

Using big data to better understand health and wellbeing

Part B: Mortality of people on the autism spectrum

Executive summary

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The Cooperative Research Centre for Living with Autism (Autism CRC) is the world's first national, cooperative research effort focused on autism. Taking a whole-of-life approach to autism focusing on diagnosis, education and adult life, Autism CRC researchers are working with end-users to provide evidence-based outcomes which can be translated into practical solutions for governments, service providers, education and health professionals, families and people on the autism spectrum.

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Executive summary

PURPOSE OF THIS STUDY

The aim of the current study was to use linked datasets from New South Wales (NSW) to describe mortality rates and cause of death for individuals (age range 5-64) on the autism spectrum with and without intellectual disability (ID). These were compared to individuals from the general population in NSW.

STUDY DESCRIPTION

For this study, we were interested in the mortality and cause of death for three different groups:

- 1. Individuals on the autism spectrum with comorbid ID (ASD with ID)
- 2. Individuals on the autism spectrum with no comorbid ID (ASD only)
- 3. Individuals from the general population in NSW (general population)

Linkage of a range of health and service datasets from NSW covering the period of January 2001 to December 2015 identified 35,929 individuals on the spectrum, 16,106 of whom also had comorbid ID.

DATA ANALYSIS

To describe and compare mortality for these groups, age-standardised death rates, comparative mortality figures and cause of death were examined for each group in comparison to one another. Factors associated with heightened risk of death in those on the spectrum was also explored via a multivariate cox proportional hazards model. Potential risk factors explored included sex, age, ID, epilepsy, mental health conditions, medical conditions (as indicated by the Charlson comorbidity index), remoteness of residence and socioeconomic status.



SUMMARY OF FINDINGS

Elevated death rates were found for those on the spectrum (both with and without comorbid ID) compared to those from the general population. The profile of top causes of death for those on the autism spectrum was different to that of the general population. 'Injury and poisoning' was the top cause of death for those on the spectrum overall and for those with no comorbid ID. For those with comorbid ID, 'Nervous system and sense disorders', encompassing epilepsy, was the top cause of death. 'Malignant neoplasms' (cancer) was the top cause of death for the general population. Heightened risk of death for those on the spectrum was associated with a range of mental and physical health comorbidities but was not associated with gender, remoteness of residence or socioeconomic status.

IMPLICATIONS/RECOMMENDATIONS

- 1. Clearer documentation of ASD in health and service datasets
- 2. Targeted research identifying the specific factors contributing to injury and poisoning deaths for those on the spectrum
- 3. Better management of comorbid physical and mental health comorbidities for those on the spectrum in order to minimize risk of death
- 4. Development of strategies, programs and initiatives that reduce those causes of death due to injury and poisoning, especially for those without comorbid ID



References

Guan, J., & Li, G. (2017). Injury Mortality in Individuals With Autism, 107(5), 791–793. https://doi.org/10.2105/AJPH.2017.303696

Hirvikoski, T., Mittendorfer-Rutz, E., Boman, M., Larsson, H., Lichtenstein, P., & Bö, S. (2015). Premature mortality in autism spectrum disorder. The British Journal of Psychiatry. https://doi.org/10.1192/bjp.bp.114.160192

Mouridsen, S. (2013). Mortality and factors associated with death in autism spectrum disorders - a review. American Journal of Autism, 1(1), 17–25. https://doi.org/10.7726/aja.2013.1002

Pickett, J., Paculdo, D. R., Shavelle, R. M., & Strauss, D. J. (2006). Update on "Causes of death in autism." Journal of Autism and Developmental Disorders, 36, 287–288.

Schendel, D. E., Overgaard, M., Christensen, J., Hjort, L., Jørgensen, M., Vestergaard, M., & Parner, E. T. (2016). Association of psychiatric and neurologic comorbidity with mortality among persons with autism spectrum disorder in a Danish population. JAMA Pediatrics, 170(3), 1–8. https://doi.org/10.1001/jamapediatrics.2015.3935

Shavelle, R. M., Strauss, D. J., & Pickett, J. (2001). Causes of death in autism. Journal of Autism and Developmental Disorders, 31(6), 569–576. https://doi.org/10.1023/A:1013247011483





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