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Potentially avoidable mortality among adults with intellectual disability

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Abstract

Persons with intellectual disabilities (ID) face pronounced health disparities. The aim of this study was to describe premature mortality by causes of death and avoidable mortality among persons with ID compared to the general Danish population. This study is based on a Danish nationwide cohort of adults (aged 18–74 years) with ID ($n = 57\ 663$) and an age- and sex-matched reference cohort ($n = 607\ 097$) which was established by linkage between several registers. The cohorts were followed in the Register of Causes of Death between 2000 and 2020. Causes of death were categorized into preventable, treatable, or unavoidable deaths using the OECD/Eurostat classification and furthermore categorized into specific interventions. We compared the observed and expected number of deaths by calculating standardized mortality ratio (SMR). Among persons with ID the number of deaths was 9400 whereof 5437 (58%) were avoidable. SMR for preventable deaths, e.g. by reducing smoking and alcohol intake or by vaccination, was 2.62 (95% CI, 2.51–2.73), and SMR for treatable deaths, e.g. by earlier diagnosis and treatment, was 6.00 (5.72–6.29). Unavoidable mortality was also six-fold increased (SMR = 6.03; 5.84–6.22). Preventable deaths were higher for persons with mild ID compared to severe ID, while treatable and unavoidable mortality were highest for persons with severe ID. The study confirmed that persons with ID have an amplified risk of mortality across all categories. There is a need for competence development of social care and healthcare personnel and reasonable adjustment of health promotion programs and healthcare services for people with ID.

Introduction

Research has established that individuals with intellectual disabilities (ID) face numerous health inequalities in comparison to the general population [1, 2]. Notably, a reduced life expectancy and a higher rate of excess mortality have been consistently observed among persons with ID relative to the general population [3–6]. Investigations into mortality causes have identified heightened mortality rates across nearly all categories, with the most significant increases seen in individuals with moderate or severe ID [7–12]. A review of studies of causes of death among persons with ID showed that mortality among persons with ID was elevated for all examined causes of death and some studies also reported increased avoidable mortality among persons with ID [11]. Avoidable mortality is defined as premature deaths that could be avoided by public health and healthcare interventions and can be divided into preventable and treatable mortality [13].

The disparities in mortality partly reflect co-existing conditions [14, 15], but it has been documented that it also includes lacking focus on health promotion including early diagnosis of common diseases and screening efforts [16, 17], lacking attention to health needs among caregivers and healthcare personnel [18], and inadequate access to relevant healthcare services [1, 19]. These barriers include both individual preferences and barriers, but also unclear responsibilities between carers and limited knowledge and negative attitudes among social care workers and healthcare sector staff due to inability to meet the persons specific needs [19]. This combination of higher morbidity of diseases associated with mortality, e.g. cardiovascular and respiratory diseases, epilepsy, and obesity, lacking focus on health promotion, poor access to preventive and hospital healthcare, and inadequately trained medical workforce exacerbates the likelihood of unfavorable outcomes among persons with ID [1, 9].

We have previously shown marked increased mortality and 20 years shorter life expectancy among persons with ID in Denmark [6]. This study aims to explore premature mortality, causes of death, and the classification of deaths as potentially preventable, treatable or unavoidable among adults with ID aged 18–74. Additionally, we will identify interventions that could potentially reduce mortality disparities, concentrating on adults due to the distinct nature of prevention and treatment strategies compared to those for children and adolescents.

Methods

Setting and study population

This nationwide cohort study consists of persons with ID and a matched reference cohort without ID described in details elsewhere [6]. Briefly, we utilized several nationwide Danish registers to establish a cohort of persons with ID utilizing somatic and psychiatric hospital diagnoses [20, 21], diagnoses from the Danish Cerebral Palsy Registry [22], the register of disability pensions, the Danish

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Register of Causes of Death [23] and residential addresses of persons with ID in the period 1976–2020. For part of the cohort, severity of ID was registered based on diagnoses from hospital records, which we included in three categories (mild, moderate, and severe (including profound) ID) [6]. Each person with ID was matched with 10 persons without ID on sex and date of birth. We included persons aged 18–74 years and followed both persons with and without ID from 2000 to 2020 in the Danish Register of Causes of Death to obtain information on underlying and contributory causes of death [23].

According to Danish law, ethical review and informed consent from participants are not required in register-based studies. In agreement with the General Data Protection Regulation, the present study is registered at University of Southern Denmark, Copenhagen.

Causes of death

By law, causes of death are given to all persons with permanent residence in Denmark who die in Denmark [23]. Since 1994, the tenth version of the international classification of diseases (ICD-10) is used. It is mandatory that all death certificates state the underlying cause of death with the possibility to add contributory causes of death. In this study, we used the underlying cause of death, which is the disease or condition which started the process that leads to death.

OECD/Eurostat has classified selected causes of death as deaths that are caused by diseases or conditions that are either preventable, treatable or both preventable and treatable (termed avoidable mortality in combination) [13]. Potentially preventable mortality is causes of death that mainly can be avoided through public health and primary prevention interventions (before the onset of disease), while potentially treatable mortality is causes of deaths that mainly can be avoided by timely and effective healthcare interventions [13]. Unavoidable mortality includes all other causes of death which includes both unavoidable mortality but also rare diseases and conditions according to the OECD/Eurostat classification [13]. We used the January 2022 version of the classification. Potentially avoidable mortality focuses on premature deaths which is set to deaths before the age of 75 years. Furthermore, we decided to focus on adult mortality (age 18 years and above), as preventive and treatment interventions among adults often have a different focus than interventions among children and young people.

For each of the avoidable causes of death, OECD/Eurostat describes the rationale for inclusion and list which interventions that could be used to prevent or treat a disease or condition [13]. We have grouped causes of death, so that diseases, conditions, and accidents that potentially can be prevented or treated with the same or similar interventions are grouped together. The grouping can be seen in Supplementary Table S1. Deaths due to unavoidable diseases cannot be divided by interventions. Instead, we divided them by ICD-10 chapters to get an overview of the organ systems most affected by fatal diseases.

Statistical analysis

Descriptive statistics of the cohort and reference population were reported as numbers and proportions.

Analyses of overall excess mortality are conducted by comparing the actual number of deaths with the expected number of deaths if persons with ID had the same mortality as those without. This excess mortality is divided into potentially preventable, potentially treatable, potentially both preventable and treatable, and unavoidable mortality.

The expected number of deaths is calculated by multiplying the mortality rates among those without ID with the risk time among persons with ID for each age, calendar time and sex. Age and calendar time are included in one-year groups. These numbers of expected deaths in each age, calendar time and sex group are summed to get the expected number of deaths for persons with ID.

We calculated the standardized mortality ratio (SMR) as the ratio between the observed and expected number of deaths thereby expressing how much higher the mortality is among persons with ID compared to those without ID. 95% confidence intervals (95% CI) of the SMR were calculated assuming that the number of deaths follows a Poisson distribution.

Analyses were performed using SAS, version 9.4, and R version 4.3.1. We used 95% CIs to evaluate statistical significance.

Results

The baseline cohort consists of 57 663 persons with ID and reference cohort of 607 097 persons (Table 1). The cohort consists of more men. Persons with ID are slightly younger compared to the reference group due to higher mortality before baseline (January 2000). Most persons with ID have mild ID and almost half of the cohort has no information about severity. Most are identified with diagnoses (84.1%).

The number of deaths is 9400 (16.3%) among persons with ID and 30 776 (5.1%) among persons without ID are listed in Table 1. Men, older persons, persons with severe ID, and persons with Danish country of origin are more prevalent among persons that die compared to the baseline cohort.

Table 2 shows that among persons with ID, 58% of deaths are potentially avoidable. Potentially treatable mortality is six times higher among persons with ID (SMR = 6.00; 95% CI, 5.72–6.29), followed by excess mortality due to potentially preventable and treatable causes (4.07; 3.87–4.28) as well as unavoidable mortality (6.03; 5.84–6.22). Potentially preventable mortality is more than doubled among persons with ID (SMR = 2.62; 2.51–2.73) compared to persons without ID. The largest absolute difference in the number of deaths is seen for avoidable deaths.

Figure 1 illustrates the age-specific mortality rates by potentially preventable, treatable, both preventable and treatable and unavoidable mortality. The figure demonstrates that unavoidable mortality (green line) is highest for persons with ID, followed by preventable mortality. For persons with ID under 45 years, the mortality rates from preventable and treatable mortality are equal, with the difference becoming apparent only beyond this age. For persons without ID, the preventable mortality rate is highest followed by unavoidable mortality and lowest for treatable mortality.

When stratified by severity, the number of deaths and the absolute difference in deaths are generally highest for unavoidable deaths for all severity levels of ID (Table 2). Furthermore, preventable mortality is most increased among persons with mild ID, while treatable mortality is most increased for persons with severe ID. Unavoidable deaths are also most increased for persons with severe ID. The absolute differences do not follow the same pattern, primarily because the number of persons with moderate and severe ID are smaller than mild ID.

As a sensitivity analysis, we stratified the analysis in Table 2 by sex (see Supplementary Table S2). Overall, the results were similar among women and men even though potential treatable mortality had higher excess mortality among men compared to women, while both preventable and treatable mortality were more increased among women compared to men.

Potentially preventable mortality is increased for almost all interventions, e.g. mortality related to smoking is 2.27 times higher (95% CI, 2.13–2.42) among persons with ID compared to the reference cohort (Table 3). For some interventions the relative excess mortality is very high, e.g. lung diseases that could be prevented by reduction of exposure to chemicals, gases, and other agents. The interventions associated with the highest number of deaths are to reduce smoking (931 deaths), reduce alcohol intake (395 deaths) and avoid deaths due to accidents (229 deaths due to injuries).

Potentially treatable mortality is increased for all interventions, e.g. mortality related to early detection and antibiotic treatment is 18.44 (95% CI, 16.75–20.20) times higher among persons with ID compared to persons without (Table 3). For diseases that can potentially be treated through early detection and treatment, there is a 4.32 (4.05–4.59) times higher mortality. For some causes of death, the excess mortality is very high, such as epilepsy, where the mortality is 42.51 (37.89–47.40) times

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Table 1. Baseline descriptives—ID and reference cohort at inclusion and those who die in the two cohorts at time of death. Age 18-74 years, Denmark, 2000-2020.

	Baseline cohort		Those who die 2000–2020	
	ID	References	ID	References
Total	57 663	607 097	9400	30 776
Sex		–		
Male	31 825 (55.2)	334 238 (55.1)	5397 (57.4)	18 695 (60.8)
Female	25 838 (44.8)	272 859 (44.9)	4003 (42.6)	12 081 (39.3)
Age				
18–34	35 255 (61.1)	358 418 (59.0)	826 (8.8)	854 (2.8)
35–44	7473 (13.0)	75 593 (12.5)	744 (7.9)	1231 (4.0)
45–54	7133 (12.4)	76 341 (12.6)	1713 (18.2)	3748 (12.2)
55–64	4978 (8.6)	58 064 (9.6)	2933 (31.2)	8829 (28.7)
65–74	2824 (4.9)	38 681 (6.4)	3184 (33.9)	16 114 (52.4)
Severity of intellectual disability				
Mild	19 219 (33.3)		3314 (35.3)	
Moderate	6 426 (11.1)		1083 (11.5)	
Severe	4 609 (8.0)		1393 (14.8)	
Unknown severity	27 409 (47.5)		3610 (38.4)	
Identification of persons with ID[a]				
Diagnosis of intellectual disability	48506 (84.1)		8018 (85.3)	
Cerebral palsy with ID	1831 (3.2)		277 (3.0)	
Down syndrome	3799 (6.6)		1227 (13.1)	
Metabolic disorders with ID	692 (1.2)		210 (2.2)	
Congenital malformations/chromosomal disorders with ID	658 (1.1)		61 (0.7)	
Unknown diagnosis, from central institution	5778 (10.0)		1469 (15.6)	
Unknown diagnosis, from sheltered residence	8359 (14.5)		846 (9.0)	
Country of origin				
Danish	52181 (90.5)	490 160 (80.7)	9132 (97.2)	29 178 (94.8)
Immigrant or descendant from a Western country	762 (1.3)	55 297 (9.1)	85 (0.9)	814 (2.6)
Immigrant or descendant from a non-Western country	4720 (8.2)	61 640 (10.2)	183 (2.0)	784 (2.7)

Number and proportion. Age 18–74 years, Denmark, 2000–2020.
a: Since persons can have more than one inclusion source or diagnosis, the same person can be included in several categories.

higher. Interventions related to most deaths are early detection and antibiotic treatment (440 deaths), early detection and treatment (983 deaths), and access to specialized epilepsy service (307 deaths).

Potentially both preventable and treatable mortality is increased for all interventions for persons with ID compared to persons without, e.g. mortality related to improved nutrition and treatment is 5.86 (95% CI, 5.27–6.48) times higher among persons with ID compared to those without ID (Table 3). For improved prevention, early detection, and more effective treatment, mortality is 3.80 (3.57–4.03) times higher. Table 3 also shows that the interventions associated with the most deaths are related to ischemic heart diseases (543 deaths) and cerebrovascular diseases (460 deaths).

Supplementary Table S3 shows deaths not categorized by OECD/Eurostat as preventable or treatable (unavoidable). For all organ systems, there is an excess mortality among persons with ID compared to those without ID. This is particularly pronounced for mental disorders and congenital malformations and chromosomal abnormalities, reflecting the inclusion of mental retardation to varying extents and Down syndrome as causes of death in these groups. For the other organ systems, the absolute difference is most pronounced for neoplasms (both malignant and benign tumors), diseases of the nervous system, diseases of the circulatory system, diseases of the digestive system, and signs and abnormal findings, while the relative differences are pronounced for rarer causes of death, such as endocrine diseases, diseases of the skin and subcutaneous tissue, diseases of the urinary and reproductive systems, and external causes of injury.

Discussion

The aim of this study was to describe mortality by causes of death among persons with ID aged 18–74 years compared to the general Danish population and to elucidate which interventions could potentially decrease any mortality disparities. Among persons with ID, 58% of deaths were potentially avoidable. Excess mortality was highest for persons with severe ID, but mortality was also increased for persons with mild ID compared to those without. Excess mortality was observed for virtually all causes of death, including deaths due to diseases that are potentially preventable (SMR = 2.62) and treatable (SMR = 6.00), as well as unavoidable mortality (SMR = 6.03). Deaths due to diseases that are potentially preventable, e.g. by reducing smoking or alcohol intake or through vaccinations, were particularly increased for persons with mild ID, while deaths due to diseases that are potentially treatable, such as through early detection and optimized treatment, were particularly increased for those with severe ID. Our findings show that interventions aimed at reducing smoking and alcohol intake and reducing accidents are associated with the highest number of potentially preventable deaths. Similarly, interventions focusing on early detection and treatment (e.g. antibiotic) were related to most potentially treatable deaths.

Our findings are consistent with most previous studies on causes of death and avoidable mortality among persons with ID [7–12]. A systematic review from 2018 showed that mortality among persons with ID was elevated for all examined causes of death [11]. An English study showed that deaths can be more attributed to lower quality of treatment of diseases among persons with ID than those without [8], which is consistent with our results where mortality is particularly increased for potentially treatable mortality. This was also observed in a Swedish study showing increased potentially treatable mortality, especially for persons with moderate and severe ID [12]. Our analyses add that excess mortality is also marked for deaths categorized as unavoidable.

In a review, Krahn [1] describes the inequalities as a cascade of disparities reflecting both congenital and co-existing conditions among persons with ID [14, 15], but, importantly, also lacking focus on health promotion, early diagnosis of common diseases, and attendance in screening programs [16, 17], lacking attention to health needs among caregivers who often lack health education [18], and

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Table 2. Potentially avoidable, preventable, treatable, and unavoidable mortality among persons with ID, Denmark, 2000–2020.

	No. of deaths	(%)	Exp	Difference	SMR	(95% CI)
Persons with intellectual disability	9400					
Potentially avoidable mortality	5437	(58)	1505.5	3931.5	3.61	(3.52–3.71)
Preventable mortality	2238	(24)	854.1	1383.9	2.62	(2.51–2.73)
Treatable mortality	1697	(18)	282.8	1414.2	6.00	(5.72–6.29)
Both preventable and treatable mortality	1502	(16)	368.6	1133.4	4.07	(3.87–4.28)
Unavoidable mortality	3963	(42)	657.5	3305.5	6.03	(5.84–6.22)
Mild intellectual disability	3314					
Potentially avoidable mortality	2236	(67)	630.3	1605.7	3.55	(3.40–3.70)
Preventable mortality	1030	(31)	347.6	682.4	2.96	(2.78–3.15)
Treatable mortality	539	(16)	125.1	413.9	4.31	(3.95–4.68)
Both preventable and treatable mortality	667	(20)	157.6	509.4	4.23	(3.92–4.56)
Unavoidable mortality	1078	(33)	282.4	795.6	3.82	(3.59–4.05)
Moderate intellectual disability	1083					
Potentially avoidable mortality	579	(53)	181.9	397.1	3.18	(2.93–3.45)
Preventable mortality	204	(19)	103.0	101.0	1.98	(1.72–2.26)
Treatable mortality	223	(21)	35.6	187.4	6.27	(5.47–7.12)
Both preventable and treatable mortality	152	(14)	43.3	108.7	3.51	(2.98–4.09)
Unavoidable mortality	504	(47)	74.4	429.6	6.78	(6.20–7.38)
Severe intellectual disability	1393					
Potentially avoidable mortality	669	(48)	166.3	502.7	4.02	(3.72–4.33)
Preventable mortality	177	(13)	94.8	82.2	1.87	(1.60–2.15)
Treatable mortality	353	(25)	30.4	322.6	11.60	(10.42–12.84)
Both preventable and treatable mortality	139	(10)	41.1	97.9	3.39	(2.85–3.97)
Unavoidable mortality	724	(52)	71.7	652.3	10.10	(9.38–10.85)

Exp, expected number of deaths; SMR, standardized mortality ratio.

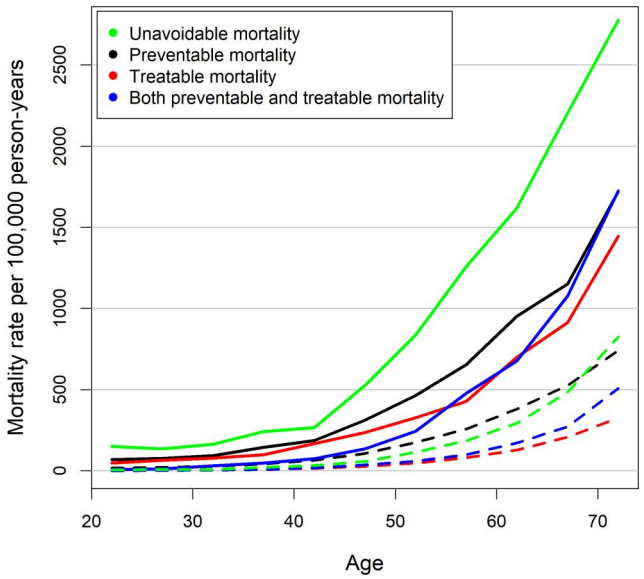


Figure 1. Age-specific mortality for persons with ID (solid lines) and without ID (dashed lines) by unavoidable, preventable, treatable, and both preventable and treatable mortality. Denmark, 2000–2020.

inadequate access to relevant healthcare services [1, 19]. Furthermore, healthcare providers may hold biased views of persons with ID [24]. Therefore a broad health promoting focus is needed among persons with ID including both focus on risk factors, e.g. smoking cessation, improving physical activity, and healthy diet [25–30], as well as participation in screening programs [31, 32], removing barriers for healthcare attendance, and ensuring that care staff assists with sufficient communication when persons with ID interact with the healthcare system [1]. Additionally, scientific evidence supports general systematic health checks among persons with ID, which may lead to detection of unmet health needs, including the identification of serious illnesses and referrals for further investigations [33, 34]. In Denmark, health checks were introduced in 2022 aimed at citizens in residential facilities, where general practitioners are obliged to offer health checks to residents every second year. The health checks aim to prevent loss of function, as well as to diagnose and treat diseases promptly. No information on the long-term effects of health checks is available and it is necessary to monitor the effects on diagnosis, prevention, and treatment, and, eventually, evaluate of effect on premature mortality. Furthermore, specific attention is warranted on prevention and treatment of dysphagia, constipation, falls, and epilepsy and on education, ensuring that doctors, nurses, and educational staff receive special training in communication and treatment of persons with ID [35].

This paper utilizes the OECD/Eurostat categorization of preventable and treatable mortality [13]. This categorization is developed for the general population and is intended to provide an indication of the quality and outcomes of disease management and broader public health policies in a country. Hosking and colleagues [5] argue that the assessment of avoidable mortality is likely underestimated for persons with ID, as the categorization does not include all causes of death that are common in this group and could be avoided with timely intervention. We observed that persons with ID have a significant excess mortality from unavoidable causes of death (SMR = 6.03), which is particularly evident for persons with severe ID (SMR = 10.10).

This paper thus demonstrates excess mortality for persons with ID, encompassing potentially preventable, treatable, and unavoidable causes of death. It applies to persons with mild, moderate, and severe ID. However, the results suggest that the focus for preventing the most deaths may be promoting healthy lifestyles among persons with mild ID, such as preventing alcohol abuse, reducing smoking, promoting physical activity, and to be vaccinated, while for persons with moderate or severe ID, the focus may be on more early diagnosis as well as timely and sufficient treatment. Additionally, the high excess mortality from unavoidable diseases may need further investigation to determine whether many of these deaths among persons with ID could potentially be avoided, or if the excess mortality primarily stems from unavoidable comorbidities associated with ID. It would be naive to expect that social care and healthcare system can completely eliminate the observed differences in survival, regardless of the resources allocated. However, it has been extensively documented that health disparities also reflect lacking focus

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Table 3. Potentially preventable, treatable and both preventable and treatable mortality by intervention for persons with ID, Denmark, 2000–2020.

Intervention	Specific diseases or injuries	No. of deaths	Exp	Difference	SMR	(95% CI)
Potentially preventable mortality						
Reduce smoking		931	410.1	520.9	2.27	(2.13–2.42)
	Lip, oral cavity, and pharynx cancer	47	25.6	21.4	1.83	(1.35–2.40)
	Esophageal cancer	59	28.7	30.3	2.06	(1.57–2.62)
	Lung cancer	317	228.1	88.9	1.39	(1.24–1.55)
	Bladder cancer	49	20.3	28.7	2.42	(1.79–3.14)
	Chronic lower respiratory disease	459	107.4	351.6	4.27	(3.89–4.67)
Reduce alcohol intake	Alcohol-specific disorders and poisoning	395	165.6	229.4	2.38	(2.16–2.63)
Reduce smoking and alcohol intake	Liver Cancer	50	21.4	28.6	2.33	(1.73–3.03)
Reduce smoking and alcohol and improve diet	Stomach cancer	69	27.3	41.7	2.53	(1.97–3.16)
Reduce sun exposure	Skin (melanoma) cancer	26	19.8	6.2	1.32	(0.86–1.87)
Reduce exposure to chemical, gases and other agents	Lung diseases due to external agents	38	1.6	36.4	23.59	(16.69–31.69)
Vaccination	Influenza	34	5.2	28.8	6.48	(4.48–8.84)
Improve water and food safety	Intestinal disease	33	2.1	30.9	15.97	(10.99–21.89)
Other preventable infections	Viral hepatitis and sexual transmitted infections	23	5.6	17.4	4.14	(2.62–6.00)
Road safety measures	Transport accidents	76	31.3	44.7	2.43	(1.92–3.01)
Injury prevention campaigns	Other external causes of accidental injuries	229	35.8	193.2	6.40	(5.60–7.26)
Suicide prevention campaigns	Intentional self-harm	102	60.0	42.0	1.70	(1.39–2.05)
Harm prevention campaigns	Assault	26	8.3	17.7	3.13	(2.04–4.44)
Drug control policies	Drug disorders and poisoning	180	51.3	128.7	3.51	(3.02–4.04)
Potentially treatable mortality						
Early detection and antibiotics treatment	Infectious diseases and pneumonia	440	23.9	416.1	18.44	(16.75–20.20)
Early detection and treatment		983	227.7	755.3	4.32	(4.05–4.59)
	Colorectal cancer	187	92.6	94.4	2.02	(1.74–2.32)
	Breast cancer (female only)	144	73.4	70.6	1.96	(1.65–2.30)
	Uterus cancer and testicular cancer	34	10.9	23.1	3.12	(2.16–4.26)
	Epilepsy including status epilepticus	307	7.2	299.8	42.51	(37.89–47.40)
	Diseases of the digestive system	132	19.3	112.7	6.86	(5.74–8.08)
	Diseases of the genitourinary system	112	11.5	100.5	9.73	(8.01–11.62)
Improved quality of care	Venous thromboembolism and misadventures to patients during surgical and medical care	81	12.0	69.0	6.72	(5.34–8.27)
Appropriate treatment		67	7.2	59.8	9.35	(7.24–11.72)
	Diseases of the respiratory system	62	6.2	55.8	9.92	(7.60–12.54)
Surgical treatment	Congenital malformations of the circulatory system	50	2.0	48.0	25.32	(18.78–32.82)
Early and improved treatment and appropriate antibiotic treatment	Sepsis	76	10.2	65.8	7.48	(5.89–9.25)
Potentially both preventable and treatable mortality						
Vaccination. screening and treatment	Cervical cancer	23	8.8	14.2	2.62	(1.66–3.80)
Improved nutrition and appropriate treatment		362	61.8	300.2	5.86	(5.27–6.48)
	Diabetes mellitus	323	53.1	269.9	6.08	(5.44–6.76)
	Other atherosclerosis	39	8.7	30.3	4.49	(3.19–6.01)
Reduce smoking. increase physical activity. improve treatment	Hypertensive disease	78	24.4	53.6	3.20	(2.53–3.95)
Prevention. early detection and effective treatment		1039	273.6	765.4	3.80	(3.57–4.03)
	Ischemic heart disease	543	155.1	387.9	3.50	(3.21–3.80)
	Cerebrovascular disease	460	98.3	361.7	4.68	(4.26–5.11)

See Supplementary Table S1 for diseases and injuries included for each intervention.
Exp, expected number of deaths; SMR, standardized mortality ratio.

on health promotion, early diagnosis of common diseases, inadequate access to relevant healthcare services [16–19].

Strengths and limitations of the study

Currently, there is no ongoing registration of persons with ID in Denmark. Our study builds upon previous work where we constructed a cohort of persons with ID based on administrative population registration, which occurs both in healthcare settings and in connection with residence and possible allocation of disability pensions [6]. Strengths and limitations of cohort establishment are discussed in a previous paper [6] and only key aspects are highlighted here. It is a strength that the cohort formation is based on multiple sources, increasing the likelihood of identifying persons with ID. Additionally, it is a strength that the sources differ in terms of how individuals are identified and registered. It is also a strength that over 90% of persons with ID are identified with a diagnosis. For the data sources, their primary purpose is not to monitor persons with ID. This may mean that even if persons with ID are in contact with hospitals, the diagnosis of ID may not be recorded. There is

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also a risk that persons with mild ID are not identified, as they may not have received a diagnosis during hospital contact or have needed disability pensions or residential care. On the other hand, the cohort is likely to be more comprehensive for persons with moderate and severe ID, who are more often identifiable through multiple sources.

In the analyses, mortality was assessed based on the underlying cause of death. The validity of the underlying cause of death depends on several factors [23]. There are examples of changes in the coding of causes of death over time, such as increased focus on accurate registration of lung diseases. We assess that this change over time is similar for persons with and without ID and thus will not affect our results. An important limitation is the low proportion of autopsies in Denmark, which has been declining in recent decades. Even for deaths in hospitals, the proportion of autopsies is less than 20%, and it is also low for sudden deaths outside hospitals [23]. Previous studies have shown that causes of death without autopsy may be subject to errors. There are no validation studies of cause of death registration among persons with ID and it has been suggested that assessment of causes of death for persons with ID is challenging [11].

This paper focuses on persons aged 18–74 with ID. We exclude children and young people under 18 years as we aim to focus the analyses on causes of death and interventions (both prevention and treatment) targeted at adults, as preventive and treatment interventions among adults often have a different focus than interventions among children and young people. It would be relevant in future work to analyse avoidable mortality among children and young people. We also exclude persons over 74 years as the OECD/Eurostat categorization of avoidable and unavoidable deaths excludes persons over 74 years [13].

Perspectives

This study adds to the literature that persons with ID is a vulnerable group with limited ability to communicate and respond to health needs, thus reliant on proper assistance from society. The results indicate a need for enhanced efforts at multiple levels, as persons with ID have a markedly increased mortality risk from causes that, with proper help, should not lead to death in a country with a strong and high-performing healthcare system as in Denmark.

Finally, in many high-income countries deinstitutionalization of persons with ID happened during the 1970s and 1980s, which may have influenced avoidable mortality [35, 36]. Deinstitutionalization improved the rights of persons with ID as well as broader inclusion in society. However, due to insufficient focus and education in the social and healthcare systems, deinstitutionalization was followed by inadequate access to health promotion and healthcare. This highlights the need for reasonable adjustments to reduce barriers for equal access to healthcare for people with ID.

In conclusion, this study confirms that persons with ID have a marked increased mortality virtually for all causes of death, including deaths due to diseases that are potentially preventable and treatable, as well as deaths deemed unavoidable. There is an exigent need for health policy reforms, competence development of healthcare personnel, and reasonable adjustment making it as easy for people with ID to access health promotion programs and healthcare services as it is for others.

Supplementary data

Supplementary data are available at *EURPUB* online.

Conflict of interest: none declared.

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Data availability

Data may be obtained from a third party and are not publicly available.

Key points

- Persons with intellectual disabilities face pronounced health disparities and marked higher mortality compared to the general population.
- In this cohort study, we examined potentially avoidable mortality in a nationwide cohort of adults with intellectual disability and compare it to a matched reference population.
- Potentially preventable deaths, e.g. by reducing smoking and alcohol intake or by vaccination, was 2.62 times higher, potentially treatable deaths, e.g. by earlier diagnosis and treatment, was 6.00 times higher, while unavoidable mortality was also six-fold higher among persons with intellectual disability compared to the reference population.
- The study shows marked increased avoidable mortality which highlights a need for competence development of social care and healthcare personnel and reasonable adjustment of health promotion programs and healthcare services for people with ID.

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