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Patterns in the prevalence of diabetes and incidence of diabetic complications in people with and without an intellectual disability in Dutch primary care: Insights from a population-based data-linkage study

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ABSTRACT

Aims: To conduct an epidemiological analysis of patterns observed in diabetes care provided to individuals with and without intellectual disabilities (ID) in primary care settings.
Methods: An ID-cohort (N = 21,203) was compared with a control group of similar age and sex from the general Dutch population (N = 267,628). Distinctive data for diabetes (both type 1 and type 2) and related complications were retrieved from national databases.
Results: The prevalence of diabetes was higher in people with ID than in the general population (9.9% versus 6.6%). Largest differences were seen in younger age groups. Women with ID had diabetes more often than men with ID. Complications were less common in people with ID than in the general population (IR 58.6 vs. 70.4). In particular, cardiological complications were noted less, while surgical interventions and hospitalization occurred more often.
Conclusions: Although diabetes was 1.5 times more prevalent in people with ID than in other people, related complications were less common, followed different patterns and were more severe than in the general population. Future research is needed to understand of the underlying causal mechanisms and to lower the risk of severe diabetic complications among people with ID.

1. Introduction

Approximately 1.5% of the population in Western countries has an intellectual disability (ID), defined by having significant limitations in both intellectual functioning and in adaptive behavior, affecting everyday social and practical skills, and originating before the age of 18 [1–3]. Multimorbidity is common in people with ID, with diabetes among its prominent contributors [4]. Many countries, including The Netherlands, promote community living arrangements for people with ID and offer them the same primary and community care as available to the general population, including for the purpose of diabetes management [5]. While the ID population already faces unique and significant health problems, little is known on the impact of diabetes in this group [6,7]. Moreover, individuals with ID are difficult to identify within population data to allow large scale health monitoring and to inform tailored (diabetes) management strategies 8.

Previous studies that tried to estimate basic insights such as the prevalence of diabetes among people with ID encountered methodological limitations such as small samples and difficulties in generalizing findings from subgroups with specific ID diagnoses to the ID population at large [7,9–15]. Prevalence rates have been found to range between 0.4 and 25%, and have been inconclusive as to whether diabetes is more prevalent than in the general population [7,16]. However, commonly observed diabetes-related risk factors such as unhealthy lifestyles and metabolic effects of psychotropic drug use, contribute to the shared belief that diabetes is more prevalent in people with ID than in the general population [17–21]. Also, hospitalizations due to diabetes-associated complications have been seen more than three times as often than in the general population in some settings [21,22].

Abbreviations: GenPop, general population; ID, intellectual disabilities; IR, incidence rate; PY, person years.

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The uncertainties in previous diabetes research warrant more large-scale studies at the ID population level in order to better inform clinical practice [7,16]. As such, comparing diabetes prevalence rates, incidence of complications, and underlying patterns between people with and without ID can point at potential disparities like they have been identified in many other areas of health [6]. The aim of this study is therefore to determine the prevalence of diabetes and incidence of diabetes-related complications in people with ID compared to the general Dutch population.

2. Material and methods

2.1. Data sources and linkage

A basic statutory health insurance system covers essentially all primary and hospital care for 99.9% of the Dutch population [23]. Healthcare providers use standardized coding for diagnoses and treatments when they submit claims to health insurance companies for reimbursement. General practitioners (GPs) also receive a (small) reimbursement from the health insurer for administrative tasks such as maintaining individual patient records, even if the patient does not visit the GP. Vektis, the Dutch Healthcare Information Centre, routinely collects claims data from all Dutch health insurance companies and has access to other national registries such as the database containing prescribed medications, and the Chronic care database [2,24]. Data for this study were retrieved by representatives of Vektis from these national databases to generate a population-based historical cohort with a five-year follow up (2012–2016). Data was aggregated into ten-year age groups to ensure patients' privacy, before data was shared with the research team. The study protocol was reviewed by the Radboud university medical center institutional Ethics Committee who passed a positive judgment (2017–3921). We report our results in accordance with the STROBE statement [25].

2.2. Study population

The ID-cohort consisted of Dutch individuals of all ages who were alive on January 31, 2012, were entitled to chronic care due to being formally diagnosed with ID and whose health insurance data indicated use of the same primary and hospital healthcare as the general population. We used a general population comparison cohort that was initially matched (1:4 ratio) by age and sex with all individuals with ID making use of chronic care facilities, including those without GP visits as their primary care was integrated in their chronic care arrangements. Since this study focused on the primary care setting, our control group did not precisely match the selected ID-group anymore, but it did not change the similar distribution in age and sex in both groups. This cohort has been used for comparative studies between people with and without ID before [26,27]. All individuals with retrievable health data were enrolled for further analyses (Fig. 1).

2.3. Outcome measures

The main outcome was a history of diabetes in the Vektis databases at any point between January 1, 2012 and December 31, 2016. The presence of diabetes was identified through either a diagnostic code containing diabetes or medication use indicative for diabetes. The in- and exclusion criteria for the diagnosis of diabetes, both type 1 and type 2, are presented in Appendix 1, and have been used before by Vektis to report on the characteristics of Dutch diabetes care. [28] Given the nature of this data, type 1 and type 2 diabetes could not be disentangled.

Diabetic complications were defined as an incident case of hospital care, for which the diagnostic code appeared on a pre-defined list with the most common diabetes-associated complications (Appendix 2). These complications and their diagnostic codes were also taken from the earlier Vektis investigation into Dutch diabetes care and consisted of retinopathy, diabetic foot, hospitalization due to diabetes at the internal medicine department, and a cardiological complication of any kind. [28] A complication was considered an incident case if no registration of the same complication was found in the previous year. Complications were only reviewed for those participants identified with diabetes and who were thus at risk for a diabetic complication, and for the same period of time (2012–2016).

2.4. Data analysis

The prevalence of diabetes in both cohorts was calculated as the total number of people identified with diabetes at any point during follow-up divided by the total number of people alive at the start of follow-up. Corresponding 2×2 tables were analyzed by means of a Chi-square test with P-values <0.05 indicating statistically significant differences.

Incidence rates (IR) of diabetes-associated complications per 1000 person-years (PY) were calculated by dividing incident complications by the PY generated in the analyzed group. PY reflect the number of people being alive per year plus 0.5 times the number of people who deceased per year, under the assumption that mortality was equally distributed over the year. Incidence rate ratios were calculated by dividing IRs from both cohorts and presented with a 95% confidence interval.

Using aggregated tables as generated by Vektis, separate analyses were conducted per sex and age group. Statistical analyses were conducted in Microsoft Office Excel 2016 and in OpenEpi, open-source software for epidemiological statistics in public health [29].

3. Results

Complete data was available for 21,203 individuals with an ID and 267,628 individuals from the general Dutch population (GenPop) (Fig. 1). Distribution across sex and age groups was comparable between both cohorts (Table 1).

3.1. Diabetes prevalence

The overall prevalence of diabetes in people with an ID was higher compared to the prevalence in the general population (9.9% versus 6.6%, $p < 0.001$; Table 1). Prevalence increased with age for males and females from both cohorts and peaked in the age group of 70–79 years, except for females from the general population for whom this peak appeared in the age group 80 years and older. Females with an ID had higher prevalence rates than males with an ID in all age groups, except for the age group 80 years and older. In the GenPop-cohort, males had higher prevalence rates than females in most age groups (Table 1). Differences in prevalence between the ID and GenPop-cohorts were greater in younger age groups compared to older age groups and greater for females than for males. For young males with ID (up to 50 years of age) prevalence rate were twice as high compared to young males without ID (1.4–9.0% versus 0.6–5.0%), and three times as high for females in the same age groups this was three times as high (2.6–11.4% versus 0.7–3.7%) (Table 1).

3.2. Overall incidence of complications

Incidence of diabetes-related complications was lower in the ID-cohort (IR 58.60) compared to the GenPop-cohort (IR 70.36; IR ratio 0.83, 95% CI 0.76–0.91). IRs were consistently lower for people

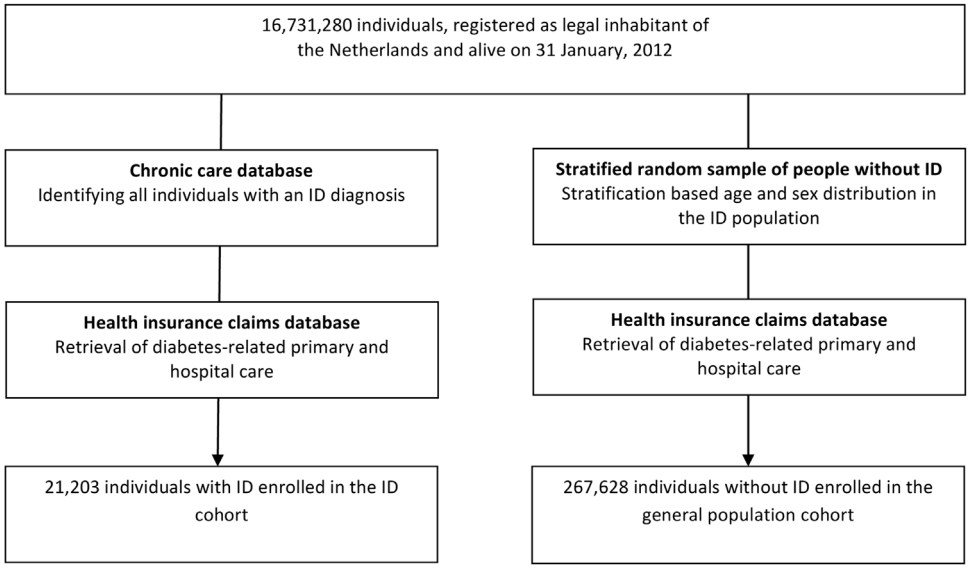

Fig. 1. Selection of cohorts of people with ID and the general population.

Table 1
The prevalence of diabetes in people with ID and the general population in the Netherlands between 2012–2016, per sex and 10-year age categories.

	People with ID			General population		
	N (%)	Diabetes, n	Prevalence, %	N (%)	Diabetes, n	Prevalence, %
Total	21,203 (100%)	2101	9.9	267,628 (100 %)	17,761	6.6*
Males	11,468 (54.1%)	1021	8.9	151,028 (56.4 %)	10,476	6.9**
Females	9735 (45.9%)	1080	11.1	116,600 (43.6 %)	7285	6.3*
Males, 0–29 years	3698 (32.2%)	51	1.4	47,364 (31.4 %)	299	0.6*
30–39	1793 (15.6%)	84	4.7	21,324 (14.1 %)	399	1.9*
40–49	2063 (18.0%)	185	9.0	28,184 (18.7 %)	1417	5.0*
50–59	2054 (17.9%)	296	14.4	28,004 (18.5 %)	3011	10.8*
60–69	1274 (11.1%)	260	20.4	17,848 (11.8%)	3324	18.6
70–79	496 (4.3%)	125	25.2	6644 (4.4%)	1635	24.6
≥80	90 (0.8%)	20	22.2	1660 (1.1%)	391	23.6
Females, 0–29 years	3153 (32.4%)	83	2.6	33,520 (28.7%)	243	0.7*
30–39	1436 (14.8%)	96	6.7	15,360 (13.1%)	269	1.8*
40–49	1764 (18.1%)	201	11.4	21,816 (18.7%)	811	3.7*
50–59	1664 (17.1%)	270	16.2	22,016 (18.9%)	1834	8.3*
60–69	1122 (11.5%)	277	24.7	14,868 (12.8%)	2167	14.6*
70–79	446 (4.6%)	127	28.5	6588 (5.7%)	1407	21.4*
≥80	150 (1.5%)	26	17.3	2432 (2.1%)	554	22.8

Statistical significance refers to the test of differences in prevalence between the ID and general population.
* $p < 0.05$.
** $p < 0.001$.

Table 2
Incidence rates and incidence rate ratios of complications of diabetes for the PID-group and the general population in the Netherlands between 2012–2016. Results are presented across the demographic variables of sex (male/female) and age (determined on 31 July 2012) in categories of 0–59 years and 60 years and above.

	People with ID			General population			Incidence rate ratio (95% CI)
		Person years	Complications, n	Incidence rate, per 1000 PY	Person years	Complications, n	Incidence rate, per 1000 PY	
Total	All ages	8328	488	58.60	72,442	5097	70.36	**0.83 (0.76–0.91)**
	0–59 years	5054	241	47.69	33,044	1843	55.77	**0.85 (0.75–0.98)**
	≥60	3274	247	75.44	39,398	3254	82.59	0.91 (0.80–1.04)
Males	All ages	3969	278	70.04	42,565	3234	75.98	0.92 (0.82–1.04)
	0–59 years	2424	148	61.06	20,388	1265	62.05	0.98 (0.83–1.17)
	≥60	1545	130	84.14	22,177	1969	88.79	0.95 (0.79–1.13)
Females	All ages	4359	210	48.18	29,877	1863	62.36	**0.77 (0.67–0.89)**
	0–59 years	2630	93	35.36	12,656	578	45.67	**0.77 (0.62–0.96)**
	≥60	1729	117	67.67	17,221	1285	74.62	0.91 (0.75–1.10)

For the first year of follow up (2012) it could not be determined if a complication was a new incident case, or pre-existing from previous year(s).
Data are presented in larger age groups to avoid presenting cells with less than ten individuals.
IR ratios that are statistically significant different from 1 are presented in bold.

with ID across all age groups and for both sexes as compared to the general population. The largest difference between the ID and GenPop cohorts was observed in females below 60 years of age (IR ratio 0.77, 95% CI 0.62–0.96). Most complications were counted in the age group of 60 years and above in both cohorts (ID IR = 75.44 versus GenPop IR = 82.59), resulting in an IR ratio in this age group of 0.91 (95% CI 0.80–1.04) (Table 2).

3.3. Incidence of complications per type

Most diabetic complications were of cardiological nature in both cohorts (ID IR = 31.46 versus GenPop IR = 48.69), followed by retinopathy (ID IR = 19.21 versus GenPop IR = 20.18). Retinopathy occurred equally often in both cohorts (IR ratio 0.95, 95%CI 0.81–1.12) and cardiological complications were less common in the ID-cohort compared to the general population (IR ratio 0.65, 95%CI 0.57–0.73). Both diabetic foot (IR ratio 1.87; 95%CI 1.41–2.49) and hospitalization (within internal medicine) occurred more often in the ID-cohort compared to the general population (IR ratio 1.83; 95%CI 1.34–2.49; Table 3). Diabetic foot was more common for males with ID than for females with ID (males IR = 9.57 versus females IR = 4.36), and hospitalization occurred more often in females with ID than in males with ID (females IR = 6.19 versus males IR 5.54).

4. Discussion

In this population-based cohort study, we found the prevalence of diabetes in routine primary care to be 1.5 times higher among Dutch individuals with ID, compared to those without ID. Within the ID-cohort, females had higher prevalence rates than males in most age categories, whereas a reversed pattern was seen in the general population. With increasing age, differences in prevalence between the ID and general population cohort decreased. Although the prevalence rates of diabetes were higher for people with ID, they received less care for diabetic complications. In particular, complications of cardiological nature occurred far less in people with ID compared to people without ID. Other complications, such as diabetic foot or hospitalization occurred in different patterns among males and females with ID, while these patterns were more alike between males and females in the general population.

This is the first study to provide an epidemiological analysis with national data on the impact of diabetes in people with ID who are being managed in the same primary care setting as people from the general population. In an earlier study, De Winter et al. screened 1050 older Dutch individuals in ID care settings, and reported that the diabetes prevalence did not differ from the prevalence in the general Dutch population of the same age [9]. The present study indicates that differences in diabetes prevalence between people with and without ID in the primary care setting are larger at younger age and become smaller at older age. High diabetes prevalence rates at young age in the ID population could be explained by a larger proportion of diabetes Type 1 or overexposure to risk factors such as obesity [21,30,31]. Another explanation for the earlier onset of diabetes could be that blood glucose in individuals with ID is tested more often and at a younger age, because 1) there generally are more (routine) doctor visits than by people without ID, providing more opportunities to test, and 2) psychotropic drug use requires regular glucose testing for monitoring metabolic side effects and proper medication management [32,33].

Our finding that females with ID had higher diabetes prevalence rates than males with ID is in line with results from several previous international studies [9,20,21]. Although a higher prevalence of diabetes among males with ID was also to be expected due to more frequent use of psychotropic drugs [34,35]. A possible explanation for the current findings could be that BMI levels among females with ID are often higher compared to males with ID [36]. Further research to explain sex differences in diabetes risks is therefore required and could help to better tailor diabetes prevention and management programs in ID settings.

People with ID, in particular females, were more likely to be administered to the hospital due to diabetic complications, and confirm earlier concerns about this. [21] However, the low overall rate of complications in the ID-cohort compared to the general population despite a higher prevalence could point at impaired access to timely and adequate care. There is ample evidence from the Netherlands and other countries indicating impaired quality of care is being provided to the ID population, in particular in relation to the recognition of cardiovascular risks which aligns with the number of complications reported in the current study [15,37–41]. It is unknown to what extent the present diabetes and cardiovascular risk management guidelines in primary care meet the specific needs of people with ID. The current results highlight the importance of further investigation into appropriate diabetes care for people with ID.

Although this was the first epidemiological study to determine the prevalence of diabetes and incidence of related complications using population-data in the Netherlands from the same primary care setting, some limitations need to be addressed as well. Firstly, for the ID-cohort we only included users of primary care services who were known with ID in the Chronic care act database. Individuals with ID who did not call upon (medical, residential, or social) support from the Chronic care act, or whose disability did not comply with the formal ID definition (e.g. mild ID and low IQ groups) were not included in this study. There is evidence, however, that these groups are even more exposed to cardiovascular risks and have a poorer overall health [9,42]. Results presented in this study could therefore even be an underestimation of the diabetes burden in this broader defined population of mentally challenged individuals. It also should be noticed that since our control group was a stratified sample, the prevalence detected in this group does not reflect the prevalence for the entire Dutch population, but gives the prevalence for a group comparable to the ID population. A second limitation is the use of routine administrative data for research purposes. Although this provided insights in patterns at the population level, availability of demographic variables was limited to sex and age, and it was therefore not possible to differentiate between diabetes types, level of ID, or comorbidity levels. Future (clinical) studies are needed to provide insights into pathogenesis and other causal mechanisms.

4.1. Conclusions

This epidemiological analysis with population-data showed that diabetes patients with ID experienced fewer diabetic complications, but required hospitalization or surgical interventions more often compared to other people with diabetes. With diabetes being 1.5 times more prevalent than in people without ID, these findings suggest that people with ID may be at risk for delays in diagnosing and treatment of diabetic complications. Further research is needed to better understand the underlying causal mechanisms, tailor diabetes management routines and reduce the risk of severe diabetic complications among people with ID.

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Table 3
Incidence rates and IR ratios of specific complications PID-group and the general population at risk for diabetic complications between 2012–2016.

Type of complication		People with ID			General population			Incidence rate ratio (95% CI)
		Person years	Complications, n	Incidence rate, per 1000 PY	Person years	Complications, n	Incidence rate, per 1000 PY	
Retinopathy (Ophthalmology)	**Total**	8328	160	19.21	72,442	1462	20.18	0.95 (0.81–1.12)
	Males	3969	87	21.92	42,565	913	21.45	1.02 (0.82–1.27)
	Females	4359	73	16.75	29,877	549	18.38	0.91 (0.71–1.16)
Diabetic foot (Surgery or orthopeadics)	**Total**	8328	57	6.84	72,442	265	3.66	**1.87 (1.41–2.49)**
	Males	3969	38	9.57	42,565	175	4.11	**2.33 (1.64–3.31)**
	Females	4359	19	4.36	29,877	90	3.01	1.45 (0.88–2.37)
Diabetes-related hospital admission (Internal Medicine)	**Total**	8328	49	5.88	72,442	233	3.22	**1.83 (1.34–2.49)**
	Males	3969	22	5.54	42,565	155	3.64	1.52 (0.97–2.38)
	Females	4359	27	6.19	29,877	78	2.61	**2.37 (1.53–3.68)**
Cardiology (all diagnoses)	**Total**	8328	262	31.46	72,442	3527	48.69	**0.65 (0.57–0.73)**
	Males	3969	152	38.30	42,565	2253	52.93	**0.72 (0.61–0.85)**
	Females	4359	110	25.24	29,877	1274	42.64	**0.59 (0.49–0.72)**

Person-years have been generated for individuals at risk for diabetic complications (i.e. individuals who have been identified with diabetes.
IR Ratios that are statistically significant different from 1 are presented in bold.

Contribution statement

MC, GL, and JN designed the study. MC and ML conducted the statistical analyses, after which GL, EB, KP, MM, and JN contributed to interpretation of the data. All authors contributed to drafting the article and provided important intellectual content. All authors have approved the final version, and GL had final responsibility for the decision to submit for publication.

Conflicts of interest

We declare that we have no conflicts of interest.

Data availability

This study used existing data that was obtained upon request from Vektis and is subject to license restrictions. Procedures to request data can be found at www.vektis.nl. Aggregated data supporting the findings of this study are available from the corresponding author (MC) upon request.

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Appendix 3 Supplementary data

Supplementary material related to this article can be found, in the online version, at doi:https://doi.org/10.1016/j.pcd.2020.11.012.

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