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Tic disorders: Administrative prevalence and co-occurrence with attention-deficit/hyperactivity disorder in a German community sample

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ABSTRACT

Coexistence of tics and attention-deficit/hyperactivity disorder (ADHD) has important clinical and scientific implications. Existing data on the co-occurrence of tic disorders, Tourette Syndrome (TS), and ADHD are largely derived from small-scale studies in selected samples and therefore heterogeneous. The Nordbaden project captures the complete outpatient claims data of more than 2.2 million persons, representing 82% of the regional population in 2003. Based upon the number of diagnosed cases of tic disorders, TS, and ADHD, we determined 12-months administrative prevalence rates as well as rates of co-occurrence. Both tic disorders and ADHD were diagnosed most often in the age group 7–12 years (any tic disorder: 0.8%; ADHD: 5.0%). With increasing age, the administrative prevalence difference in favor of males disappeared, with tic disorders being somewhat more frequently reported in females than males in the age groups above 30 years. The highest rate of ADHD co-occurring with tic disorders was found in adolescents (age 13–18 years, 15.1%). Tic disorders were observed in 2.3% of patients with ADHD. Administrative prevalence rates of tic disorders and TS were substantially lower compared to rates found in community-based epidemiological studies, suggesting that a large number of cases remain undetected and untreated under present conditions of routine outpatient care.

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Tic disorders are neuropsychiatric disorders of childhood onset that are characterized by the presence of motor and/or vocal tics. Tics are sudden, repetitive motor movements or phonic productions that involve discrete functional muscle groups and vary in their anatomical location, intensity, frequency and complexity [16]. The combination of motor and vocal tics lasting longer than one year is called Tourette Syndrome (TS). In contrast to the anatomically circumscribed tic movements, attention-deficit/hyperactivity disorder (ADHD) is characterized by a more general hyperactivity present in at least two settings before age 7 [1]. First tics often arise 2–3 years after the onset of ADHD [16]. The frequent coexistence of tic disorders and ADHD is of high clinical and scientific importance, because the presence of ADHD exerts a strong influence on the burden of disease in patients with tic disorders [9,12,21,24–27,30]. Furthermore, the coexistence of tics and ADHD has also implications for treatment choice e.g. because

of concerns about induction of first-onset tics or increase in severity of coexisting tics in patients taking stimulants [28]. Prevalence rates [22,23] and mechanisms of this coexistence are the subject of ongoing research and debate [2].

In contrast to the increasing consensus about the worldwide prevalence of ADHD of about 5% [20], the prevalence of tic disorders has been estimated in a broad range from 3.4% to 24.4% among children and adolescents, with TS affecting between 0.43% and 3.8% of school children between the ages of 6 and 17 [21]. The reasons for the difficulty to quantify the prevalence of tic disorders are diverse, e.g. different previous and present definitions of TS, their individually waxing and waning course and the common remission of tics with increasing age [22,23]. In addition, different methods used to collect data (e.g., interview, examination, etc.) contribute to inconsistent findings between studies.

ADHD as the most frequently encountered psychiatric condition in children and adolescents has been reported to be associated in about 20% with tic disorders [29]. International studies have found ADHD to occur in 55 to 60% of patients with TS referred to specialized centers [10,11]. These figures (as well as the present

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data) may however be inflated by referral and Berkson's bias¹ [2,3]. But coexistence of tic disorders and ADHD is not a phenomenon of clinic patients only but can also be found in the general population [39].

To date there is no study on the prevalence of tic disorders in a large epidemiological sample across all age groups. This also applies to the prevalence of the practically relevant coexistence of tic disorders and ADHD. Hence, available data on prevalence rates are limited to specific subpopulations, and vary according to sample characteristics such as age, sex, type of school attended, etc. [22,23].

Our present report extends the existing epidemiological data by providing, for the first time, information on the "administrative prevalence" of tic disorders and Tourette syndrome in a large regional sample, covering all persons insured by Statutory Health Insurance (SHI) in Nordbaden, Germany. Administrative prevalence rates can be retrospectively derived from secondary data such as the Nordbaden database (cf. *Methods*, below). They describe diagnosis rates reported in real-world settings, implying that the underlying diagnostic process reflects actual clinical practice, not a standardized clinical algorithm. Patients must have come to the attention of a service provider in order to be identified. These limitations are inevitably associated with the study design and may be seen as a disadvantage; importantly, research based on claims data may yield insights complementing the results of epidemiological studies. On the other hand, advantages of using a comprehensive claims database include the size of the sample and its representativeness [34].

Additionally, our analyses provide for the first time cross-sectional information over all ages probably reflecting the high remission of tics with increasing age. Furthermore, the rates of the coexistence of tic disorders and ADHD are presented from both directions, i.e. frequency of ADHD in the group of patients suffering from any tic disorders as well as the rate of tics in the group of patients suffering from ADHD.

1. Methods

Nordbaden is a region in the Southwest of Germany with a population of 2.723 million in 2003, 82.2 percent of which ($n = 2.238$ million) are covered by Statutory Health Insurance (SHI). The SHI system provides comprehensive coverage of medical services, without co-payments by children and adolescents below the age of 18 years, and with only moderate out-of-pocket payments required from adults, which are further capped by a social hardship clause. In 2003, physician services were reimbursed on a fee-for-service basis, making underreporting unlikely and hence justifying the expectation that identified cases were indeed reported.

The Nordbaden database comprises the complete outpatient claims data of 2.238 million lives during the four quarters of calendar year 2003, i.e., the total regional population insured by SHI [31,32]. Key sociodemographic population characteristics including age and gender were broadly similar to Germany as a whole [31], with the notable exception of a relatively higher number of physicians in private practice in Nordbaden (in total, 219/100,000 persons insured by SHI, compared to 181/100,000 in Germany). For specialists in child and adolescent psychiatry, the ratio was even 1.3 doctors/100,000 insured persons in Nordbaden versus 0.7/100,000 in Germany as a whole.

For retrospective analysis, all persons with a reported diagnosis of a tic disorder in 2003 were selected (any ICD-10 code of the F95

group; WHO, 1992), and patients with combined chronic vocal and multiple motor tic disorder (Tourette syndrome, F95.2) were identified. Similarly, all patients were screened for a diagnosis of ADHD (ICD-10 codes F90.0 and F90.1 for "hyperkinetic disorder" and "hyperkinetic conduct disorder", respectively; cf. [32]). On this basis, 12-months-year-prevalence rates of any tic disorder, TS and ADHD were determined for the total regional population covered by SHI. Period prevalence estimates were calculated with the numerator defined as the sum of all patients with at least one respective diagnosis during any one of the four quarters, and the denominator defined as the stable total population insured by SHI during the period of observation.

In a similar way, prevalence rates were computed for the referred samples of "primary care physicians" (here defined to comprise general practitioners, specialists for internal medicine acting as family doctors, and pediatricians) and "medical specialists" (considering the symptoms of tic disorders, broadly defined here to include psychiatrists, neurologists, otorhinolaryngologists, and ophthalmologists, in addition to child and adolescent psychiatrists). Finally, patients with both diagnoses (any tic disorder or TS plus ADHD) were identified to determine rates of co-occurrence.

Of note, in the present study we interpret reported diagnoses of "hyperkinetic (conduct) disorder" (ICD-10 codes F90.0 and F90.1) as attention-deficit/hyperactivity disorder (ADHD), despite the somewhat different diagnostic criteria. Our approach is supported by the observed prevalence rates (see results) and by an ad hoc survey we conducted with a convenience sample of six German pediatricians, who without exception confirmed that they adhered to DSM-IV diagnostic criteria for ADHD, while being required by the administrative system to code according to ICD-10 (for a discussion, please see Schlander et al. [32]).

2. Results

The administrative prevalence rates of tic disorders, TS, and ADHD observed in Nordbaden (2003) are summarized by age and gender in Table 1. They reflect the number of diagnoses reported by physicians to obtain reimbursement for services provided. For all three diagnoses, i.e. any tic disorder, TS, and ADHD prevalence rates were highest among children aged 7 to 12. Fig. 1 clearly shows an increase in diagnosed tic disorders around ages 3–6 years and a decrease around ages 10–16 years. In general, males were more often diagnosed than females with any of the three disorders under study; however, this difference disappeared with increasing age, even reverting in patients aged 50 years or more. Interestingly, female patients above age 30 received more often a diagnosis of a tic disorder than males of same age.

For children, the rate of patients with any tic disorder was slightly higher among the sample seen by primary care physicians, whereas adolescent and adult patients with any tic disorder were seen more often by medical specialists (Fig. 1). Of note, the overall rate of patients with any tic disorder was comparable among the sample referred to specialists compared to the patients referred to primary care physicians.

Detailed prevalence findings for ADHD in the present sample were reported earlier [32].

Among children (up to age 12 years), 11.2% of the patient group with any tic disorder (boys, 15.0%; girls, 4.5%) received an additional diagnosis of ADHD compared to 3.1% (boys, 4.4%; girls, 1.7%) of the same age group of the whole population covered by SHI in Nordbaden. Among adolescents (age 13 to 18 years), a diagnosis of ADHD was more than tenfold more likely in patients with any tic disorder (overall rate, 15.1%; boys, 18.5%; girls, 7.7%) compared to adolescents within the general community insured by SHI (1.5%; boys, 2.3%; girls, 0.7%). Correspondingly, also in patients with

¹ The Berkson's bias is the higher mathematical chance to be referred: referral rate for disorder A + referral rate for disorder B. Referral bias mostly reflects the higher rate of referral due to higher impairment in case of two disorders (A + B).

Table 1

Prevalence by age and gender of tic disorders and ADHD (in Nordbaden, Germany 2003; with a population of 2.2 million persons covered by Statutory Health Insurance, SHI).

Age group [years/gender]	Prevalence of any tic disorder		Prevalence of Tourette syndrome		Prevalence of ADHD		Population n
	(%)	n	(%)	n	(%)	n	
0-6	0.52	778	0.007	10	1.26	1893	150,476
hereof:							
male	0.58	452	0.008	6	1.72	1331	77,386
female	0.45	326	0.005	4	0.77	562	73,090
7-12	0.79	1127	0.040	57	4.97	7046	141,857
hereof:							
male	1.05	765	0.060	44	7.16	5220	72,901
female	0.52	362	0.019	13	2.65	1,826	68,956
13-18	0.22	337	0.038	57	1.49	2242	150,711
hereof:							
male	0.30	233	0.057	44	2.26	1744	77,334
female	0.14	104	0.018	13	0.68	498	73,377
19-29	0.06	168	0.009	26	0.10	287	288,011
hereof:							
male	0.07	99	0.017	24	0.14	195	140,920
female	0.05	69	0.001	2	0.06	92	147,091
29-49	0.07	457	0.006	40	0.04	297	682,570
hereof:							
male	0.06	182	0.008	26	0.05	161	325,519
female	0.08	275	0.004	14	0.04	136	357,051
50+	0.09	751	0.003	25	0.01	110	824,835
hereof:							
male	0.08	279	0.003	12	0.01	47	351,334
female	0.10	472	0.003	13	0.01	63	473,501
Total	0.16	3618	0.010	215	0.53	11,875	2,238,460
hereof:							
male	0.19	2010	0.015	156	0.83	8698	1,045,394
female	0.13	1608	0.005	59	0.27	3177	1,193,066

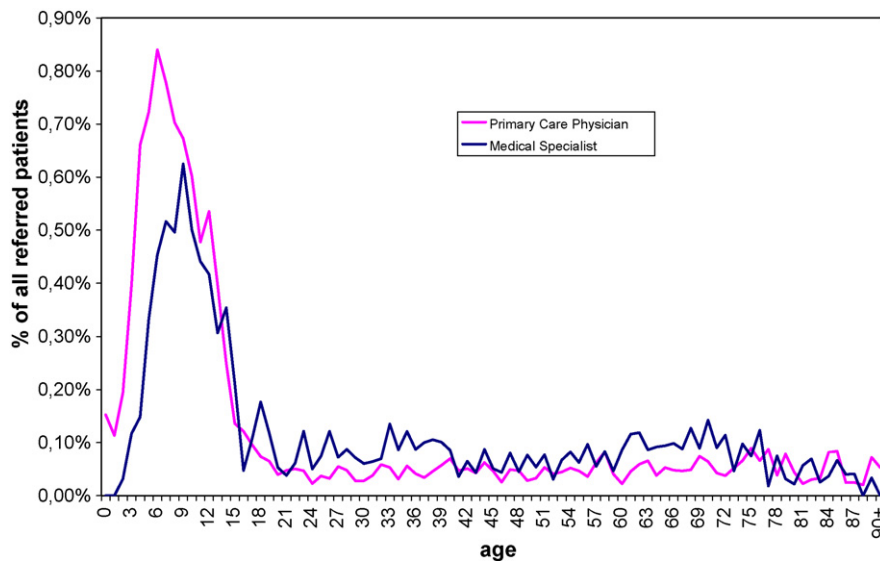


Fig. 1. Age-specific prevalence of tic disorders among referred patient samples in Nordbaden, Germany, 2003: (a) among patients seen by “primary care physicians”; (b) among patients seen by “medical specialists” (for definitions of physician groups, cf. *Methods*).

ADHD the rate of tic disorders was higher compared to the community reference group matched by age and gender, reaching 2.4% in children (up to age 12 years) and 2.3% in adolescents (age 13 to 18 years) with ADHD (compared to 0.7% and 0.2%, respectively, in the general population of SHI-insured patients; cf. *Table 1*). Thus a diagnosis of any tic disorder was more than 10 times more likely in adolescents with ADHD than in the age-matched general population, and, again, the association was more pronounced in males compared to females (*Table 2*).

3. Discussion

For the first time, administrative prevalence rates of any tic disorder and TS were analyzed in a large sample, covering 82.2 percent of the regional population in Nordbaden, Germany, and comprising all age groups. The present data are in agreement with the remitting course of tics and TS over the lifetime that has been shown by a few studies with a maximum follow-up period of 20 years [8,22].

Table 2
Coexistence of tic disorders and ADHD in Nordbaden, Germany 2003: absolute number of patients and relative share of patient group with any tic disorder and ADHD.

Age group	Any tic disorder and ADHD	Any tic disorder in patients with ADHD	ADHD in patients with any tic disorder
[years/gender]	<i>n</i>	(%)	(%)
0–12	214	2.39	11.23
hereof:			
male	183	2.79	15.04
female	31	1.30	4.51
13–18	51	2.27	15.13
hereof:			
male	43	2.47	18.45
female	8	1.61	7.69
19+	4	0.58	0.29
hereof:			
male	3	0.74	0.54
female	1	0.34	0.12
Total	269	2.27	7.44
hereof:			
male	229	2.63	11.39
female	40	1.26	2.49

Although the present data are limited due to their cross-sectional nature [15], the apparent decline in the administrative prevalence of tic disorders from childhood to late adulthood adds important information to the available data about the natural course of tic disorders. Another finding might be in line with an improvement of tics with increasing age: in contrast to children, in adults the diagnosis of a tic disorder is made more often by a medical specialist than by a primary care physician. This supports the assumption that especially tic disorders diagnosed by primary care physicians in childhood and adolescence often decrease in severity below the diagnostic threshold [7], but many adults might still have persistent tics [18]. Additionally, the finding that peak of diagnostic frequency in medical specialists is almost 3–4 years later than that of primary care physician, indicates more adequate referral over time.

The about 10-fold lower prevalence rate of TS compared to that of all tic disorders is in accordance with previous findings in non-specialized samples [39]. Additionally, the observed decrease of the male predominance in tic disorders with increasing age has also been reported in reviews on the epidemiology of tics [39]. The reasons for such a decrease are also under discussion concerning ADHD [33] and still unclear. Possibly, it might be due to changes in the motivation to search for medical advice, e.g. from parents to the patient himself.

Finally, our analyses confirm the well-known higher than by-chance rates of the co-occurrence of tic disorders and ADHD in children and adolescents. Based upon our analysis of the comprehensive Nordbaden claims database, we present data from both perspectives, i.e., the rate of ADHD in patients with tic disorders as well as the rate of tic disorders in patients with ADHD.

The prevalence rate of any tic disorder in children and adolescents with ADHD, found to be 2.4% in the Nordbaden population (with a total of $n = 11,875$ patients with a diagnosis of ADHD), is more difficult to compare with previous reports [37]. Interestingly in several studies and reviews focusing on coexisting conditions in ADHD there is no information about the prevalence of tics in subjects with ADHD even when the authors are experts on tic disorders [36,37]. This might be due to the high variety of reported rates of coexisting tics in ADHD patients (0.4–33%), which is obviously related to different study designs [23], such as focusing on tics during treatment of ADHD with methylphenidate in clinical trials [17,28], using relatively small clinical samples focusing on coexisting conditions in ADHD [6,13] or studying a

mainstream school population of Swedish 7-year-olds [14]. In a study perhaps best comparable with the present design, Steinhilber et al. [38] reported a prevalence of tic disorders of about 9% in approximately 1,500 children with ADHD observed by about 300 investigators in various European regions within the Attention-Deficit/Hyperactivity Disorder Observational Research in Europe (ADORE) project that was designed as a prospective, non-interventional study. Whereas in the ADORE project specialized physicians assessed the study group under a research protocol, in the present sample primary care physicians as well as specialists were not participating in a scientific study. Hence, the relatively lower administrative prevalence rate of 2.4% might point to diagnostic difficulties to detect tics of lower severity under conditions of routine care in Nordbaden as well as to differentiate between tics and ADHD symptoms.

Much more is known about the prevalence of ADHD in populations with tic disorders [35] and unfortunately only these prevalence data are commonly given when the coexistence of tics and ADHD is discussed. The rate of about 13% of children and adolescents with any tic disorder suffering from an additional ADHD is in accordance with previous reports in non-clinical samples [35,40].

Compared to all these 'relative' data interrelating prevalence rates that are evaluated with the same method, the present 'absolute' administrative prevalence rates should be interpreted more cautiously. For example, the observed age group specific prevalence rates of all tic disorders and especially the prevalence rate of 0.04% TS in the best studied age group, i.e. youngsters between the ages of 5 and 18 years is 20 times lower than that of the actual consensus of about 1% for the overall international TS prevalence in this age group [22,23]. This low rate of 0.04% is in line only with older studies, e.g. that of Bruun [4], whose prevalence rate of TS was generally accepted for many years and is cited to the present time [23].

This discrepancy highlights the methodological differences of studies on the prevalence of tic disorders [22,23]. Here we report about diagnosed tic disorders, i.e., those detected and reported under the conditions of routine clinical care for outpatients in Nordbaden, having no detailed information about the exact diagnostic procedures. We therefore also lack information on the severity of the impairment caused by the tics at the time of diagnosis. Hence, the present rates are likely underestimations, like those reported in previous studies, because presumably a substantial number of individuals with tic disorders remain undiagnosed in the community [5,19]. The underestimation of the rate of tic disorders but not of that of ADHD might be ascribed to the fact that the latter has more impact on several aspects of daily life [24,26,27] and therefore comes more regularly to attention.

In conclusion, the present data interrelating prevalence rates within the present large sample, i.e. the remitting course of tic disorders as well as the rates of coexistence of tic disorders and ADHD, add valuable evidence to the heterogeneous base of epidemiological data derived from relative small and selective study samples. In contrast, the administrative prevalence rates of tic disorders should be interpreted more cautiously in light of the limitations mentioned above, most likely indicating a substantial number of cases that remain undetected under conditions of routine outpatient care. This observation points to a gap between the true prevalence of tic disorders as described in epidemiological studies and the frequency of its detection in routine care.

Note

This research meets the ethical guidelines, including adherence to the legal requirements of the study country; permission to use this data has been obtained from the data protection officers of the

Kassenaerztliche Vereinigung Baden Wuerttemberg (KV Nordbaden). Informed patient consent policies do not apply in the case of a retrospective administrative database analysis.

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Authors' roles

MS initiated the Nordbaden Project, acted as project leader, and prepared the manuscript jointly with VR.

OS did the statistical analyses.

AR provided clinical input.

VR provided clinical input and assumed a leading role in writing the manuscript.

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