



Billstedt, E., & Gillberg, C. (2005). Autism after adolescence: Population-based 13- to 22-year follow-up study of 120 individuals with autism diagnosed in childhood. *Journal of Autism and Developmental Disorders*, 35(3), 351-360. doi: 10.1007/s10803-005-3302-5.

Annotated by Kerry Thompson – 10/09/2014

ABSTRACT Prospective population-based follow-up study of 120 individuals with autism followed from childhood to adulthood. Methods: Individuals with autism, diagnosed in childhood, were followed prospectively for a period of 13-22 years and re-evaluated at ages 17-40 years. The instruments used at follow-up were the DISCO, WAIS-R, WISC-III, Vineland Adaptive Behavior Scales, psychiatric-medical examination and GAF-scale. A set of criteria was used for the classification of outcomes, taking into consideration employment, higher education/vocational training, independent living and peer relations. Results: Six of the 120 (5%) had died at the time of follow-up, and six declined participation. Overall outcome was poor in 78% of cases. Only four individuals were independent albeit leading fairly isolated lives. Childhood IQ-level was positively correlated with better adult outcome, as was the existence of some communicative phrase speech at age six years. Conclusions: Children with autism as diagnosed in the 1960s, 1970s, and 1980s may have an even worse psychosocial outcome than previously believed.

SUMMARY

Purpose of Study

Longitudinal design looking at the progression of individuals with autism from 13-22 years of age onward to later evaluation at 17-40 years of age

Specifically, authors hypothesized:

- Autism would have psychosocially poor outcome for 2/3 of individuals showing no independence in early adult life
- An association with a history or current epilepsy in 1/3 of the group (and this group would have high puberty aggravation and a very poor outcome in comparison to a group without epilepsy)
- Association in poorer outcomes in females rather than males
- Significantly worse outcome in core condition (autistic disorder) rather than atypical variant (autistic-like conditions)



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Framework

Quality of life among individuals with autism appears to be the guiding framework

Population and Sample

120 individuals (84 males, 36 females)

- with autistic/infantile autism (61 males, 17 females)
- with autistic-like conditions/atypical autism (23 males, 19 females)

Longitudinal study first study done in 1980s, then again in 2001.

Overview of Methods

- Assessment of autism with state of the art autism instruments (at the time); indepth interview, the Handicaps, Behaviors, and Skills Schedule, the Childhood Autism Rating Scale, and the Autistic Behavior Checklist
- All examined by the same two experts in the field of autism
- All received a full medical assessment 2001 Follow Up
- 6 individuals in the original cohort had died
- 114 received in-depth examinations
- 105 took the DISCO (Diagnosis of Social and Communication Disorder)
- 25 took the WAIS-R (Wechsler Intelligence Scales; only 25 due to the lack of ability)
- All took the Vineland adaptive behavior scale
- All received a psychiatric-medical examination

GAF score was used independently by the first and second author in all cases

Variables or Broad Topics

- Must have a diagnosis of autism
- must have been involved in the original study to be a part of the follow up study
- Independent/Predictor variables of primary interest
- Individuals with autism
- Outcome/Criterion/Dependent variables
- The quality of health



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Findings/Results

- 52% (autistic disorder), 69% atypical autism had a “very poor outcome”
- 62% (autistic disorder), 71% atypical autism had a GAF of 20 or lower
- 47% (autistic disorder), 57% atypical autism engaged in severe self-injury
- 53% (autistic disorder), 49% atypical autism engaged in severe violence
- (Poor and very poor outcome affected more individuals than predicted, epilepsy was even more common than expected, and it did not predict deterioration or poor outcome to any considerable degree.
- Female gender was not associated with worse outcomes, and the outcome of atypical autism was as restricted as that of “classic” autistic disorder.)

Implications

Over time deterioration appears to be apparent for this population. What is happening that is making this occur? How can we help in an increase outcomes?

CRITIQUES & LIMITATIONS

Conceptual

Health deterioration; what was considered a good outcome very vague and broad (e.g. being employed or in higher education/vocational training and if over the age of 23 years, living independently, if 22 years of younger having two or more friends/a steady relationship

- There are many more confounding variables that could contribute to these definitions that were not mentioned

Data

- Sample all coming from Gothenberg, Sweden ; cannot generalize easily (although the amount of people in the study is a strength)
- Issue with sample mortality (actual death and those who did not want to participate)



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Analysis

Issues with the standardization of analysis and what we really can just gather from giving participants a series of assessments and there not being more of an understanding of the environmental/history that has occurred for participants of the years.

Interpretation

Hard to follow the write up in this study; seemed more survey based with conjectures that the authors had based on previous research.

Application

Difficult to do a longitudinal study with this group with the advances in assessment scales and changes in diagnostic criteria for individuals with autism; weary of the ability to accurately compare the results.

FOLLOW-UP

Little Questions

- The write up had different percentages than the table that was presented. Confusing.

Big Questions

- Deterioration is a huge issue and the way it was conceptualized in this article was the lack of employment/higher education and or independence of living/having friends depending on age

Next Steps

- Understand what would happen if a group did engage in higher education/employment
 - Looking at a longitudinal design comparing groups of individuals with autism
 - Understanding that time plays a role in this as well; resources for individuals to go to work/attend higher education may be different than they are now
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Other Resources

- Looking at using the Satisfaction with Life Scale to gain a better perspective; also a better definition of "outcome" should be defined to encompass more variables

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