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Original Article

Patterns of Mortality among People with Autism Spectrum Disorder in South Korea

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Abstract

Background: Detailed statistics on the death status of persons with autism spectrum disorder (ASD) are lacking. We aimed to identify and compare recent mortality rates in persons with ASD in Korea.

Methods: From 2012 to 2021, databases were established by linking data on persons with ASD registered in Korea with data on cause of death from the National Statistical Office.

Results: Between 2012 and 2021, the mortality rate of persons with ASD and age-standardized mortality rates fluctuated annually. The crude mortality rates in the population with ASD were 91.6, 113.8, and 74.5 in 2012, 2016, and 2021, respectively, which were lower than the rates in the general population; however, the age-standardized mortality rate was observed to be five times higher. Intentional self-harm, as a cause of death in persons with ASD, was ranked high annually. The mortality rates in persons with ASD from diseases (50.7%) and injury (49.3%) were in a ratio of 1:1. Diseases and injury were more causes of death in males with ASD. The average age of persons with ASD at death was confirmed to be approximately 50 years lower than that of the general population.

Conclusion: Deaths and causes of death in persons with ASD differ from those of the general population. Therefore, preventive measures and efforts are required to reduce avoidable deaths among persons with ASD.

Keywords: Autism spectrum disorder; Crude death rate; Mortality; Intentional self- harm; South Korea

Introduction

Autism spectrum disorder (ASD) is a developmental disorder characterized by defects in social interaction and communication skills and limited and repetitive interests and activities (1). ASD is a neuro-developmental disorder of biological origin that generally occurs before the age of 3 years. The age at disability diagnosis continues to become younger as early detection during infancy has become possible (2-4).

In Korea, persons with ASD were designated as nationally registered persons with disabilities in 2000, during which 11,874 persons with ASD were registered, accounting for 0.56% of all registered disabilities. Since then, the incidence has steadily increased, reaching 33,650 ASD cases in 2021, accounting for 1.27% of all people with disabilities. In particular, the increasing trend is noticeable among those in their 20s and 30s, and the rate of occurrence is five times higher in females than in males (5). The crude mortality rate in persons with ASD is 287.1 persons, twice as

high as that in the general population (574.8 persons) (6).

Companion diseases, such as schizophrenia, attention-deficit/hyperactivity disorder, epilepsy, and depression, have been reported to lead to premature death in persons with ASD (7-10). In addition to the causes of death, persons with ASD are at high risk of dying from unintended accidents (11-13).

Mortality is a commonly used indicator of population health (14). However, in Korea, it is difficult to find data that systematically examines the mortality rates and causes of death in persons with ASD. Among the 15 types of disabilities stipulated in the Welfare of Persons with Disabilities Act, the Act on Support for Persons with Developmental Disabilities (hereafter referred to as the Developmental Disabilities Act) was enacted in May 2014 and enforced in November 2015 (15). Article 6 of this Act presents a fact-finding survey on persons with developmental disabilities and their families every 3 years to use as basic data for identifying the status of persons with developmental disabilities and establishing welfare policies. However, detailed statistics on the death status of persons with ASD are lacking. Moreover, data and research on healthcare for ASD using this approach are limited. As there are no similar statistics related to the causes of death in persons with ASD in Korea, it is necessary to produce basic data to review all deaths related to ASD.

We aimed to examine trends in the crude and age-standardized mortality rates of persons with ASD over the past 10 years, examine the causes of death in persons with ASD, and analyze the average age at death of persons with ASD. Therefore, we sought health-management measures for ASD.

Materials and Methods

Data source

From the end of 2012 to 2021, a database of causes of death of people with disabilities was established by obtaining data on individuals with disabilities registered with the Ministry of Health and Welfare and data on causes of death from the National Statistical Office. Individuals with disabilities are those who have registered with the Korean government as having a disability and other matters prescribed by the Ordinance of the Ministry of Health and Welfare with the Mayor of the Special Self-Governing Province, Mayor Gun, or the head of Article 32 of the Welfare Act (16, 17). Data of registered individuals with disabilities included sex, age, main disability type, and comprehensive disability grade; if any of these variables were absent, they were treated as missing and excluded from the analysis. Cause of death data from Statistics Korea was collected through the patients' medical certificate. There may be missing data due to delays in the registration of the cause of death, but this was not considered in this study. Cause of death codes were derived using the International Classification of Diseases (ICD-10) codes. Information on the cause of death was recorded on the death certificate, and the World Health Organization (WHO) 103 classification criteria were used (18). In other words, mortality rates were calculated based on these 103 items. However, 57 items that integrate malignant neoplasms into a single item among the general death selection classification table (80 items) recommended by the WHO for death reports were applied to the selection of cause of death (19).

Korean Disability Registration System

Korea's disability registration system is based on the Welfare Act for the mentally and physically disabled, which was enacted in 1981. People with disabilities in Korea are registered according to the disability registration system and managed by the government. Registered people with disabilities receive support for daily living activities such as income, medical care, and housing. In Korea, the types and degrees of disabilities are legally regulated. There are 15 types of disabilities, and ASD is one of them. The ASD according to the diagnostic criteria of ICD-10, does not show the stage of normal development and has an IQ of 70 or less, and due to impaired function and abil-

ity, persons with ASD have a Global Assessment Scale (GAS) score between 20 and 50.

Statistical analysis

An ASD Cause of Death database was established to calculate the status of deaths of persons with ASD. To this end, survey mortality, mortality by cause, and age-standardized mortality indicators were used (18). The crude death rate was calculated per 100,000 person-years by dividing the annual death toll by the mid-year population. The age-standardized death rate is an indicator of mortality that eliminates the effect of age on mortality to compare death levels among groups with different population structures. The standard population used was the 2005 resident-registered mid-year population. The death population in 2012–2021 was based on the end of each year. The population of registered individuals with disabilities was defined operatively as (registered individuals with disabilities in the previous year + registered individuals with disabilities in the current year)/2. The 95% confidence interval (95% CI) was calculated assuming that the observed number of deaths followed a Poission distribution. Data were analyzed using SAS version 9.4. This study was approved by the National Rehabilitation Centre Clinical Research Review Committee (NRC-2012-04-026). Informed consent was obtained from all participants.

Results

The 10-year crude mortality rate was 66.2–122.8 per 100,000 person-years in people with ASD, whereas that in the general population was 526.6–582.5 per 100,000 person-years. However, the mortality rate of persons with ASD examined according to the age-standardized mortality rate was 61.2–4302.4 per 100,000 person-years, varying greatly from year to year. Table 1 shows a decline in the age-standardized mortality rate in the general population.

Table 1: Annual mortality rates per 100,000 person-year

Year	Autism spectrum disorder			General population		
	Person-years	Crude mortality rate	Age-standardized mortality rate (95% CI*)	Person-years	Crude mortality rate	Age-standardized mortality rate (95% CI*)
2012	15	91.6	1396.2 (462.6–4214.0)	267,221	530.8	392.2 (390.6–393.7)
2013	20	114.2	61.8 (32.9–116.1)	266,257	526.6	372.0 (370.6–373.5)
2014	17	90.3	95.0 (27.1–333.7)	267,692	527.3	355.7 (354.3–357.1)
2015	18	88.7	61.2 (16.8–105.6)	275,895	541.5	347.6 (346.3–349.0)
2016	25	113.8	72.6 (40.5–130.2)	280,827	549.4	337.2 (335.9–338.5)
2017	32	134.6	4302.4 (868.4–21315.3)	285,534	557.3	324.3 (323.1–325.6)
2018	17	66.2	767.6 (165.3–3565.2)	298,820	582.5	322.6 (321.3–323.8)
2019	34	122.8	287.1 (95.5–863.7)	295,110	574.8	305.4 (304.2–306.6)
2020	26	87.5	3615.9 (918.6–14233.8)	304,948	593.9	300.0 (298.8–301.1)
2021	24	74.5	773.5 (167.7–3567.3)	317,680	618.9	298.3 (297.2–299.4)

*CI: confidence interval (standardized using the 2005 South Korean population)

The causes of death in persons with ASD by year varied considerably over the past 10 years. There were 134 ASD deaths over 10 years, with 50.7% due to disease and 49.3% due to injury. For 10 years, the number one cause of death in ASD was intentional self-harm, accounting for 14.9% (n=20). This was followed by heart disease at 14.2%, falls at 13.4%, and malignant neoplasm at 11.9%. Heart diseases, malignant neoplasms, and pneumonia account for 34.3%, or about one-third of the causes of disease in ASD deaths. Intentional self-harm, falls, and transport accidents account for 35.8% or about one-third of the causes of disease in ASD deaths (Fig. 1).

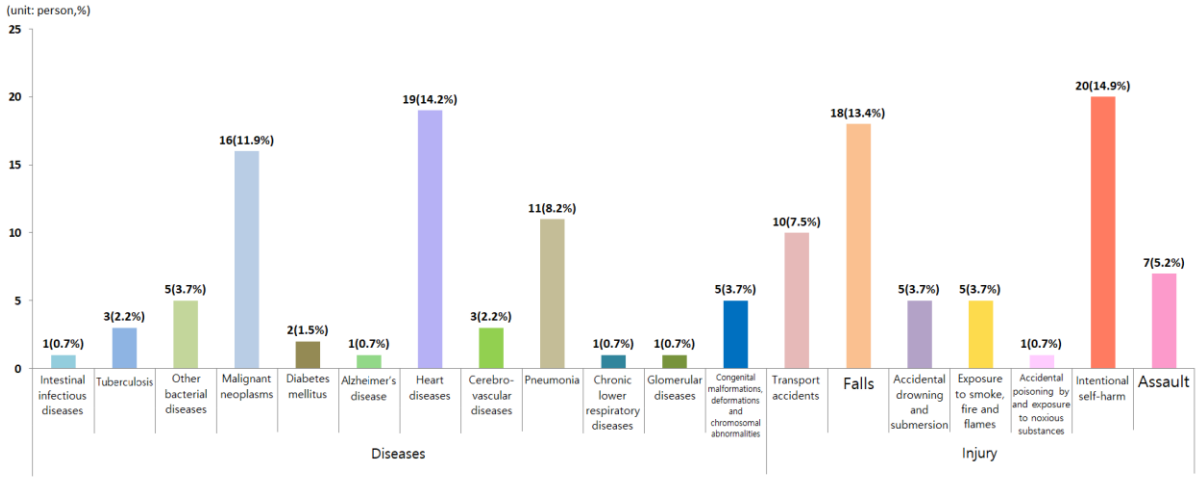

Fig. 1: Total number of the causes of deaths in persons with autism spectrum disorder from 2012 to 2021

The 10-year ASD-related cause of death was disease and unintentional injury in an approximate ratio of 1:1. Over the past 10 years, 68 (50.8%) patients died from diseases and 66 (49.2%) from unintentional injuries. In 2015 and 2018, the rates of deaths from diseases and unintentional injuries remained consistent at a ratio of 1:1. By year, the number of deaths from diseases was higher (five times) than the number of deaths from unintentional injuries (three times); however, the number of deaths was not large. Thus, there seems to be a limit to revealing a certain pattern (Table 2).

Table 2: Death rate by diseases and unintentional injury in patients with autism spectrum disorder (2012–2021)

Year	Diseases (%)[a]		Unintentional injury (%)[b]		N
	Male	Female	Male	Female	
2012	4	2	2	1	9
2013	3	0	4	2	9
2014	4	1	4	0	9
2015	4	2	6	0	12
2016	5	1	12	1	19
2017	8	3	8	2	21
2018	2	3	5	0	10
2019	10	1	8	2	21
2020	6	0	6	1	13
2021	7	2	2	0	99
Total	53	15	57	9	134

[a]: intestinal infectious diseases, tuberculosis, other bacterial diseases, malignant neoplasms, diabetes mellitus, Alzheimer's disease, heart diseases, cerebrovascular diseases, pneumonia, chronic lower respiratory diseases, glomerular diseases, congenital deformities, and chromosomal abnormalities

[b]: traffic accidents; falls; accidental drowning; exposure to smoke, fire, and flames; accidental poisoning; exposure to toxic substances; intentional self-harm (suicide); and assault (murder)

Regarding the average age at death of persons with ASD, the most frequently observed age category was the 20s for the 10-year period without a significant change. Compared with males, the

change in the average age of females at death was considerable, with a significant difference. The average age of persons with ASD was approximately 50 years lower than that of the general population, and it was observed to last for 10 years (Table 3).

Table 3: Average age at death of persons with autism spectrum disorder and the general population (2012–2021)

Year	Autism spectrum disorder (A)			General population (B)			Absolute difference age (A-B)		
	Average (yr)	Male	Female	Average (years)	Male	Female	Average (yr)	Male	Female
2012	28.2	23.1	38.4	71.4	67.5	76.2	-43.2	-44.4	-37.8
2013	16.6	17.8	9.7	71.6	67.8	76.3	-55.0	-50.0	-66.6
2014	18.6	18.7	18.0	72.1	68.3	76.7	-53.5	-49.6	-58.7
2015	20.1	20.6	18.3	72.9	69.1	77.4	-52.8	-48.5	-59.1
2016	19.0	19.9	14.3	73.3	69.6	77.8	-54.3	-49.7	-63.5
2017	24.2	24.2	24.2	74.0	70.1	78.6	-49.8	-45.9	-54.4
2018	25.1	20.6	33.3	74.5	70.7	78.9	-49.4	-50.1	-45.6
2019	19.7	20.1	17.9	74.6	71.0	79.0	-54.9	-50.9	-61.1
2020	23.8	25.0	14.7	75.1	71.6	79.4	-51.3	-46.6	-64.7
2021	26.5	25.2	32.8	75.6	72.1	79.8	-49.1	-46.9	-47.0

Discussion

Although ASD research has been carried out in many countries, mortality rates and causes of death in persons with ASD have not been fully studied in Korea. We investigated the mortality rates in persons with ASD using a death database at the national level. The mortality rate in persons with ASD was not higher than that in the general population; however, it was difficult to determine the age-standardized mortality rate. This is because half of the age-standardized mortality rates over the past 10 years were high for persons with ASD, and the other half were high for the general population. This is because the analysis was limited, as the number of deaths was small. However, several previous studies have reported that the mortality rate in persons with ASD is twice as high as that in the general population (7, 12, 20-23).

The main causes of death in persons with ASD have changed significantly over the past 10 years. However, intentional self-harm, malignant neoplasms, cardio-cerebrovascular diseases, congenital disabilities, deformations, chromosomal abnormalities, and injuries (falls and transportation accidents) have been reported to be major causes. Studies on persons with ASD in the United States (22, 24), Canada (25), Sweden (8), Denmark (9), and Australia (26) have also shown similar results. Suicide, epilepsy, heart problems, and cancer have been cited as early causes of death in persons with ASD. Previous studies have reported that the suicide rate among persons with ASD is twice as high as that in the general population and is increasing (27).

We found that the age at death in the population diagnosed with autism who died was approximately 50 years younger than that in the general population after analyzing the ASD death database in Korea. Regarding the average age at death of persons with ASD in Korea, the most frequently observed age category was the 20s. This was confirmed to be lower than the average ages

at death in the United States (36.2–39.4 years) (11, 28), Canada (46.2 years) (25), Sweden (53.8 years) (8), Denmark (33.3 years) (12), and Australia (35.3 years) (26). This discrepancy may be due to the differences in research designs. This study from South Korea was conducted using a retrospective cross-sectional design, whereas those from other countries were conducted using a cohort design. Although direct comparisons are limited, the observation that the average age at death of individuals with ASD in Korea was low should not be overlooked. Additionally, accidental death was investigated in this study, and prevention strategies were required.

This study has some limitations. First, ASD in this study did not cover overlapping disorders, such as intellectual or mental disorders. Persons with ASD may have other disorders with an estimated higher mortality risk and a lower average age at death compared to those with ASD alone. However, the strength of this study is that all registered data on persons with ASD in Korea were analyzed. Second, the death data used in this study were based on death reports, and the accuracy was estimated to be somewhat reduced. This is because findings from the literature on the accuracy of death certificate data vary considerably and may vary depending on the disease studied. Finally, it is possible that the mortality rate was underestimated due to the potential impact of the COVID-19 pandemic on ASD and registration.

Based on the results of this study, active strategies are required to identify risk factors in persons with ASD and reduce avoidable deaths.

Considering that people with ASD have a high risk of death from suicide, further research is required to identify the key influencing factors. Quantitative and qualitative studies are required, and cohort studies should be conducted simultaneously.

It is necessary to find a way to reduce the number of deaths in persons with ASD, to identify and take preventive measures to reduce deaths from accidents, such as transportation accidents, drowning, and falls, and to consider the type of disability and target age to prevent accidents.

People with ASD had a lower age at death than the general population in this study. Medical examinations are required to identify health characteristics that lead to early death. In Korea, general health check-ups for the entire nation must be differentiated and implemented for persons with ASD. Adjustments to the timing and age of medical examinations are required.

Conclusion

People with ASD are at risk for various diseases and injuries. This leads to an imbalance in mortality patterns, resulting in differences in average age at death. The observed number of deaths from all causes is nearly five times higher in the ASD population than in the general population. In addition, the mortality rate was high in male with ASD. Furthermore, individuals with ASD are at a significantly higher risk of death from intentional self-harm and injury. Therefore, it is important to recognize the mortality risk factors experienced by people with ASD. Reducing avoidable mortality in people with ASD requires a particular focus on managing injury risk, heart disease, and pneumonia. Therefore, regular health checkups, accident risk prevention, and management measures are necessary to minimize mortality and optimize the health and quality of life of persons with ASD.

Journalism Ethics considerations

Ethical issues (Including plagiarism, informed consent, misconduct, data fabrication and/or falsification, double publication and/or submission, redundancy, etc.) have been completely observed by the authors.

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Conflict of interest

The authors declare that no competing interests exist.

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