

# Mortality in 787,666 school pupils with and without autism: A cohort study

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## Abstract

Studies on children and adults combined suggest higher mortality rates for autistic than other people, but few report mortality rates for autistic children. In addition, past studies may not be representative of the current generation of children diagnosed with autism. We examined mortality in children using data from Scotland's annual pupil census, linked to National Records of Scotland deaths register, between 2008 and 2015. In total, 9754 (1.2%) of 787,666 pupils had autism. They were more likely to live in neighbourhoods of greater deprivation and receive free school meals. Six autistic pupils died; crude mortality rate 15.8/100,000 person-years (95% CI = 7.1–35.1), compared with 458 other pupils; crude mortality rate 12.5/100,000 person-years (95% CI = 11.4–13.7). The indirectly standardised mortality ratio was 1.1 (95% CI = 0.5–2.5). In the autistic pupils, the most common causes of death were nervous system diseases, for example, epilepsy. Avoidable causes were common. In the comparison group, external causes and cancers were the most common causes of death. We cautiously conclude that mortality in the current generation of autistic children is no higher than for other children, perhaps due to recent widening of criteria for autism spectrum diagnosis, but some deaths could have been avoided by better care.

## Lay abstract

There are few studies on the deaths of children and young people with autism; some studies on children and adults combined suggest that those with autism may have higher death rates than other people. More children are diagnosed with autism than in the past, suggesting that there are now more children with milder autism who have the diagnosis than in the past, so studies in the past might not apply to the current generation of children and young people diagnosed with autism. We examined the rates of death in children and young people in Scotland using recorded information in Scotland's annual pupil census, linked to the National Records of Scotland deaths register, between 2008 and 2015. In total, 9754 (1.2%) out of 787,666 pupils had autism. Six pupils with autism died in the study period, compared with 458 other pupils. This was equivalent to 16 per 100,000 for pupils with autism and 13 per 100,000 pupils without autism; hence, the rate of death was very similar. In the pupils with autism, the most common causes of death were diseases of the nervous system, whereas they were from external causes in the comparison pupils. The autism group had some deaths due to epilepsy which might have been prevented by good quality care. We cautiously conclude that the death rate in the current generation of children and young adults with autism is no higher than for other children, but that even in this high-income country, some deaths could be prevented by high quality care.

## Keywords

adolescents, autism spectrum disorders, death, mortality, prevalence, risk factor epidemiology, school-age children

## Introduction

People with autism are at additional risk of mental and physical health conditions (Croen et al., 2015; Rydzewska et al., 2018a, 2018b; Simonoff et al., 2008), so may be at risk of earlier mortality than other people. A recent large

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Danish study of children and adults with autism reported a mortality hazard ratio of 2.0 (95% CI = 1.5–2.8) or 2.6 (95% CI = 2.0–3.3) for those born 1980–1995, and 1.3 (95% CI = 0.6–2.9) for those born 1996–2010 (Schendel et al., 2016). For the 1996–2010 birth cohort, diagnosis was determined using both outpatient attendance and inpatient admission data, while the older cohort used inpatient data only. This likely resulted in the older cohort including only those with more severe problems. The 1996–2010 cohort was right censored at a younger age, approximately 17 years of age, and so unlike the older cohort and unlike other studies, excluded adults (Schendel et al., 2016). A recent large Swedish study of children and adults diagnosed between 1987 and 2009 with autism not only reported a standardised mortality ratio (SMR) of 2.8 (95% CI = 1.8–4.2) but also included diagnoses at inpatient admission only prior to 2001 (Hirvikoski et al., 2016). A review pooled data on mortality in children and adults with autism from three prior studies conducted in Denmark, Sweden, and California, USA and reported an SMR of 2.8 (95% CI = 1.8–4.2) (Woolfenden et al., 2012). These two studies did not report mortality rates separately for children with autism. Hence, the risk of mortality at younger ages is currently poorly understood. In addition, the number of children diagnosed with autism has increased in recent years, due to a broadening of the criteria for the autism spectrum and greater awareness of autism. Consequently, mortality rates reported in the past may not be representative of children and young people diagnosed with autism more recently. Therefore, the aim of this cohort study was to compare all-cause and cause-specific mortality rates in Scotland's school-aged population with and without autism.

## Methods

Education data from Scotland's annual pupil census between 2008 and 2013 were used to establish a cohort of children and young people with and without autism. Individual records were linked based on probabilistic record matching (on date of birth, sex, and postcode) to the National Records of Scotland deaths register, to ascertain all deaths up to February 2015 in Scotland. The Scottish pupil census is completed annually each September for every child in local authority funded primary, secondary, and special schools in Scotland. The information includes whether the child has a record of Additional Support Need and the reason for support. It is held by the Scottish Exchange of Education Data (ScotXed).

The record linkage methodology required date of birth, sex, and postcode; however, since names were not used to link pupil records to the health data, we excluded non-singleton births (available for Scottish-born pupils only, identified from linkage to maternity records). Unlikely matches were excluded and the most likely match was selected as

the correctly linked pupil record. We also excluded any records with duplicate pupil records or where the linkage was tied with another patient. In this study, we excluded non-singleton births (available for Scottish-born pupils only, identified from linkage to maternity records). Pupils with intellectual disabilities were excluded from the main analysis, due to the frequent comorbidity with autism. The analysis was then repeated without exclusion of these pupils from the control group. Pupils with both intellectual disabilities and autism were included in the autism group. We included pupils aged between 4 and 19 years in their first census year and included census years between 2008 and 2013. We censored follow-up for pupils at the age of 25 years if they reached this age. Only pupils with two or more records of Additional Support Need due to autism were included in the autism group. Pupils who were included in at least two pupil censuses over the study period and had no records of autism were used as the comparison group.

The pupil census included data on age, gender, ethnicity, and Scottish Index of Multiple Deprivation 2012 (SIMD 2012), which measures neighbourhood deprivation and is derived from individual pupil postcode of residence. Descriptive data on sex, ethnicity, and SIMD were taken from the pupils' first recorded year in the census. Data on disability requirements, including physical, communication or curriculum needs, were taken from multiple pupil census years.

Explorative statistical analyses using t-tests and  $\chi^2$  tests were used to examine the differences in the characteristics of pupils with autism compared to their peers. Differences in age of death were investigated using t-tests (Table 1). The crude mortality rates were calculated using the censor date, 13 February 2015 or the date of death. Since only those pupils who attended school in at least two of the years over the observed study period were eligible, the entry to the study was defined as the date of their second pupil census record. For indirect standardisation, observed deaths were assumed to be independent and vary with the Poisson distribution. Expected rates were calculated using fixed age and sex-specific rates, from the large population of pupils without autism. The mortality rates were indirectly standardised using STATA's 'strate' command to calculate SMRs for pupils with versus without autism, using standard Wald confidence intervals.

All deaths were coded according to International Classification of Diseases–10th Revision (ICD-10) chapters. The cause of death was analysed using the underlying cause of death and then contributing causes were analysed using codes from either the underlying or secondary causes. Avoidable deaths were defined using the United Kingdom's Office of National Statistics revised definition for children and young people (Olatunde et al., 2016). All statistical analyses were undertaken using Stata, version 15.0 (StataCorp).

**Table 1.** Demographic information for pupils with autism compared with pupils without autism.

Demographic information	Autism	Comparison group	p-value
Total, n (person-years)	9754 (38,059)	777,912 (3,672,224)	
Gender			
Male, n (%)	8349 (86)	389,160 (50)	<0.001
Age, person-years (%)			
<10	7452 (20)	995,297 (27)	
10–14	16,424 (43)	1,332,123 (36)	
15–19	12,840 (34)	1,178,608 (32)	
>19	1343 (4)	166,196 (5)	
Disability adaptations, n (%)			
Physical adaptation	657 (7)	1837 (0.2)	<0.001
Curriculum adaptation	4150 (43)	6341 (0.8)	<0.001
Communication adaptation	2602 (27)	1760 (0.2)	<0.001
SIMD <sup>a</sup> quintile, n (%)			
1 (most deprived)	2303 (24)	169,038 (22)	<0.001 <sup>a</sup>
2	1870 (19)	149,290 (19)	
3	1974 (20)	152,415 (20)	
4	7940 (20)	158,228 (20)	
5 (least deprived)	1667 (17)	148,941 (19)	
Free school meals, n (%)	3636 (37)	194,648 (25)	<0.001
Ethnicity <sup>b</sup> , n (%)			
White	8958 (91.8)	708,941 (91.1)	0.015
Asian	218 (2.2)	23,791 (3.1)	<0.001
Mixed or multiple ethnicities	103 (1.1)	8035 (1.0)	0.823
African, Caribbean or black	55 (0.6)	4710 (0.6)	0.599
Other ethnic groups	45 (0.5)	4665 (0.6)	0.078
Not disclosed/unknown	375 (3.8)	27,770 (3.6)	0.146
Linked deaths data			
Deaths, n	6	458	
Age of death, mean (SD)	14.0 (3.4)	16.1 (3.8)	0.166

SIMD: Scottish Index of Multiple Deprivation.

<sup>a</sup>For SIMD,  $\chi^2$  test was performed across all categories, overall p-value shown.

<sup>b</sup>(White-Scottish, -British, -Other) (Asian -Indian/British/Scottish, -Pakistani/British/Scottish, -Bangladeshi/British/Scottish, -Chinese/British/Scottish).

This study received approval from the NHS National Services Scotland (NHS NSS) Privacy Advisory Committee. Patient consent was not required.

*Data policy statement:* The University of Glasgow was authorised to receive data controlled and held by the Information Services Division, NHS NSS, via access through the national safe haven. Data processing and sharing agreements were drafted with NHS NSS and ScotXed. The Information Services Division Statistical Disclosure Control Protocol was followed. Therefore, data cannot be shared with other parties but could be requested from the data controllers subject to the approval processes.

## Results

There were 946,681 pupils in the school census between 2008 and 2013 who were eligible singleton births, after removal of duplicate records and records where the linkage was tied with another patient. Children with only one record of autism (n=3329) were excluded from the study,

as were 23,910 children with a record of intellectual disabilities but not autism, and 131,776 other children who only had a record for 1 year of the study period. The remaining 787,666 children comprised the study population. Of these, 9754 (1.2%) pupils had two or more records of autism, of whom 2105 (22%) had both autism and intellectual disabilities. The remaining 777,912 pupils attended school for at least 2 years over the study period and were designated as the comparison group.

Pupils with autism were more likely to be male, and more likely to reside in the areas of greater neighbourhood deprivation, and to have been registered for free school meals, compared to their peers (Table 1). A larger proportion of pupils with autism required physical adaptations (7%) and communication (27%) or curriculum adaptations (43%) at school.

Linking to the National Records of Scotland (NRS) deaths register up to February 2015 resulted in 3,710,284 person-years of follow-up. There were 464 deaths overall. In pupils with autism, there were six recorded deaths over

38,059 person-years (<0.1%). This was equivalent to 15.8 deaths per 100,000 person-years (95% CI = 7.1–35.1). In the comparison group, there were 458 deaths over 3,672,224 person-years of follow-up (<0.1%) which was equivalent to a crude mortality rate of 12.5 deaths per 100,000 person-years (95% CI = 11.4–13.7). For pupils with autism, the SMR was 1.1 (95% CI = 0.5–2.5). In addition, when 23,910 pupils with intellectual disabilities and no autism were included in the control group, the total number of deaths rose to 612, and the SMR for pupils with autism versus without autism was 0.9 (95% CI = 0.4–1.9). The mean age at death for pupils with autism was 14.0 years (95% CI = 10.4–17.5) and 16.1 years (95% CI = 15.8–16.5) in the comparison group ( $p=0.166$ ). Due to small numbers, we were unable to derive sex-specific mortality rates.

The underlying causes of death by ICD-10 chapters could not be reported due to disclosure control; however, the most common ICD-10 chapters for both underlying cause and all contributing causes of death in the pupils with autism were diseases of the nervous system, for example, epilepsy. For the comparison group, the most common underlying causes were from external causes and cancers. There were multiple instances of avoidable deaths in both the autism group of six who had died and also among the comparison group; however, further comparison was not possible.

## Discussion

Contrary to our expectation, children and young people with autism in Scotland aged 5–24 years do not appear to have a higher overall risk of mortality compared to their peers; mortality rates were comparable with SMR of 1.1 (95% CI = 0.5–2.5). This is contrary to previous studies of children and adults combined, from an earlier time period than our study (Hirvikoski et al., 2016; Woolfenden et al., 2012). It is similar to the hazard ratio of 1.3 (95% CI = 0.6–2.9) reported in the Danish birth cohort 1996–2010, at ages 1.5 to approximately 17 years (Schendel et al., 2016). Differences between the studies could be due to the age ranges investigated, or there may have been a temporal change. There has been considerable increase in diagnosis of autism in recent years due to broadening of the criteria for the autism spectrum and raised awareness, so pupils with an autism diagnosis now are likely to include a higher proportion at the milder end of the spectrum than in previous decades. This could account for the differences in findings of our study with older reports. Among pupils with autism who died in the study, the most common contributing factor was neurological diseases, including epilepsy. Several of the deaths were potentially amenable to quality healthcare according to the definition used in the United Kingdom. As expected, the pupils with autism were more likely to be male. In addition, they were more likely to live in areas of greater neighbourhood deprivation, and to have

been registered for free school meals, compared to their peers, highlighting the added disadvantages that pupils with autism experience while growing up.

Our study has the advantage of covering a whole country, and the pupil census has approximately 95% coverage. Multi-disciplinary autism diagnostic services are available across Scotland, and receiving a diagnosis is advantageous as the child then receives additional support at school. However, there may still be some recording error in the census; hence, we required the children to have a record of autism on at least two occasions to be included in the autism group. Despite the large scale of our study, it was still limited in statistical power in that only a small number of deaths occurred. This resulted in limitations to analysing our results; we were unable to conduct a sensitivity analysis for pupils who had both autism and intellectual disabilities.

We cautiously conclude that mortality in the current generation of children and young people with autism is no higher than for their peers, but that even in this high-income country, some deaths could have been prevented by high quality care. Hence, it is extremely important to study the cause of death among children and young people with autism, and very few studies have previously done so. Future investigations of mortality in this age group are necessary to validate this conclusion. Studies further exploring the health outcomes for children and young people with autism and neurological comorbidities, such as epilepsy, are warranted.

## Declaration of conflicting interests

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