age at death (GH):

- 65.2 (all); 58.8 (DS); 71.5 (ID)
- Males age at death: 66.6
- 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

Original cohort n=15
Survival cohort n=8 (53%)

Mean years from entry to death – DS: 6.5y
Average age at entry for ID: 66.2; DS: 53.5y
Deaths began at T4 (two years after admission)

- Sinai et al. (2017)*, in a UK study of ~250 adults with DS and dementia, noted a significant 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

*Source: Sinai, A., Mokrysz, C., Bernal, J., Bohnen, I., Bonell, S., Courtenay, K., ... Head, E. (Ed.) (2017). Predictors of Age of Diagnosis and Survival of Alzheimer's Disease in Down Syndrome. *Journal of Alzheimer's Disease*, 61(2), 717-728. DOI: 10.3233/JAD-170624

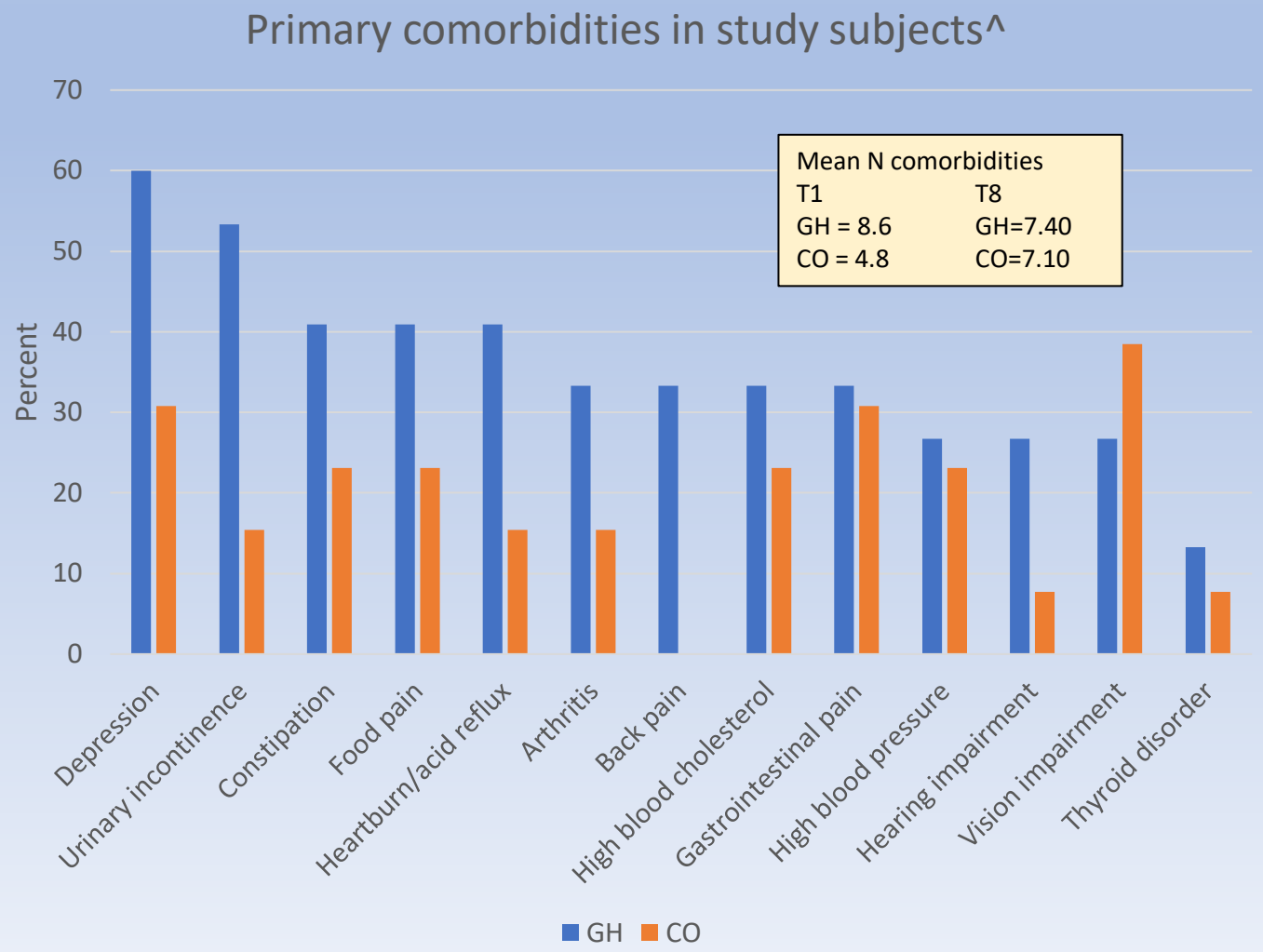
Comparative comorbidities

5 most prevalent comorbidities among GH residents*

- Urinary incontinence
- Depression
- Constipation
- Heartburn
- Back and foot pain

5 most prevalent comorbidities among Controls

- High cholesterol
- High blood pressure
- Impaired vision
- Depression
- G-I pain



* T8 data subjects
^ All T-T8 subjects

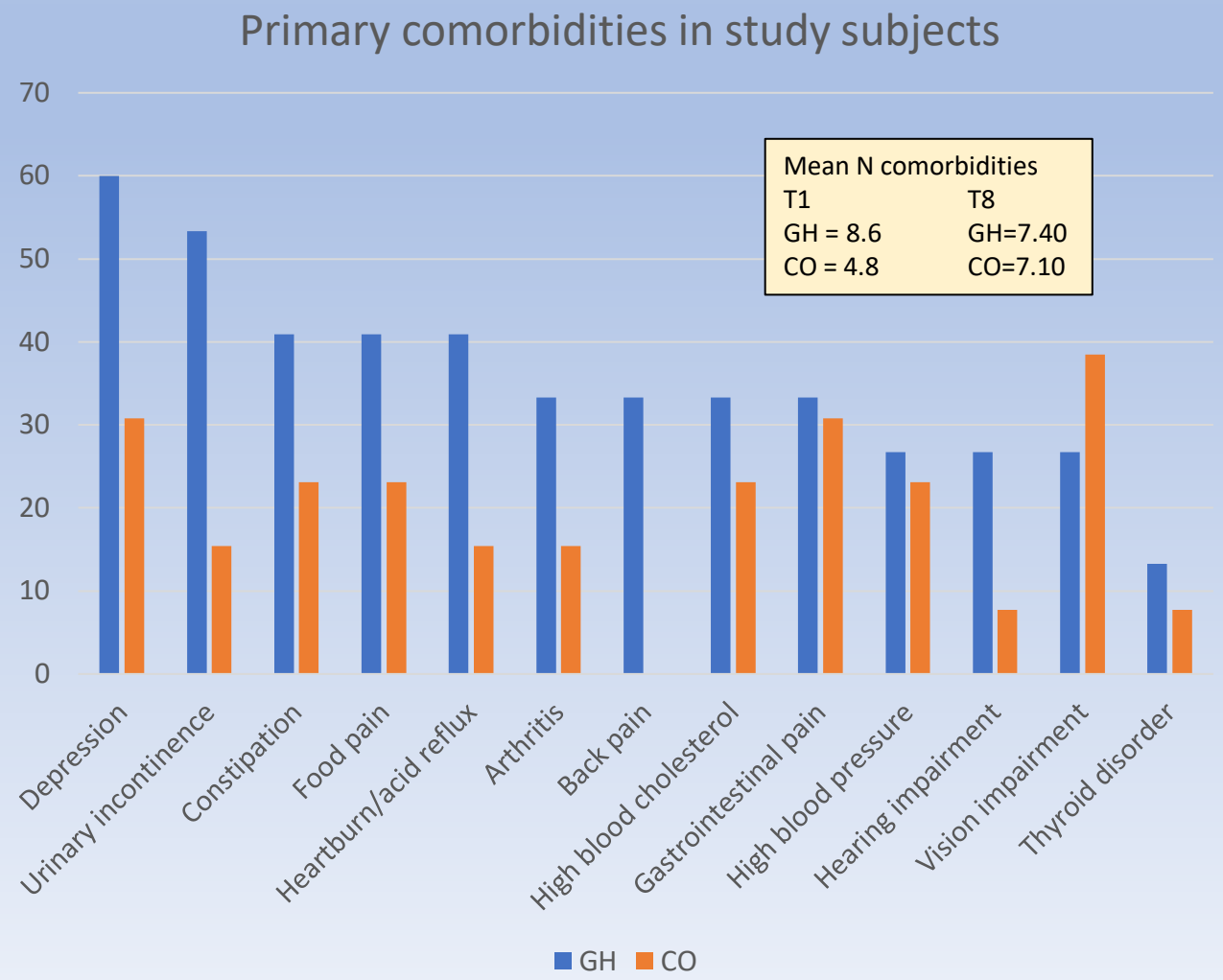
Comparative comorbidities

5 most prevalent comorbidities among ID residents

- GI pain
- Urinary incontinence
- Constipation
- Heartburn
- Foot pain

5 most prevalent comorbidities among DS residents

- Depression
- Urinary incontinence
- High cholesterol
- Heartburn
- High blood pressure



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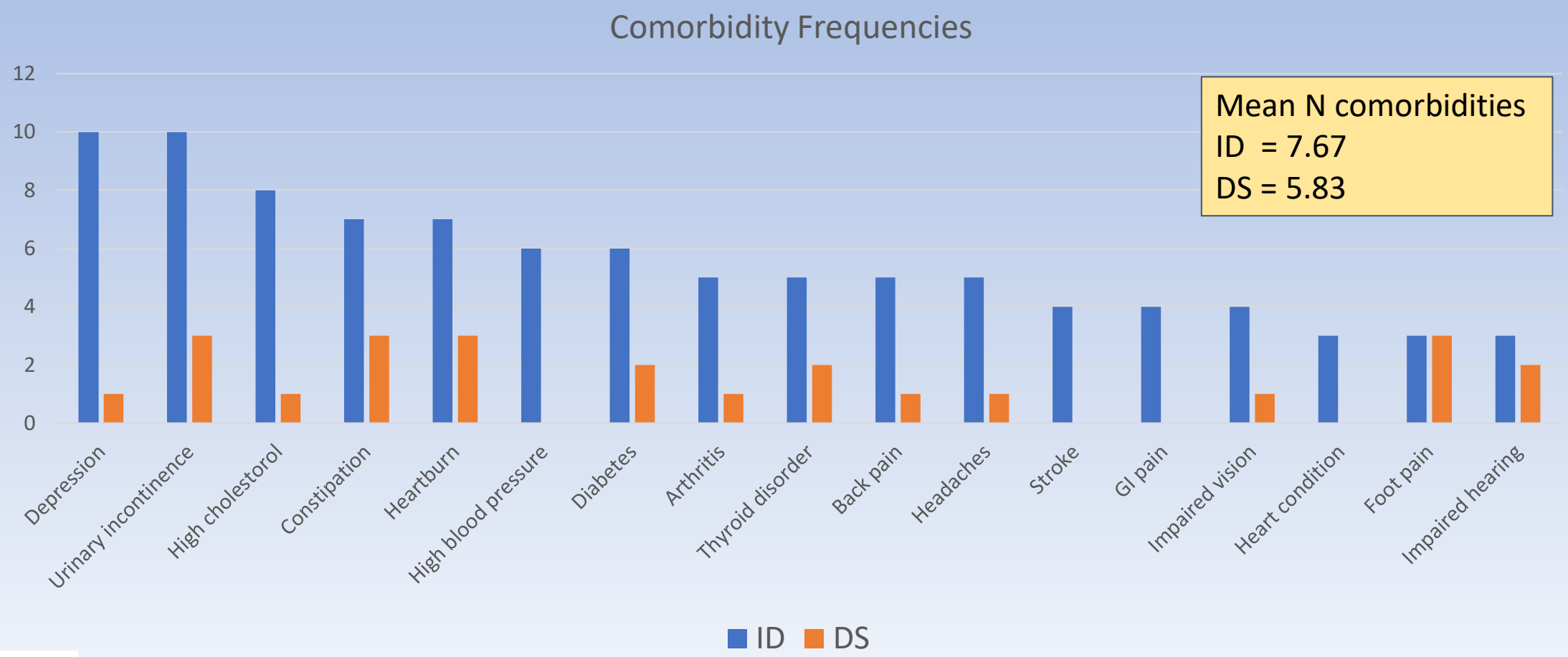
Comparative frequencies of comorbidities of GH residents – ID vs DS (base: 3 or more for ID)



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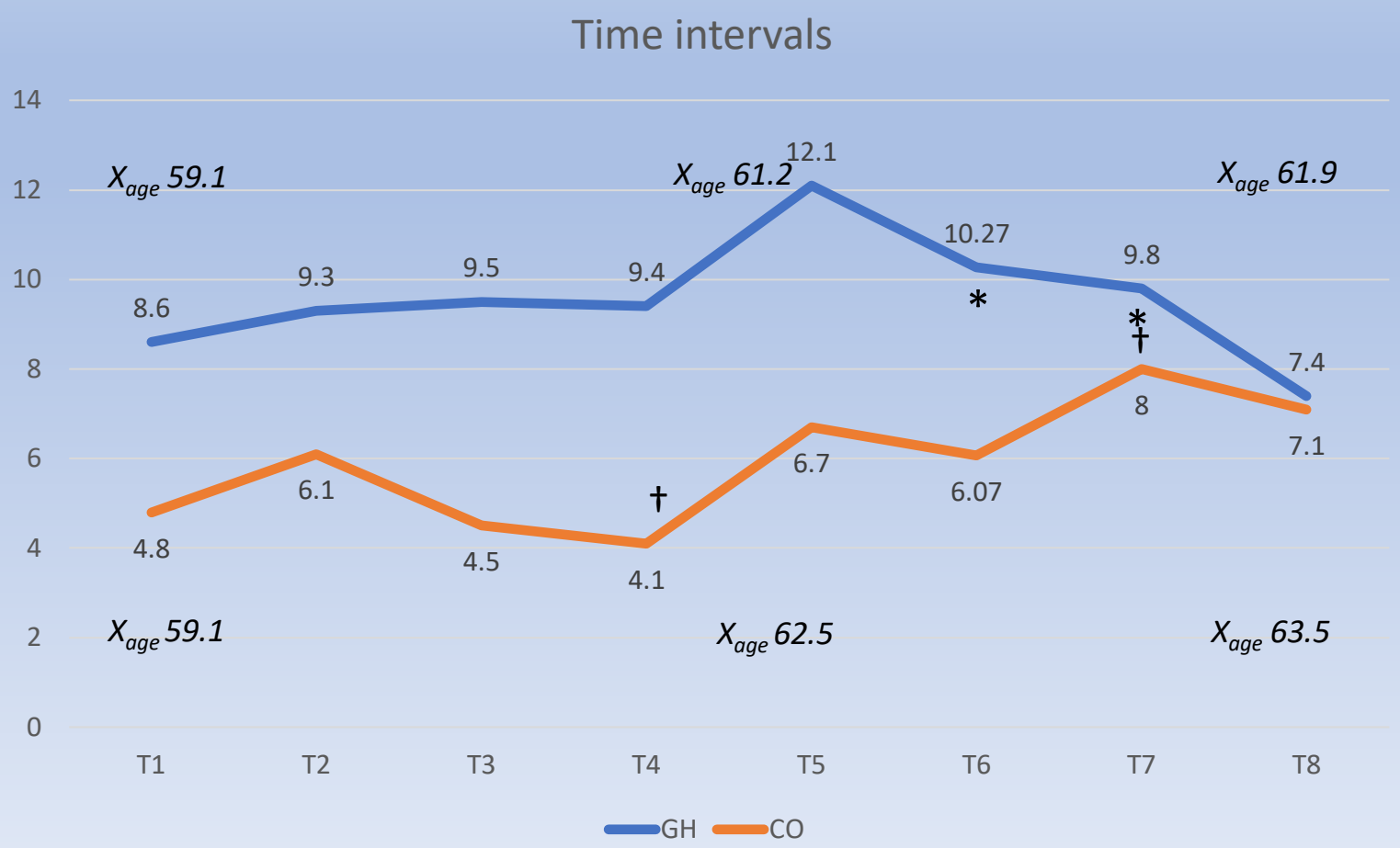

T_1-T_4 at 6m intervals; T_4-T_5 at 2yr interval, T_5-T_8 at 1 year interval

Progression: # of Comorbidities

(GH vs CO) T_1-T_8

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

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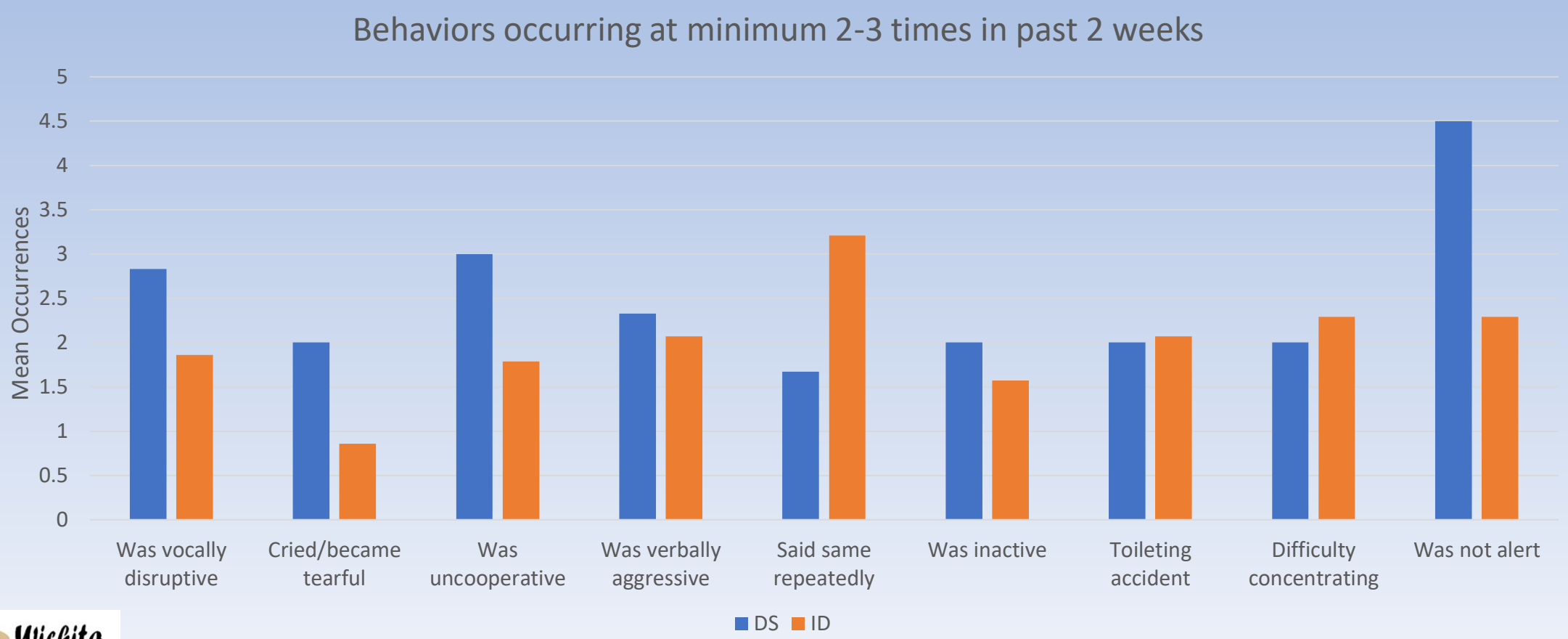
AADS behavior symptom related Items– DS vs ID



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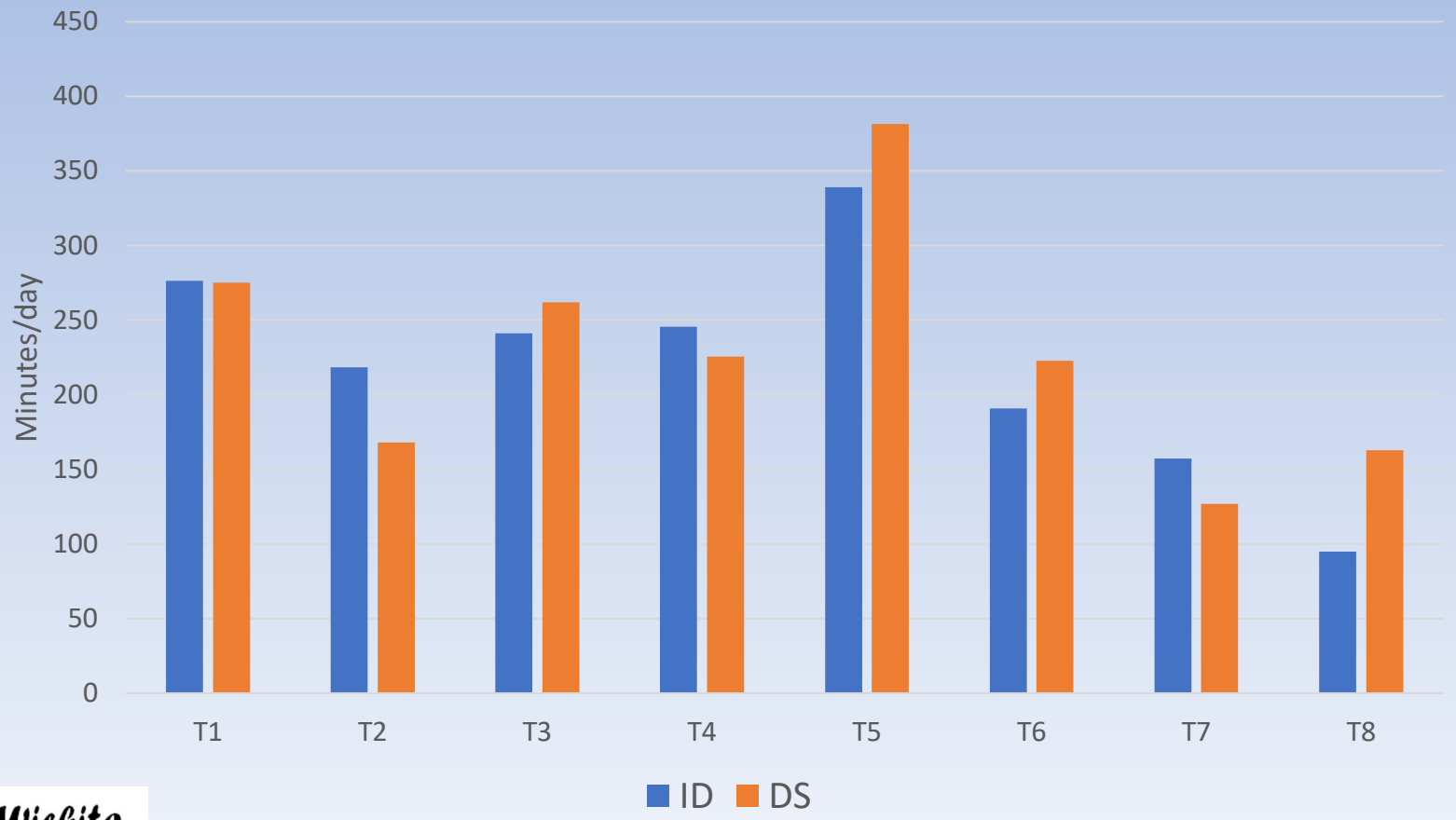
PowerPoint [ISTAART PIA File]

$N_{DS}=6$
$N_{ID}=14$

CAS-ID – minutes per day spend in caregiving



- Staff spent an average of **222.5** min/day providing care to residents of dementia group homes (or about 9.27 minutes per hour over a 24-hour period)
- Staff spent **220.4** min/day with residents with ID
- Staff spent **228.1** min/day with residents with Down syndrome

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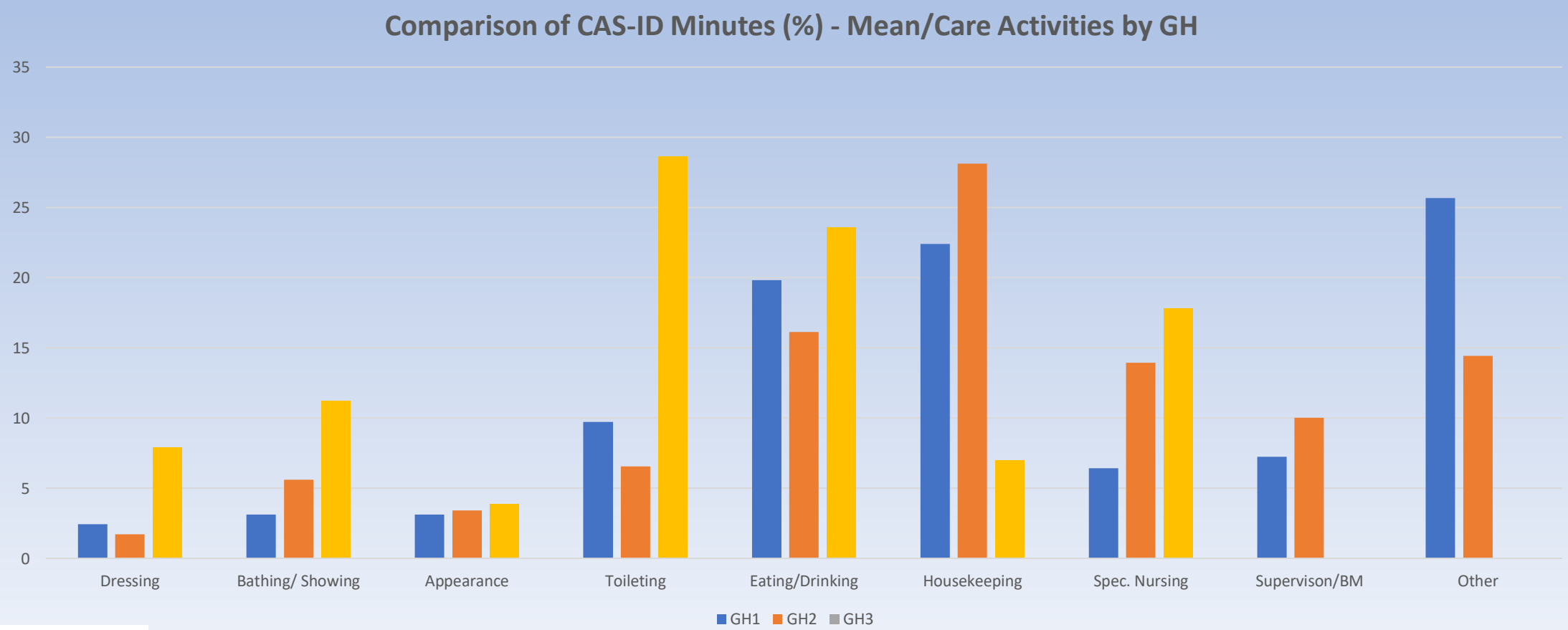
CAS-ID - %/Minutes Spent on Care Activities



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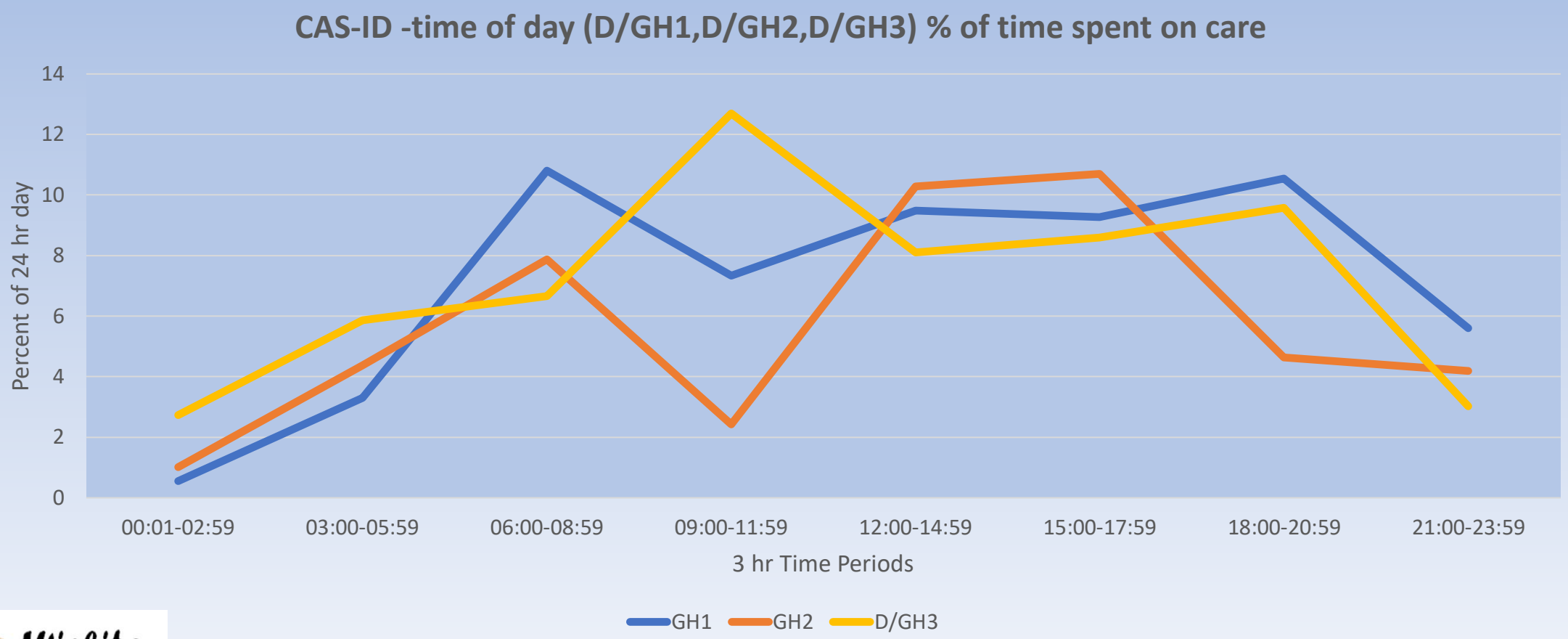
Times collapsed: GH staff care patterns (T4,T5,T8)



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Data aggregated over 3 data collections, 2012, 2015, 2017

LOS – by GH (ID vs DS)

- Home #2 has had the most change/movement
  - Some residents from D/GH#1 moved to D/GH#2
- 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**

Lighter color is DS

* Moved from one house to another

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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

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Conclusions

Further research is needed to get 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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