Mortality in Individuals with Autism Spectrum Disorder: Predictors over a 20-Year Period

Leann Smith DaWalt, **Jinkuk Hong**, **Jan S. Greenberg**, **Marsha R. Mailick**

Waisman Center, University of Wisconsin-Madison

Abstract

Research has shown that individuals with autism spectrum disorder (ASD) have higher rates of health problems throughout childhood, adolescence, and adulthood, and that this may result in elevated risk of early mortality. The present study reported the rate, timing, and causes of death in a large community-based cohort of adolescents and adults with ASD (n = 406) over a 20-year period (1998 – 2018), and identified predictors of mortality. Over this period, 6.4% of individuals died at an average age of 39 years. Causes of death included chronic conditions (such as cancer and heart disease), accidents (such as choking on food and accidental poisoning), and health complications due to medication side effects. Even after controlling for age and health status, significant predictors of mortality were early childhood levels of impairments in social reciprocity and high levels of functional impairments at the start of the study period. The results suggest the importance of social engagement and functional self-sufficiency across the life course, as well as adequate access to health care for individuals with ASD.

Although studies have shown that there is some abatement of autism symptoms over time (e.g., Woodman et al., 2014), many individuals with autism spectrum disorder (ASD) continue to experience significant challenges throughout adulthood. For example, adults with ASD, with and without intellectual disability, have high rates of unemployment and underemployment (Roux et al., 2015; Taylor & Seltzer, 2011; Taylor et al., 2015). Most individuals with ASD continue to have problems with social relationships during adulthood and many do not live independently (Henniger & Taylor, 2013; Roux et al., 2013; Howlin & Moss, 2012).

In addition to these difficulties, individuals with ASD have been shown to have higher rates of health problems across a wide range of health domains compared to controls (Croen et al 2015; Fortuna et al., 2015). Individuals with ASD also have limited access to healthcare (Nicolaidis et al. 2012; Weiss et al 2018), and are at risk for taking increasing numbers of medications over time (Esbensen et al 2009). Notably, disparities in healthcare access for individuals with ASD that are apparent during childhood (Chiri & Warfield 2012; Vohra et al 2014) persist throughout the transition to adulthood (Cheak-Zamara 2013; Cheak-Zamara 2014). Relatively little is known, however, about mortality risk for this population and what factors might be associated with this risk. To address this gap, the present study prospectively examined risk for mortality over a 20-year period in a large, well-characterized sample of adolescents and adults with ASD and predictors of death.

There is a small but growing literature suggesting than individuals with ASD may have an increased risk of mortality compared to the general population (Woolfenden et al. 2012). For example, in a Danish cohort of 341 individuals with ASD followed from 1960 to 2006, individuals with ASD died at twice the expected rate of the general population (Mouridesen et al., 2008). In this study, there were no differences in mortality risk between those with ASD and intellectual disability (ID) compared to those with ASD without ID, with frequent causes of death including epilepsy, infectious diseases, and accidents. More recently, Hirvikoski and colleagues (2016) conducted a population-based case-control study of Swedish health registries and found an increased mortality for individuals with ASD compared to the population; this risk was found across the range of the autism spectrum and for both males and females, although the risk was highest among low-functioning females with ASD.

In the US, Bishop-Fitzpatrick and colleagues (2018) recently analyzed diagnostic codes from electronic health records of decedents with ASD and matched decedent community controls. Results from machine learning suggested that there were distinct lifetime diagnostic patterns, with the decedents with ASD having higher rates of most health conditions. The decedents with ASD also died at younger ages (about 20 years earlier than control decedents). Finally, a follow-up of a statewide autism prevalence study in Utah found elevated mortality risk for individuals with ASD (Bilder et al., 2013). Medical comorbidities and intellectual disability were related to death. Common causes of death included respiratory, cardiac, and epileptic events. Interestingly, in this study, in addition to community controls, individuals with autism were compared to family controls (i.e., siblings and cousins); findings suggested that some of the mortality risk observed for individuals with ASD may be explained by familial factors (Bilder et al., 2013).

Taken together, these studies suggest that individuals with ASD may be at a greater risk for early mortality compared to the general population. However, little is known about the factors that explain this risk. The most consistent finding is that certain co-occurring health conditions, particularly seizures, may be associated with elevated risk (Gilberg et al., 2010; Pickett et al., 2011). Evidence is mixed regarding the relative risk for males vs females; some studies have found elevated risk for females (Gillberg et al., 2010; Hirvikoski et al 2016) whereas others have not (Bilder et al., 2013).

However, to the best of our knowledge, no past research has examined which aspects of the behavioral phenotype of ASD (e.g., severity of autism symptoms, behavior problems, and daily living skills) might signal elevated risk years before the death occurs. While some aspects of the behavioral phenotype may be fixed, others are malleable and hence may be targets for intervention that could reduce early mortality in this population. Some past research (e.g., Bilder et al., 2013; Hirvikoski et al., 2016) has examined whether co-occurring ID increases the risk of mortality, but ID status tends not to be a malleable factor, which is the focus of the present research. There is thus a need for more research to explore what aspects of the behavioral phenotype of ASD may contribute to mortality.

Present Study

Although factors such as autism symptom severity and daily living skills have been shown to be predictive of adult outcomes such as independence and employment (Eaves & Ho, 2008; Farley et al., 2009; Shattuck et al., 2012; Taylor & Mailick, 2014), these behavioral features of individuals with ASD have not been yet been studied as predictors of mortality. The present study addressed this gap by examining the timing and cause of death and identified the factors associated with mortality risk in a large, community sample of adolescents and adults with ASD who were prospectively followed over a 20 year period.

Methods

Data and Sample

Data for the present study were from a large, longitudinal study of families of adolescents and adults with ASD in Massachusetts and Wisconsin (Seltzer et al. 2011). The study began in 1998 with families of 406 adolescents and adults with ASD who were then aged 10 years or older, and was carried out over 14 years. Families were recruited via informational packets distributed by agencies, schools, and diagnostic clinics as well as media announcements. All families met three initial inclusion criteria: (a) they had a child age 10 or older; (b) the parent reported that the child had received a diagnosis of ASD from a medical, psychological, or education professional; and (c) there was a confirmation of parent report of diagnosis based on research-administered ADI-R (Lord, Rutter, & Le Couteur, 1994).

Mortality information was collected in three phases. During the 14-year study period, information about the death of adolescents and adults with ASD was reported by the mother (or other family respondents if the mother predeceased the adult with ASD); 19 individuals with ASD were consequently identified as deceased. Second, in December 2017, we contracted with the University of Wisconsin Survey Center (https://https:uwsc.wisc.edu) to trace all 406 cases to confirm family-reported deaths and to identify additional deceased cases whose death occurred after the study ended. Specifically, the Survey Center traced mortality using LexisNexis, and confirmed via obituaries. Identity was triangulated using the names of the adult child, the parent, and the parent's spouse, along with last known and historical addresses and phone numbers. Five additional cases were thus identified as deceased. Lastly, in February 2018, an on-line obituary search on all 406 cases identified two additional deceased adults with ASD. The deaths of these two cases were subsequently confirmed by their family members. Combined, these methods identified 26 deceased individuals with ASD out of the original 406 cases over a 20-year period.

The average household income for families in 1998 (Time 1) was about $43,000, with an average of 2.8 children per family (including the adolescent or adult with ASD). About two-thirds (65%) of the individuals with ASD were living at home with their parents at Time 1. Nearly half (45.1%) of mothers had college degree or higher level of education. There were no significant differences in these family background variables between those whose son or daughter died and those who remained alive.

Measures

We examined the following predictors of mortality of individuals with ASD: age, sex, intellectual disability status, health status, maladaptive behavior, lifetime autism symptomatology, and daily living skills. All predictors were measured at the start of the study (referred to as Time 1) and based on maternal reports unless noted otherwise.

Age was calculated in years based on date of birth and date of the Time 1 interview.

Intellectual disability (ID) status.—ID status was determined using various sources including the Wide Range Intelligence Test (Glutting et al. 2000), the Vineland Screener (Sparrow et al. 1993), and a review of available educational records. As noted in Taylor and Seltzer (2010), intellectual disability status (0 = *no intellectual disability*, 1 = *intellectual disability*) was determined using a variety of sources. Standardized IQ was obtained by administering the Wide Range Intelligence Test (WRIT; Glutting, Adams, & Sheslow, 2000) and adaptive behavior was assessed by administering the Vineland Screener (Sparrow, Carter, & Cicchetti, 1993). The WRIT is a brief measure with strong psychometric properties and both verbal and nonverbal sections. The 45-item Vineland Screener measures daily living skills in the youth with ASD, and correlates well with the full-scale Vineland score ($r = .87$ to .98). It has high interrater reliability ($r = .98$) and good external validity (Sparrow et al., 1993). Individuals with standard scores of 70 or below on both IQ and adaptive behavior measures were classified as having an intellectual disability (ID), consistent with diagnostic guidelines (Luckasson et al., 2002). For cases where the individual with ASD scored above 70 on either measure, or for whom either of the measures was missing, a review of records by three psychologists, combined with a clinical consensus procedure, was used to determine ID status.

Physical health status of individuals with ASD was rated by mothers on a 4-point scale: 0 = *poor*, 1 = *fair*, 2 = *good*, and 3 = *excellent*. Considerable previous research has provided evidence of the validity of such health ratings in predicting mortality (Idler & Benyamini, 1997). For the present study, due to the small number in the "poor" category, the "poor" and "fair" categories were combined to create a three-category variable: poor/fair health, good health, and excellent health. Criterion validity of health ratings in the present sample is indicated by the significant association with worsening health during the past 12 months (chi square = 123.50, p < .001) and with number of prescription medications (F = 4.42, p < .05).

Maladaptive behaviors were measured by the Problem Behavior subscale of the Scales of Independent Behavior-Revised (Bruininks, Woodcock, Weatherman, & Hill, 1996). Respondents indicated whether eight categories of behavior problems were manifested during the past six months: hurtful to self, unusual or repetitive habits, withdrawal or inattentive behavior, hurtful to others, destructive to property, disruptive behavior, socially offensive behavior, and uncooperative behavior. The summary score was a count of the number of behavior problems manifested, ranging from 0 to 8. Reliability and validity have been established by Bruininks et al. (1996).

Autism symptomatology.—Autism symptoms were assessed using the Autism Diagnostic Interview-Revised (ADI-R; Lord et al. 1994), a standardized diagnostic interview

administered to the parent. The ADI-R yields two ratings: the "lifetime" rating and the "current" rating. The present analysis focused primarily on the "lifetime ratings", which reflected the severity of symptoms when the individual with ASD was age 4 to 5 or the most severe level of impairment ever exhibited by the individual. Summary scores are computed that reflect lifetime impairments in non-verbal communication, lifetime impairments in reciprocal social interaction, and repetitive behaviors and interests. We also measured "current" ratings on these same symptoms, reflecting severity of autism symptoms at Time 1.

Daily Living Skills.—To measure the degree of *independence in activities of daily living*, the Waisman-Activities of Daily Living scale (W-ADL; Maenner et al., 2013) was used. The W-ADL consists of 17 items assessing the level of independence in typical daily activities such as self-care, meal preparation, household tasks, and community activities such as running errands. Each item was rated on a 3-point scale (0 = *does not do at all*, 1 = *does with help*, 2 = *independent*), and summed up to create a total score. The internal consistency (Cronbach's α) of the W-ADL was .903. Criterion validity of the W-ADL for adults with ASD was previously established (Maenner et al., 2013). Specifically, Maenner et al. (2013) reported how the W-ADL differentiated among individuals with mild, moderate, severe, and profound ID. Of the 34-point scale, those with mild ID scored 24.9 on average, those with moderate ID scored 21.8 on average, those with severe ID scored 16.1 on average, and those with profound ID scored 5.8 on average. Although these benchmarks were generated by data on individuals with Down syndrome, other research has shown that the scale works similarly for adults with ASD (Smith et al., 2012).

Plan for Data Analysis

Descriptive data were computed comparing those adults with ASD who died during the study period and those who survived using chi squares and analyses of covariance (controlling for age of the individual with ASD). "Premature death" was computed based on age at Time 1, using sex-specific life tables (CDC - National Center for Health Statistics) and was defined as the number of years between age at death of an individual and his or her life expectancy at Time 1. Causes of death were enumerated, with the sex of the decedent noted as well as whether the decedent had intellectual disability. Cox proportional hazard modeling was used to predict survival vs. mortality over the 20-year period, with all predictors measured at Time 1.

Results

Descriptive Findings

Table 1 presents a comparison of the characteristics of individuals with ASD who died between 1998 and 2018 and those who remained alive. In 1998, at the beginning of the study period, the sample members ranged in age from 10 to 52 years of age. Those who died during the next 20 years averaged nearly nine years older at Time 1 than those who survived. Additionally, those who died were in significantly poorer health at Time 1, with half as many rated as being in excellent health and more than twice as many rated as being in fair or poor health at Time 1 as those adults who survived over the next 20 years. However, the two

groups did not differ in sex or ID status, with the majority of both groups classified as having ID.

Adults who later died were significantly less independent in their activities of daily living at Time 1 than those who remained alive over the next 20 years. The specific Time 1 W-ADL items that significantly differentiated those who later died from those who remained alive (controlling for age) were independence in toileting; making one's bed; doing household tasks (including picking up around the house, putting things away, light housecleaning, etc.); doing home repairs (including simple repairs around the house, non-technical in nature, for example, changing light bulbs or repairing a loose screw); and preparing complete meals (all $p < .05$), and at a trend level running errands (including shopping in stores) and banking and managing daily finances (including keeping track of cash, checking account, paying bills, etc. (all $p < .10$).

Additionally, adults who later died had significantly greater lifetime impairments in social reciprocity. However, they did not differ in other core domains of autism symptoms (lifetime impairments in non-verbal communication, lifetime restricted repetitive behaviors and interests). They also did not differ in the severity of their behavior problems at the start of the study period.

Table 2 presents data on the age at death and causes of death of the 26 individuals with ASD who died during the 20-year study period. The youngest death was at age 18 and the oldest was at age 65, with the average age at death being 39. Decade by decade, most deaths occurred during the 40s (n = 8), but nearly that many died in their 20s (n = 6) or 30s (n = 6).

We calculated the extent of "premature death", defined as the number of years the individual died before his or her life expectancy (life expectancy was calculated at Time 1 for each individual). The average number of years of premature death in the current sample was 38.5 years (range = 16.8 years to 57.7 years before the individual's life expectancy).

Also shown in Table 2 are causes of death. The most common causes of death were cardiac arrest and cancer, each reported for five adults. Cancers included breast, colon/liver, rectal, and spine, as well as one unspecified type of cancer. Three adults died due to seizures, three from respiratory failure or pneumonia, two died from choking on food, and two others died following health complications due to medication side effects (Thorazine, Depakote). The causes of death of five adults were unknown.

Prediction of Mortality in Adults with ASD

We used Cox proportional hazard models to predict the factors associated with the mortality of individuals with ASD over 20 years. See Table 3. The predictors, all measured at Time 1, were evaluated in three blocks. The first block included age, sex, and ID status. The second block added health status. The third block included behavior problems, lifetime autism symptomatology, and daily living skills. As shown in Model 1, the age of the individual with ASD in 1998 was a significant predictor of mortality. For every one year older age at the start of the study period, the individual had a 7% greater risk of dying over the next 20 years. Sex and ID status were not predictive of mortality.

Model 2 shows the incremental effect of health status at Time 1 in predicting mortality, net of age, sex, and ID status. Being in fair or poor heath at Time 1 conferred a 46% greater risk of dying over the next 20 years as compared with being in excellent health at Time 1.

Model 3 indicates that even controlling for initial age and health status (both of which remained significant predictors), two additional factors predicted mortality over the next 20 years: independence in activities of daily living and lifetime impairments of social reciprocity. For every one point higher score on the measure of activities of daily living in 1998 (signifying higher levels of independence), individuals with ASD had a 6.5% lower risk of mortality over the next 20 years. For every one point higher score on the measure of lifetime impairments in social reciprocity (signifying greater levels of impairment at age 4– 5), there was a 27% higher risk of mortality during the 20-year study period. The other two "lifetime" measures of autism symptoms (lifetime impairments in non-verbal communication and restricted repetitive behaviors and interests) were not significant predictors of mortality.

In follow-up analyses (data not shown), we examined whether each of these lifetime measures of autism symptoms would be predictive of mortality if the other two lifetime measures were not included in the Cox regression model. The only one that was a significant predictor was lifetime impairments in social reciprocity. Notably, none of the ADI-R measures that reflect current functioning at Time 1 was a predictor of mortality.

Discussion

The present study reports on predictors of mortality over a 20-year period in a large community-based cohort of adolescents and adults with ASD. In this cohort, 6.4% died during the 20-year follow-up period, and the average age at death was 39 years. These individuals died an average of 38.5 years prior to their life expectancy. Causes of death were diverse, including chronic conditions (such as cancer and seizures), accidents (such as choking on food and accidental poisoning), and health complications due to medication side effects. Our results build on previous research that has indicated that individuals with ASD have a higher risk for mortality than the general population (Hirvikoski et al., 2016; Mouridsen et al., 2008; Woolfenden et al., 2012) and have health risks that could contribute to earlier death (Croen et al., 2015; Fortuna et al., 2016). Specifically, our results confirm prior research showing that seizures and accidents are common causes of death for individuals with ASD (e.g., Hirvikoski et al., 2016; Mouridsen et al., 2008). However, our study differs from past research in that we investigated behavioral factors that predict mortality as well as causes of death.

Not surprisingly, age and health were major factors that predicted death in the present study. Being in fair or poor health was the strongest predictor of mortality, increasing the risk of dying over the next 20 years by 46% (compared to being in excellent health). In a review of 27 US and international studies of representative community samples, the validity of self-reported heath ratings in predicting subsequent mortality was firmly established, above and beyond other indicators of health such as physicians' ratings and biomarkers (Idler & Benyamini, 1997). The review concluded that health ratings are valuable because they are

holistic, capturing the "full array of illnesses a person has and possibly even symptoms of disease as yet undiagnosed but present in preclinical or prodromal stages" (p.27). In the present study, the health ratings were made by mothers of the adolescents and adults with ASD, and the findings reported here underscore the importance and predictive validity of parent-reported health ratings for individuals who have compromised ability to communicate on their own behalf.

Even after controlling for age and health status, we found that limited self-sufficiency in activities of daily living was an important predictor of mortality for adults with ASD. Past research has indicated that children with ASD show poorer adaptive functioning than typically-developing children (Franchini et al., 2018), and that adolescents and adults with ASD have greater impairments in ADL self-sufficiency than individuals with other developmental disabilities, such as those with Down syndrome (Esbensen et al., 2008; Esbensen et al., 2010; Smith et al., 2012). Furthermore, it has been shown that ADL skills that are acquired by adults with ASD are not maintained over time to the same extent as those with Down syndrome (Smith et al., 2012). Importantly, ADL self-sufficiency by adults with ASD has been shown to be responsive to environmental influences (Taylor et al., 2014). For example, employed adults with ASD are more likely to improve their ADL skills over time than unemployed adults with ASD, perhaps due to expectations set by the workplace for personal hygiene and related ADL skills (Taylor et al., 2014). ADL skills are malleable and dynamic and hence interventions aimed at building self-sufficiency in daily living skills are important to provide to children, adolescents, and adults with ASD. In addition, setting high expectations for maintaining such skills during the life course may have implications for health maintenance and even survival.

Perhaps the most intriguing finding of the present study concerns the extent to which impairments in social reciprocity, as evidenced in early childhood, are predictive of mortality that occurs decades later in adulthood. Confirmation of this finding in future research is needed, but the magnitude of the effect in our sample is notable. Examples of impairments in social reciprocity include abnormalities in joint attention, social smiling, responsivity to the approaches of others, interest in people, exhibiting a range of appropriate facial expressions to communicate, and social overtures. Early intervention has been shown to ameliorate the core symptoms of autism, including social reciprocity impairments (Kasari et al., 2015; Kasari & Patterson, 2012; Schreibman et al., 2015; Tachibana et al, 2017), and reduction in the severity of symptoms early in childhood has been shown to have long-term effects on later adaptive behavior and autism symptoms (Kasari et al., 2012; Klintwall et al., 2015; Perry et al., 2017). Our findings suggest that these effects may extend into adulthood, potentially influencing mortality. Future research that elucidates the mechanism by which impairments in social reciprocity may directly or indirectly affect survival in adulthood is needed to understand this finding fully, but the findings point to the importance of lifelong social engagement.

This study is not without methodological limitations. The analysis suffers from both right and left censoring, as only individuals who survived to age 10 were eligible to participate in the longitudinal study and 75% of the members of the study cohort are still alive. Although this research was based on a volunteer community sample, the adults were largely

Caucasian, and hence the results may not be representative of a more diverse population of adults with ASD. Further, compared to children diagnosed today, a larger proportion of adults with ASD in this generation had co-occurring intellectual disability; they also experienced a different service landscape. For this reason, generalizability of findings may be limited. Finally, knowing the cause of death is informative but it does not fully capture the sequence of health problems that may have led to deaths. Juxtaposed against these limitations are strengths of the research, including the long follow-up period, the large sized sample, and the utilization of measures of risk factors that are commonly available on children and adults with ASD. For this reason, clinical screening for these risk factors would potentially be feasible.

Taken together, the findings of the present study suggest that the risk of mortality in adults with ASD might be reduced by identification of individuals judged by their parents to be in fair or poor health and attending to any unmet health care needs, participating in early intervention to reduce impairments in social reciprocity symptoms, and receiving interventions across the life course to support acquisition and maintenance of self-sufficiency in ADL skills. Studies of the effects of these population health approaches are needed to confirm the findings of the present research and to enhance the survival of adults with ASD.

References

Bilder D, Botts EL, Smith KR, Pimentel R, Farley M Viskochil J, et al. (2013). Excess mortality and cause of death in autism spectrum disorders: A follow up of the 1980s Utah/UCLA Autism Epidemiologic Study. Journal of Autism and Developmental Disorders, 43, 1196–1204. [PubMed: 23008058]

Bruininks RH, Woodcock RW, Weatherman RF, Hill BK. (1996). Scales of Independent Behavior Revised Rolling Meadows IL: Riverside Publishing.

CDC - National Center for Health Statistics – Homepage. https://www.cdc.gov/nchs/products/life_tables.htm

Croen LA, Zerbo O, Qian Y, Massolo ML, Rich S, Sidney S, & Kripke C (2015). The health status of adults on the autism spectrum. Autism, 19, 814–823. [PubMed: 25911091]

Eaves LC, Ho HH. (2008). Young adult outcome of autism spectrum disorders. Journal of Autism and Developmental Disorders, 38(4):739–747. [PubMed: 17764027]

Esbensen AJ, Bishop S, Seltzer MM, Greenberg JS, Taylor JL. Comparisons Between Individuals With Autism Spectrum Disorders and Individuals With Down Syndrome in Adulthood. Am J Intellect Dev Disab 2010;115(4):277–290.

Esbensen AJ, Greenberg JS, Seltzer MM, & Aman MG (2009). A longitudinal investigation of psychotropic and non-psychotropic medication use among adolescents and adults with autism spectrum disorders. Journal of Autism and Developmental Disorders, 39(3), 1339–1349. [PubMed: 19434487]

Esbensen A, Seltzer MM, & Krauss MW (2008). Stability and change in health, functional abilities and behavior problems among adults with and without Down syndrome. American Journal on Mental Retardation, 113(4), 263–77 [PubMed: 18564887]

Farley MA, McMahon WM, Fombonne E, et al. Twenty-year outcome for individuals with autism and average or near-average cognitive abilities. Autism Res 2009;2(2):109–118. [PubMed: 19455645]

Fortuna RJ, Robinson L, Smith TH, Meccarello J, Bullen B, Nobis K, & Davidson PW (2015). Health conditions and functional status in adults with autism: a cross-sectional evaluation. Journal of General Internal Medicine, 31, 77–84. [PubMed: 26361965]

Gillberg C, Billstedt E, Sundh V, & Gillberg IC (2010). Mortality in autism: A prospective longitudinal community-based study. Journal of Autism and Developmental Disorders, 40, 352–357. [PubMed: 19838782]

Glutting JJ, Adams W, Sheslow D. (2000). Wide Range Intelligence Test Wilmington, DE: Wide Range.

Henninger NA, & Taylor JL (2012). Outcomes in adults with autism spectrum disorders: a historical perspective. Autism, 17, 103–117. [PubMed: 22914775]

Hirvikoski T, Mittendorfer-Rutz E, Boman Marcus, Larsson H, Lichtenstein P, & Bolte S (2016). Premature mortality in autism spectrum disorder. The British Journal of Psychiatry, 208, 232–238. [PubMed: 26541693]

Howlin P, & Moss P (2012). In review: Adults with autism spectrum disorders. Canadian Journal of Psychiatry, 57(5).

Idler EL, Benjamini Y. (1997). Self-rated health and mortality: A review of twenty-seven community studies. Journal of Health and Social Behavior, 38, 21–37. [PubMed: 9097506]

Lord C, Rutter M, Le Couteur A. (1994). Autism Diagnostic Interview-Revised: A revised version of a diagnostic interview for caregivers of individuals with possible pervasive developmental disorders. Journal of Autism and Developmental Disorders 24, 659–685. [PubMed: 7814313]

Luckasson R; Borthwick-Duffy S; Buntinx WHE.; Coulter DL; Craig EM; Reeve A, et al. Mental retardation: Definition, classification, and systems of supports. 10 Washington, DC: American Association on Mental Retardation; 2002.

Nicolaidis C, Raymaker D, McDonald K, Dern S, Boisclair WC, Ashkenzay E, & Baggs A (2012). Comparison of healthcare experiences in autistic and non-autistic adults: A cross-setional online survey facilitated by an academic-community partnership. Journal of General Internal Medicine, 28, 761–769. [PubMed: 23179969]

Maenner MJ, Smith LE, Hong J, Makuch R, Greenberg JS, Mailick MR. (2013). Evaluation of an activities of daily living scale for adolescents and adults with developmental disabilities. Disability and Health Journal, 6 (1), 8–17. [PubMed: 23260606]

Mouridsen SE, Bronnum-Hansen H, Rich B, & Isager T (2008). Mortality and causes of death in autism spectrum disorders. Autism, 12, 403–414. [PubMed: 18579647]

Pickett J, Xiu E, Tuchman R, Dawson G, & Lajonchere C (2011). Mortality in individuals with autism, with and without epilepsy. Journal of Child Neurology, 26, 932–939. [PubMed: 21471551]

Roux Anne M., Shattuck Paul T., Rast Jessica E., Rava Julianna A., and Anderson Kristy A. (2015). National Autism Indicators Report: Transition into Young Adulthood Philadelphia, PA: Life Course Outcomes Research Program, A.J. Drexel Autism Institute, Drexel University: http://drexel.edu/autismoutcomes/publications-and-reports/publications/National-Autism-Indicators-Report-Transition-to-Adulthood/#sthash.V4YjBzEn.dpuf

Roux AM, Shattuck PT, Cooper BP, Anderson KA, Wagner M, & Narendorf SC (2013). Postsecondary employment experiences among young adults with an autism spectrum disorders, Journal of the American Academy of Child and Adolescent Psychiatry, 52, 931–939. [PubMed: 23972695]

Seltzer MM, Greenberg JS, Taylor JL, Smith L, Orsmond GI, Esbensen A, & Hong J (2011). Adolescents and adults with autism spectrum disorders. In Amaral DG, Dawson G, & Geschwind D (Eds.), Autism spectrum disorders (pp. 241–252) New York: Oxford University Press.

Shattuck PT, Narendorf SC, Cooper B, Sterzing PR, Wagner M, Taylor JL. (2012). Postsecondary education and employment among youth with an autism spectrum disorder. Pediatrics,129(6): 1042–1049. [PubMed: 22585766]

Sparrow SS, Carter AS, Cicchetti DV. (1993). Vineland Screener: Overview, reliability, validity, administration, and scoring New Haven: Yale University Child Study Center.

Taylor JL, Henninger NA, Mailick MR (2015). Longitudinal patterns of employment and postsecondary education for adults with autism and average-range IQ. Autism, 19, 785–793. [PubMed: 26019306]

Taylor JL, Mailick MR. (2014). A longitudinal examination of 10-year change in vocational and educational activities for adults with autism spectrum disorders. Developmental Psychology, 50(3), 699–708. [PubMed: 24001150]

Taylor JL, Seltzer MM (2010). Changes in the autism behavioral phenotype during the transition to adulthood. Journal of Autism and Developmental Disorders, 40:1431–1446. [PubMed: 20361245]

Taylor JL, & Seltzer MM (2011). Employment and post-secondary educational activities for young adults with autism spectrum disorders during the transition to adulthood. Journal of Autism and Developmental Disorders, 41, 566–74. [PubMed: 20640591]

Vogan V, Lake JK, Tint A, Weiss JA, & Lunsky Y (2017). Tracking health care service use and the exeriences of adults with autism spectrum disorder without intellectual disability: A longitudinal study of service rates, barriers, and satisfaction. Disability and Health Journal, 10, 264–270. [PubMed: 27899267]

Woodman AC, Mailick MR, Anderson KA, & Esbensen AJ (2014). Residential transitions among adults with intellectual disability across 20 years. American Journal of Intellectual and Developmental Disabilities 119(6):496–515.

Woolfenden S , Sarkozy V, Ridley G, Coory M, & Williams K (2012). A systematic review of two outcomes in autism spectrum disorder—epilepsy and mortality. Developmental Medicine and Child Neurology, 54, 306–312. [PubMed: 22348343]

Table 1.

Descriptive Statistics of Individuals with ASD and Family Background (all measured at Time 1).

	Alive (n=380)	Deceased (n=26)	F-value[a]
Individuals with ASD			
Age	21.4 (8.9) [10, 48]	29.6 (12.5) [11, 52]	t = 4.38 ***
Sex (percentile of males)	275 (72.4%)	22 (84.6%)	Chi-sq = 1.86
Intellectual Disability	263 (69.2%)	21 (80.8%)	Chi-sq = 1.55
Health rating			
Excellent	141 (37.1%)	4 (15.4%)	Chi-sq = 10.3 **
Good	187 (49.2%)	13 (50.0%)	
Fair/poor	52 (13.7%)	9 (34.6%)	
Number of behavior problems (SIB-R[b] items)	4.8 (2.0) [0, 8]	4.3 (2.0) [1, 8]	F = 0.05
ADI-R[c] Lifetime Impairments in Social Reciprocity	25.0 (3.9) [10, 30]	27.2 (1.9) [24, 30]	F = 4.14 *
ADI-R[c] Lifetime Impairments in Non-verbal Communication	12.1 (2.3) [3, 14]	12.9 (1.8) [7, 14]	F = 0.64
ADI-R[c] Lifetime Repetitive Behavior and Interests	6.9 (2.5) [0, 12]	6.6 (2.3) [3, 11]	F = 0.08
W-ADL[d]	19.8 (6.6) [3, 34]	17.3 (6.6) [3, 34]	F = 7.07 **
Seizure disorder			
No seizures	294 (78.0%)	17 (64.5%)	Chi-sq = 5.02
Has seizures	86 (22.0%)	9 (35.5%)	
Family Characteristics			
Maternal age	50.7 (10.0) [32, 81]	58.3 (12.7) [37, 79]	t = 3.69 ***
Marital status of mother	290 (78.8%)	19 (73.1%)	Chi-sq = 0.48
Maternal education (college graduate or higher)	174 (45.8%)	9 (34.6%)	Chi-sq = 1.02
Household income[e]	9.7 (3.4) [2, 13]	8.8 (2.9) [3, 13]	F = 0.38
Number of children in the family	2.83 (1.3) [1, 8]	3.31 (1.4) [2, 7]	F = 1.14

*
$p < 0.05$

**
$p < 0.01$

***
$p < 0.001$

a. From ANCOVA with Time 1 age as a covariate, unless other statistics are reported.

b. SIB-R – Scales of Independent Behavior-Revised.

c. ADI-R – Autism Diagnostic Interview – Revised.

d. W-ADL –Waisman Activities of Daily Living

e. Based on the original scale: (1) 0 - $4,999; (2) $5,000 - $9,999; ….(8) $35,000 - $39,999; (9) $40,000 - $44,999; (10) $45,000 - $49,999; (11) $50,000 - $59,999; (12) $60,000 - $69,999; (13) $70,000+

Table 2.

Age and Causes of Death of Individuals with ASD

Ages.	mean, (s.d.) [min, max]
Age of death	39.0 (13.7) [18.4, 65.7]
Average years lived beyond Time 1	9.5 (5.6) [0.2, 18.0]
Average years of premature death	38.5 years [18.6, 57.7]

Causes of Death	age at death
Cancer	23^a, 26, 32, 44^{ab}, 46
Cardiac arrest	31, 37^b, 47, 48, 57
Seizures	18, 30, 49
Respiratory failure, pneumonia	20, 34^b, 50
Choking on food	47, 61
Medication side effects	20, 43
Accidental poisoning	54
Unknown cause of death	20, 24, 34^{ab}, 41, 65^{ab}

Note: Premature death defined as the number of years the individual died before his or her life expectancy.

[a] female

[b] does not have ID

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript

Table 3.

Predictors of mortality for individuals with ASD (Cox proportional hazard models)

Predictors	Model 1		Model 2		Model 3	
	HR[a]	[95% CI]	HR	[95% CI]	HR	[95% CI]
Age	1.071***	[1.04, 1.11]	1.066***	[1.03, 1.10]	1.068***	[1.03, 1.11]
Sex (female=1)	0.420	[0.14, 1.22]	0.448	[0.15, 1.31]	0.473	[0.16, 1.39]
Intellectual Disability	1.262	[0.46, 3.43]	1.214	[0.44, 3.33]	0.616	[0.19, 2.01]
Health rating (ref. excellent)						
Good			2.358	[0.77, 7.23]	2.132	[0.69, 6.60]
Fair/poor [b]			4.661*	[1.42, 15.28]	4.300*	[1.28, 14.45]
Number of Behavior problems					0.923	[0.75, 1.14]
ADI-R Lifetime Social					1.275*	[1.05, 1.55]
ADI-R Lifetime Non-verbal					0.894	[0.68, 1.18]
ADI-R Lifetime Behavior					0.976	[0.82, 1.17]
WADL					0.935*	[0.88, 0.99]

*
$p < 0.05$

**
$p < 0.01$

***
$p < 0.001$

[a.]HR hazard ratio; CI confidence interval.

[b.]The difference between "Good" and "Fair/poor" was not significant (p = 0.115).