

Mental Health of Adults with Down Syndrome

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Down Syndrome Longitudinal Study

- ▶ 40 years in 2018
- ▶ Original purpose - mother-baby interaction (Cohort 1)
- ▶ Re-oriented purpose (1) - impact of early intervention (Cohort 2)
- ▶ Re-oriented purpose (2) - longitudinal tracking (natural history)
- ▶ Re-oriented purpose (3) - address issues relevant to families and individuals

Research into mental health of adults with Down syndrome

- ▶ Rate of mental health disorder have typically reported that between 22 and 35% (Määttä et al., 2011; Mallardo, et al., 2014; Prasher, Glenn, Cunningham, & Glenholmes, 2012),
- ▶ Depression is generally identified to be the most common diagnosis (Dykens, 2007).

Mallardo, Cuskelly, White & Jobling (2014)

- ▶ The young adults had a mean age of 26.75 years (range 20.3–31.3 years) [not the longitudinal group]
- ▶ 45% met 'caseness' criteria using the Mini – PAS ADD*
- ▶ 30% had a diagnosis* - 50% of these with Depression
- ▶ Associated with reduced 'engagement' [QEPS}

Dementia

- ▶ Vulnerability to Alzheimer Disease - due to trisomy 21
- ▶ Diagnosis rates increases after approx. 50 years of age
- ▶ Identified by loss of function, especially memory
- ▶ Process likely to begin substantially earlier than diagnosis

Purpose of this study

- ▶ Identify proportions and types of mental health problems in the sample
- ▶ Establish baseline data for follow up work on mental health and dementia
- ▶ Consider usefulness of the IQCODE with persons with Down syndrome
- ▶ Determine if there are associations with earlier performance and mental health and/or dementia

Measures of levels of functioning

STANFORD-BINET INTELLIGENCE SCALE, 4TH EDITION (SB-IV)

- ▶ a standardised measure of cognitive abilities with normative information from early childhood to 70 years plus

PEABODY PICTURE VOCABULARY TEST, 4TH ED (PPVT-4).

- ▶ norm-referenced instrument which measures the receptive vocabulary

EXPRESSIVE VOCABULARY TEST, 2ND ED. (EVT-2)

- ▶ norm-referenced instrument that assesses expressive vocabulary

ADAPTIVE BEHAVIOR ASSESSMENT SYSTEM, 2ND ED. (ABAS-2)

- ▶ provides a comprehensive, norm-referenced assessment of independent functional skills necessary for daily living, in individuals aged 0 to 89 years [Communication, Community use, Functional academics, Home living, Health & safety, Leisure, Self-care, Self-direction, Social and Work]

Measures of mental health

MINI PAS-ADD (Prosser et al., 1998)

- ▶ a screening tool for undertaking mental health assessments with people with intellectual disabilities. Threshold scores indicate the person may have mental health problems

MOOD, INTEREST AND PLEASURE QUESTIONNAIRE. (MIPQ; ROSS & OLIVER, 2003).

- ▶ two subscales: (a) Mood and (b) Interest and Pleasure, which combine to give a total score. The scale was devised specifically for those with an intellectual disability and is completed by an informant. Items are based on observations of the affective mood of the individual over the preceding 2 weeks.

Measures re dementia

THE ADAPTIVE BEHAVIOUR DEMENTIA QUESTIONNAIRE (ABDQ; Prasher, Farooq, & Holder, 2004)

- ▶ The ABDQ is an informant- based clinical screening tool for dementia in Alzheimer's disease in adults with Down syndrome.

INFORMANT QUESTIONNAIRE ON COGNITIVE DECLINE IN THE ELDERLY (IQCODE; Jorm et al., 1989)

- ▶ The IQCODE is widely used as a screening test for dementia, particularly where the subject is unable to undergo direct cognitive testing or for screening in populations with low levels of education and literacy.

TEST FOR SEVERE IMPAIRMENT (TSI; Appollonia et al., 2001)

- ▶ The TSI assesses cognitive function of people with severe cognitive impairment. Declines over time in scores on the TSI are suggestive of dementia. Baseline measure in this study.

Data so far

DESCRIPTORS

- ▶ 38 participants (17 women)
- ▶ Age: $M = 39.09$; $SD = 2.65$ (Range: 34-09 - 43.09 yrs)
- ▶ SB-IV AE: $M = 4.89$; $SD = 1.14$ (Range: 3.03 - 7.03 yrs)
- ▶ PPVT-4 AE: $M = 6.16$; $SD = 2.15$ (Range: 3.04 - 12.05 yrs)
- ▶ EVT-2 AE: $M = 5.64$; $SD = 1.55$ (Range: 2.08 - 9.03 yrs)
- ▶ ABAS GAC: $M = 63.25$; $SD = 14.12$ (Range: 40-91)

Results re mental health

- ▶ 42% met threshold criteria
 - ▶ 1/3 Depression
 - ▶ 1/3 Psychosis
 - ▶ 1/3 OCD

- ▶ Mood was reported to be relatively positive: $M = 78.52$; $SD = 11.93$

Results re dementia

- ▶ Only 1 individual met criteria for dementia on the ABDQ
- ▶ 4 individuals were above the threshold for the IQCODE.
- ▶ All four met screening criteria for at least one psychiatric diagnosis.

Results cont.

- ▶ No differences between groups with a mental health screening diagnosis and any of the other measures collected in this study
- ▶ Too few to examine this with respect to dementia
- ▶ Females significantly more likely to meet threshold for mental health diagnosis than males (Fisher's exact, $p < .05$)
- ▶ No other differences for gender
- ▶ Only significant correlation apart from expected - MIPQ & GAC (rho = .44, $p < .01$)

Discussion

- ▶ Approximately the same percentage of ‘caseness’ as in Mallardo et al. 2014
- ▶ Issues of females needs consideration - may relate to willingness of individuals or families to participate
- ▶ Why are we not seeing any associations with other measures for those who meet threshold?
- ▶ Not done yet

Ongoing work

- ▶ Collect data from additional participants for this tranche of data collection
- ▶ Look back at previously collected data (cognitive data; receptive language; ?adaptive functioning) re predictive capacity
- ▶ Continue to collect data from the individuals as they age at regular intervals

Limitations

- ▶ Small participant group
- ▶ Loss of participants from longitudinal group
 - ▶ Increasing challenge over time
- ▶ Lack of medical assessment

References re measures

Appollonio, I.; Gori, C.; Riva, G. P.; Spiga, D.; Ferrari, A.; Ferrarese, C.; & Frattola, L. (2001). Cognitive assessment of severe dementia: The test of severe impairment (TSI). *Archives of Gerontology and Geriatrics*, 7, 25-31.

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