Health condition variations among adults with intellectual disability and dementia

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Abstract

A longitudinal study of adults with intellectual disability and dementia living in several dementia-care group homes in the USA provided an opportunity to examine rates of co-present health conditions and disparities in four categories: disease conditions, behavior/function conditions, pain/discomfort conditions, and sensory conditions. Study followed 2 cohorts of adults [#1: n=22 w/ID & dementia (I/AD); #2: n=15 matched controls (CO)] over 9 years. Instrument used was the NTG-EDSD. Health disparity (measured by differences in BMI and comorbidities) revealed differences between I/AD residents and controls and between I/AD residents with ID (I/AD-ID) and those with Down syndrome (I/AD-DS; 33% of I/AD cohort). ***More co-incident health conditions were present in I/AD adults.*** *Some health disparities noted were age-associated, pre-existing, or genetically derived; others were the result of conditions/ complications that evolved from having dementia (e.g., diet, mobility impairments, toileting self-control).*

Background

A longitudinal study, begun in 2011, offered a chance to follow-along a cohort of adults with intellectual disability (ID) and dementia (along with non-dementia community-dwelling adults as matched controls) resident in three 5-person dementia care group homes over a period of 10 years. About 1/3 of adults had Down syndrome (DS).

The study offered opportunity for comparisons between adults with dementia and controls absent dementia and between adults with ID and adults with DS, both with dementia, on several health and behavioral factors.

Instrument & Method

Opportunistic study undertaken following the concurrent 2011 opening of three co-located 5-person dementia care group homes in a large Midwestern USA city.

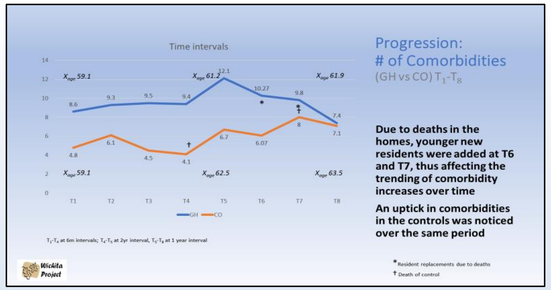
Process

Data were collected using the **NTG-EDSD** (Esralew et al., 2013; 2017) at select intervals over time by agency personnel, anonymized, and provided to study principals for analysis. Co-morbidity and health factors were extracted from NTG-EDSD and reviewed/ compared for changes over time. Health condition variations (disparities) were measured by differences in BMI and number and type of comorbidities.

Participants

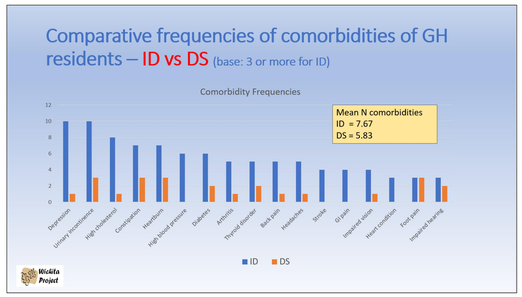
Adults with ID & DS dx'd with dementia (I/AD)
Adults with ID dx'd with dementia (I/AD-ID)
Adults with DS dx'd with dementia (I/AD-DS)

Results – Longitudinal Aspects



With advancing age, longitudinal trends showed increases in the mean number of comorbidities over time among both I/AD and CO groups. Longitudinal outcomes show that original residents with I/AD-ID trend upwards with number of comorbidities but after death and replacement home means generally trend downward over time.
Adults with I/AD-DS trend progressively upward over time as they survive for longer periods of time whilst in the homes (due to earlier age at admission).

Results – Comorbidities/disparities



Differences were observed between I/AD residents and controls (CO) and between I/AD residents with ID (I/AD-ID) and with DS (I/AD-DS; 33% of I/AD cohort).

- **Mean BMI differences were notable between I/AD (X=29.8) and CO (X=36.1),** but not between I/AD-ID (X=31.8) and I/AD-DS [DS (X=31.4).
- **I/AD adults had more typical disease and behavior/ function conditions generally associated in adults who have dementia and a greater number of comorbidities at admission** (mean comorbidities, I/AD = 5.1 and CO = 2.9).
- Differences were observed in the number of mean comorbidities between I/AD-ID (X=7.7) and I/AD-DS (X=5.8).

Most prevalent comorbidities (5 or more) among the I/AD group **included depression, urinary incontinence, back pain, constipation, foot pain, heartburn/acid reflux, arthritis, high blood cholesterol, and gastro-intestinal pain**.

Within-cohort comparative data showed that among the I/AD-ID cohort the most prevalent comorbidities included depression, urinary incontinence, constipation, foot pain, and heartburn/acid reflux and within the I/AD-DS cohort the most prevalent comorbidities included urinary incontinence, constipation, heartburn, foot pain, diabetes, thyroid disorder, and impaired hearing).

Most prevalent (ranked) comorbidities among COs included impaired vision, G-I pain, depression, high blood pressure, and constipation.

Conclusions

- **Adults with ID who have early-stage dementia have more co-incident health conditions than same age adults with ID without dementia.** Most disparities are in comorbid disease and behavior function conditions.

- **Some health condition variations are age-associated, pre-existing, or genetically derived, but others may be the result of debilitating conditions that evolved from having dementia** (e.g., diet/nutrition, mobility impairments, toileting self-control).

- **By tracking health and function longitudinally, outcome information can pinpoint markers that are associated with premorbid dementia** and can help health providers introduce and maintain surveillance over select functions and health conditions of those adults already affected.

Limitations

Data reflect informant provision and not direct medical assessments. Also, small sample size may not reflect larger population of adults with intellectual disability diagnosed with dementia living under different conditions.

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Study was considered 'exempt' by UIC IRB.

References

- Esralew, L., Janicki, M.P., DiSipio, M., Jokinen, N., Keller, S.M. and Members of the National Task Group Section on Early Detection and Screening. (2013). National Task Group Early Detection Screen for Dementia (NTG-EDSD) Manual. *NADD Bulletin*, 16(3), 47-54.
- Esralew, L., Janicki, M.P.., & Keller, S M. (2017). National task group early detection screen for dementia (NTG-EDSD) [Chapter 11]. In V.P. Prasher (Ed.), *Neurological assessments of dementia in Down syndrome and intellectual disabilities* (pp. 197-213, Appendix I). Basel, Switzerland: Springer. DOI 10.1007/978-3-319-61720-6_11

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