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Specialized service use for psychiatric and neurodevelopmental disorders by age 14 in Finland

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Abstract

Objective—There is a lack of studies on the longitudinal diagnostic patterns childhood psychiatric and neurodevelopmental disorders specialized services as most studies have been cross-sectional.

Methods—The Medical Birth Register and the Finnish Hospital Discharge Register were used to study inpatient or public outpatient specialized service use for psychiatric and neurodevelopmental disorders between birth and age 14 in 2010 (cumulative incidence) and in year 2010 at age 14 (one-year prevalence) among all Finnish singleton live born children born in 1996 (n=58,538).

Results—The cumulative incidence of specialized service use for any psychiatric or neurodevelopmental disorders between birth and age 14 was 12.9% and the one-year prevalence in 2010 at 14 years was 3.9%. The cumulative incidence by age 14 was 5.5% for learning and coordination disorders, 2.2% for anxiety disorders, 2.0% for hyperkinetic disorders, 1.7% for conduct disorders, 1.4% for depression, 1.0% for autism spectrum disorders and .7% for stress and adjustment disorders. Learning and coordination, hyperkinetic and autism spectrum disorders showed male excess, were often diagnosed before school age and had 9-51% lifetime comorbidity with each other. Depressive, anxiety and stress and adjustment disorders had similar distributions in the sexes, were often diagnosed in early adolescence and showed 8-31% lifetime comorbidity with each other.

Conclusions—Every eighth Finnish child has visited specialized services for psychiatric or neurodevelopmental disorders sometime between birth and age 14. Learning and coordination disorders are diagnosed more than twice as often as anxiety, hyperkinetic and conduct disorders.

INTRODUCTION

Less than every fourth child with a psychiatric disorder is in contact with specialized services (1). Even among adolescents with severe disorders only approximately every second has used mental health service during their lifetime (2). For service system planning, it is important to know the patterns of service use e.g. at what age do children enter the service system, for how long do they use services, what is the sex distribution, what are the common diagnoses and which diagnoses overlap. However, there is a lack of such reliable information due to methodological issues.

Longitudinal population-based studies with information from interviews have described the longitudinal course of common developmental psychiatric disorders, such as anxiety and conduct disorders (3, 4), but their sample sizes are not large enough to study service use of some rare but clinically important disorders such as autism spectrum disorders. In fact, it has been proposed that a different approach than surveys is needed for studying relatively rare but clinically important disorders (5). Large cross-sectional studies with information from questionnaires or registers can be used when calculating service use prevalence during one year, but when calculating lifetime estimates, longitudinal data sets are preferable to cross-

sectional data because of recall bias (6). When studying longitudinal service use patterns, register-based data is especially valuable (7).

Ideally, standardized nationwide registered-based longitudinal data from birth is needed to study longitudinal patterns of service use of common and rare disorders. In Finland, all public outpatient and inpatient clinics report standardized person-level data to the nationwide outpatient and inpatient register. These free-of-charge public clinics serve all children who are referred from primary care and who are suspected to have disorders that require diagnostic evaluation or treatment by a specialist and a multi-professional team. In primary care, medical and psychosocially related health problems should be comprehensively recognized during childhood as there are routine health check-ups to all children performed by a trained nurse at least once a year and by a physician at least six times before the age of two and later at the age of four, seven, eleven and 14 years (8).

A complete nationwide birth cohort was retrieved from the Finnish register of specialized services to overcome the methodological problems with previous studies. First, the cumulative incidences from birth to age 14 of a wide range of psychiatric and neurodevelopmental disorders are described and compared to cross-sectional one-year-prevalence at age 14. Second, sex-specific cumulative incidences of diagnoses in specialized services from birth to age 14 are described. Third, the lifetime comorbidity of disorders diagnosed in specialized services is described.

METHODS

Registers and participants

The data are derived from two Finnish health care registers. The numbers of live born children are derived from the Medical Birth Register (MBR), which is maintained by the National Institute of Health and Welfare (THL) and contains information on all children born in Finland. Information on the annual incidence of visits due to psychiatric and neurodevelopmental disorders during inpatient (1996-2010) and outpatient (1998-2010) units among live born singletons are derived from the Finnish Hospital Discharge Register (HDR), also maintained by THL. The register includes information on inpatient care in all hospitals and outpatient care in public hospitals, e.g., child's personal identification number (PIN), sex, day of admission and discharge, the medical specialty, and a main diagnosis and secondary diagnoses according to the International Classification of Diseases, tenth revision (ICD-10). The diagnoses could be based on any of the main or secondary diagnoses.

All singletons born alive in Finland in 1996 ($n=58,538$) were included. Children born in 1996 were chosen, because ICD-10 was introduced during that year. The outpatient register was established in 1998, but generally, few psychiatric or neurodevelopmental disorders are treated before the age of two (in 1996-1997). Therefore, this was not expected to considerably affect the results.

This study is describing some of the outcomes in the ongoing FinESSI-project (9), but does not assess medication use effects as the FinESSI-study does. The register administrators and the data protection authority at the National Institute of Health and Welfare (THL) have

approved the use of register data in the FinESSI-study (9). The children were not contacted and informed consent was therefore not required according to the Finnish legislation. All frequency tabulations were done internally with encrypted PINs at THL, and no individual-specific data was extracted from the registers.

Diagnostic groups

The diagnostic groups are studied accordingly: any psychiatric or neurodevelopmental disorder (ICD-10 codes F00-F99); substance use disorders (F10-F19); non-affective psychotic disorders (F20-F29; abbreviated “psychotic disorders”); bipolar disorder (F30-F31); unipolar depression and undefined mood disorders (F32-F39; abbreviated “depression”); anxiety disorders (F40-F42, F93); stress and adjustment disorders (F43); eating disorders (F50); mental retardation (F70-F79); learning disabilities and/or motor coordination disorder, i.e. developmental disorders of speech, language, scholastic skills and/or motor coordination (F80-F83; abbreviated “learning and coordination disorders”); pervasive developmental disorders, i.e. autism spectrum disorders (F84, abbreviated “ASD”); hyperkinetic disorders (F90); conduct disorders including oppositional defiant disorder (F91, F92); and tic disorders (F95). The lifetime comorbidity was studied between birth and age 14. Lifetime comorbidity was defined as the presence of at least two different diagnostic classes at any time during the follow-up period.

Statistical analysis

The follow-up started at birth and ended in December 31st, 2010, when the participants were 14.0-14.9 years old (born between January 1st, 1996, and December 31st, 1996). The age of the cohort members is defined as the age on December 31st of the studied year in completed years: the age of 14.0-14.9 years is described as 14 years. One-year-prevalence in 2010 was defined as the number of subjects with visits during year 2010, while cumulative incidence was defined as the number of subjects with an incident diagnosis between birth and 2010. The cumulative incidence of the diagnostic groups was extracted per year of incidence diagnosis and sex from the HDR.

RESULTS

Altogether 12.9% (n=7,561/58,538) of children had used specialized services for psychiatric or neurodevelopmental disorders between birth in 1996 and year 2010 (age 14). For a psychiatric or neurodevelopmental disorder, 2,785 children had visited pediatric neurology clinics (cumulative incidence 4.8%), 3,077 had visited child or adolescent psychiatry clinics (cumulative incidence 5.3%), and 2,989 had visited pediatric clinics (cumulative incidence 5.1%). 1,290 children had visited two or more of these specialties. 962 had been admitted to a child or adolescent psychiatry inpatient unit (cumulative incidence 1.6%).

Cumulative incidence and one-year-prevalence

Table 1 shows the one-year-prevalence in 2010 and the cumulative incidence until 2010 of specialized service use for different diagnostic classes among children born in 1996. The rank order of the cumulative incidence in both sexes by age 14 was learning and coordination disorders (5.5%), anxiety disorders (2.2%), hyperkinetic disorders (2.0%),

conduct disorders (1.7%), depression (1.4%), autism spectrum disorders (1.0%) and stress and adjustment disorders (.7%), as ordered in Table 1. The cumulative incidence between birth and age 14 versus the one-year prevalence at age 14 of specialized service use was 1.6 to 8.5-fold higher depending on the diagnostic group (Table 1). The largest difference between cumulative incidence and one-year prevalence was seen for learning and coordination disorders (5.5% versus .6%). Some diagnostic groups of special interest given in Table 1 were analyzed as more specific diagnoses and shown as supplementary material (Supplemental Table).

Cumulative incidence by age

As shown in Figure 1A, the cumulative incidence of specialized service use for any psychiatric or neurodevelopmental disorder by age 14 was 15.8% among boys and 9.9% among girls. Parts B-H of Figure 1 show the sex-specific cumulative incidence from birth to age 14 for the seven diagnostic groups with highest cumulative incidence. Males had higher cumulative incidence than females with regard to learning and coordination disorders (B; boy:girl ratio 2.5:1), hyperkinetic disorders (D; boy:girl ratio 5.5:1), conduct disorders (E; boy:girl ratio 2.7:1) and ASDs (G; boy:girl ratio 3.8:1). The cumulative incidence was similar for males and females or slightly higher for females for anxiety disorders (C), depression (F) and stress and adjustment disorders (H). The cumulative incidence increased throughout the follow-up for all diagnostic groups in Figure 1, i.e. new diagnoses were given also at age 13-14 in all diagnostic groups. However, the new diagnoses were typically given before the age of 7 for learning and coordination disorders (B), hyperkinetic disorders (D) and ASDs (G), but after the age of 10 for anxiety disorders (C), conduct disorders (E), depression (F) and stress and adjustment disorders (H). Further, when the cumulative incidence for childhood autism, Asperger's syndrome and PDD-NOS were analyzed separately, childhood autism was typically diagnosed at an earlier age than Asperger's syndrome and PDD-NOS (Supplemental Figure).

Lifetime comorbidity

Table 2 illustrates the lifetime comorbidity between the seven most common diagnostic groups, shown as the percentage of children with comorbid diagnoses between age 0 and 14. Lifetime comorbidity ranged between 2% and 51% across diagnostic combinations and lifetime comorbidity was present in over 20% of the cases with the following diagnostic groups: hyperkinetic disorders with comorbid learning and coordination disorders; ASDs with comorbid learning and coordination disorders or comorbid hyperkinetic disorders; anxiety disorders with comorbid depression; depression with comorbid anxiety disorders; and stress and adjustment disorders with comorbid anxiety disorders or comorbid depression.

DISCUSSION

The diagnostic groups clustered into three groups with regard to the sex distribution, to the age period when the disorders is first diagnosed and to lifetime comorbidity in specialized care. First, learning and coordination disorders, ASD and hyperkinetic disorder had a male predominance, were often diagnosed before school age and the diagnostic groups

overlapped to a certain degree. According to a review on sex differences (10), these disorders have male excess and typically involve neurodevelopmental impairment. In fact, they are often termed neurodevelopmental disorders (11). However, the cumulative incidence for these neurodevelopmental disorders continued to increase until the end of follow-up, that is, many subjects were diagnosed in late childhood though the symptoms per definition have to be present before school age. For example, the cumulative incidence of specialized service use for ASD was .5% by age 8 and 1.0% by age 14. According to a systematic review from 2012 (12), the prevalence of ASD in recent European studies has ranged between .3% and 1.2% with a median of .6%. This indicates that a large proportion of Finnish children with ASDs are sometime diagnosed in specialized services, but the diagnosis is often set in school age.

Second, conduct disorders including ODD also had a male predominance in line with other studies (10), but were seldom diagnosed before school age and overlapped to a maximum of 11% with the other diagnostic groups. It is notable that the proportion of children with conduct disorder and comorbid disorders was low compared to the level of comorbidity in population-based surveys (13, 14). Though it cannot be ruled out that hyperkinetic and internalizing disorders are undiagnosed among children with conduct disorder, it is more likely that the low level of comorbidity among children with conduct disorders relates to the diagnostic classification in ICD-10. There is a specific code for 'hyperkinetic disorder associated with conduct disorder' (F90.1) under the chapter of hyperkinetic disorders (F90) in the ICD-10 and there is also a separate group for 'mixed disorders of conduct and emotions' (F92). Accordingly, hyperkinetic disorders associated with conduct disorder were classified as hyperkinetic disorders and mixed disorders of conduct and emotions were classified as conduct disorders.

Third, anxiety disorders, depression and stress and adjustment disorders had a relatively equal sex distribution, were often diagnosed in late childhood or early adolescence and lifetime comorbidity between these disorders was present in many cases. In line with a previous review (10), anxiety and depressive disorders had a similar sex distribution in prepubertal years but increase among females after puberty. Depression and anxiety are often termed emotional disorders, while stress and adjustment disorders can involve both emotional and disruptive symptoms. The diagnostic pattern of stress and adjustment disorders resembled mostly the ones of emotional disorders. Some children have first been diagnosed with stress and adjustment or anxiety disorders and later been diagnosed with depression, because there was a high proportion of comorbidity between these disorders and the incidence age of stress, adjustment and anxiety diagnoses was earlier than the one of depression.

Several methodological issues should be considered when comparing the cumulative incidence results with the results from other service use studies. For example, survey-based studies potentially are prone to recall bias while registers-based studies are not; register-based studies only include specified services while surveys can collect information for different forms of service; and some registers allow for long-term follow-up at the individual level while other registers do not. A novel finding was that 8% of boys and 3% of girls had used specialized services for learning and coordination between birth and age 14 when the

data was treated as longitudinal data, but the corresponding proportion was only .9% for boys and .4% for girls when the register-based data was treated as cross-sectional data at age 14. This indicates that most Finnish children with learning and coordination disorders visit specialized care only for a short period of time and that long-term follow-up designs are necessary for identifying these disorders in register-based research. The longitudinal cumulative incidence estimates of learning and coordination disorders rather than the cross-sectional one-year prevalence resemble results from surveys. For example, in a cross-sectional US survey from 1997-2008 (15), teachers or health professionals had identified 9% and 5% of 3-17 years old boys and girls, respectively, with learning disabilities. Future studies with both survey-based and register-based information are needed to investigate to what extent these kinds of information differ.

The cumulative incidence of specialized service use for conduct disorders was 1.7% by age 14 (including also ODD). The comparison with community-based samples is challenging because of methodological issues, but these figures can be considered low. For example, the 3-month prevalence of conduct disorder and ODD among Finnish 8-9 year old children was 5% in a study based on parental interviews (16), and similar figures have been found in the UK (17) and the US (18). Similarly, anxiety disorders in specialized care had a cumulative incidence of 2.2% by age 14, whereas the 3-month prevalence of anxiety was 5% at age 8 in a sample of Finnish children including both treated and non-treated children (16). In line with previous studies (1, 2), this indicates that some psychiatric problems, such as conduct and anxiety disorders, are underrecognized in primary care or not referred to specialized services.

It is well known that neurodevelopmental disorders occur more often among boys than girls, because of different risk and protective factors in the sexes (10). It is also acknowledged that the sex ratio for service use for disorders might be even higher than the sex ratio for the disorders per se (10). As when comparing cumulative incidence with other studies, comparing sex ratios with other studies is challenging because of methodological differences. For example, the boy:girl ratio of ASDs was 3.8:1 compared to 2.5:1 in a recent epidemiological study from Southern Korea (19) and 3.9:1 in another epidemiological study from the UK (20). It indicates that there is no major gender bias of ASD in referral to specialized services in Finland, but studies with more detailed data on non-treated cases are needed to confirm these findings and give insight into possible gender biases of the full spectrum of disorders.

Strengths and limitations

The strengths include total nationwide longitudinal data from birth, both inpatient and outpatient units from all specialties and a uniform diagnostic system (ICD-10). There are also several limitations to consider. The results represent all children with specialized service use for psychiatric and neurodevelopmental disorders in Finland, but lack information about children who are not recognized by primary care and are not referred to specialized services. This would allow drawing definitive conclusions regarding unmet need of services and under- and overdiagnosis. Furthermore, the data rely on complete information concerning specialized service use, since the data on primary care visits are not

yet available for research purposes in Finland. Additionally, the diagnostic validity of childhood autism has been assessed and found to be high (21), but it is not known how well other disorders correspond to research diagnostic criteria. Moreover, the total sample was based on all singleton live births, but emigration, immigration and deaths were not taken into account in the analyses. However, mortality is very low, emigration ranges between .1 and .4% per year, and immigration ranges between .3 and .8% per year among Finnish people aged 0-14 (22). It is therefore unlikely that these factors would affect the results substantially.

Conclusions

Every eighth Finnish child has visited specialized services for psychiatric or neurodevelopmental disorders sometime between birth and age 14. The most common diagnosis was learning and coordination disorders, which were diagnosed more than twice as often than anxiety, hyperkinetic and conduct disorders. It is also evident that many children were diagnosed at a later age than would be expected from what is known about the typical age-of-onset of symptoms. One way to improve the early recognition of childhood psychiatric and neurodevelopmental disorders in the population is to implement systematic screening of mental health problems in child welfare and school health clinics. Such an arrangement would be in line with the systematic assessment and referral policies of e.g. scoliosis and deviant growth patterns during childhood (23). However, this would require that children with unmet needs have access to effective mental health interventions, which currently are mainly available in specialized services. The long-term burden of childhood mental health problems is likely to remain high if only a proportion of children with problems access appropriate treatment. Therefore, early identification and a smooth referral system are important to decrease the long-term burden of these problems in the population. Other important ways to promote mental health in childhood and adolescence include educational programs in school settings to increase the knowledge concerning mental health, pathways to care and stigma (24), and easily accessible interventions in primary care.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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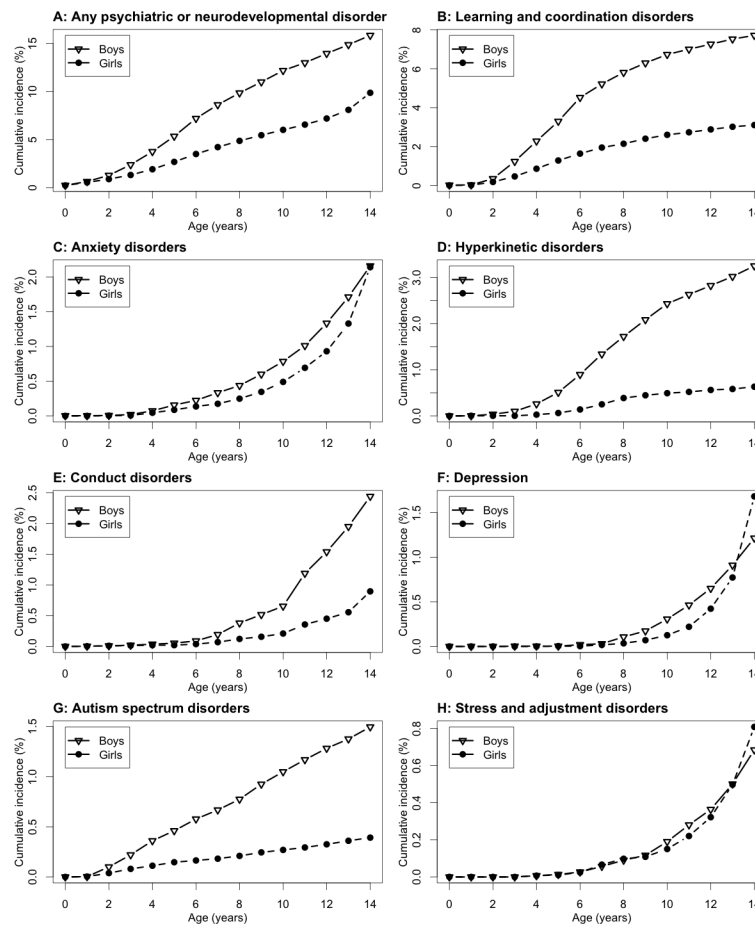


FIGURE 1.
LEGEND

The cumulative incidence of specialized service use per sex between birth (year 1996) and age 14 (year 2010) for any psychiatric or neurodevelopmental disorder (A), learning and coordination disorders (B), anxiety disorders (C), hyperkinetic disorders (D), depression (E), conduct disorders (F), autism spectrum disorders (G) and stress and adjustment disorders (H).

Table 1

Specialized service use among all Finnish singletons born in year 1981 (age 14 in year 2010).

Specialized service use for (ICD-10 codes)	Boys (n=29,959)			Girls (n=28,579)			Both sexes (n=58,538)		
	1-year-prevalence in 2010 (%)	Cumulative incidence until 2010 (%)		1-year-prevalence in 2010 (%)	Cumulative incidence until 2010 (%)		1-year-prevalence in 2010 (%)	Cumulative incidence until 2010 (%)	
Any psychiatric or neurodevelopmental disorder (F00-F99)	4.6	15.8		3.9	9.9		4.2	12.9	
Learning and coordination disorders (F80-F83)	.9	7.7		.4	3.1		.6	5.5	
Anxiety disorders (F40, F41, F42, F93)	.9	2.2		1.3	2.1		1.1	2.2	
Hyperkinetic disorders (F90)	1.2	3.3		.1	.6		.7	2.0	
Conduct disorders (F91, F92)	1.1	2.4		.5	.9		.8	1.7	
Depression (F32-F39)	.6	1.2		1.3	1.7		.9	1.4	
Autism spectrum disorders (F84)	.6	1.5		.2	.4		.4	1.0	
Stress and adjustment disorders (F43)	.3	.7		.4	.8		.4	.7	
Mental retardation (F70-F79)	.3	.9		.2	.5		.2	.7	
Tic disorders (F95)	.2	.7		<.1	.2		.1	.4	
Eating disorders (F50)	.1	.1		.4	.6		.2	.4	
Substance use disorders (F10-F19)	.1	.2		.2	.2		.1	.2	
Psychotic disorders (F20-F29)	.1	.2		<.1	.1		.1	.1	
Bipolar disorder (F30-F31)	<.1	<.1		<.1	<.1		<.1	<.1	

Abbreviations: ICD-10, International Classification of Diseases, tenth revision.

Note: The diagnostic groups are ranked according to the cumulative incidence until 2010 in both sexes (last column).

Table 2

Lifetime comorbidity in specialized services among children born in 1996 and followed up to 2010. The percentages indicate the proportion of comorbidity of the diagnostic classes in the rows.

	Total	Lifetime comorbidity with									
		Learning and coordination disorders	Anxiety disorders	Hyperkinetic disorders	Conduct disorders	Depression	Autism spectrum disorders	Stress and adjustment disorders			
	N	%	%	%	%	%	%	%	%	%	%
Learning and coordination disorders	3,197	-	7.9	16.3	2.8	3.9	9.0	1.9			
Anxiety disorders	1,259	19.9	-	11.0	6.4	20.6	7.7	7.8			
Hyperkinetic disorders	1,155	45.1	11.9	-	9.9	6.3	11.9	2.5			
Conduct disorders	987	9.1	8.2	11.6	-	8.9	2.8	2.5			
Depression	845	14.7	30.7	8.6	10.4	-	5.6	12.7			
Autism spectrum disorders	560	51.4	17.3	24.5	5.0	8.4	-	2.1			
Stress and adjustment disorders	436	14.2	22.5	6.7	5.7	24.5	2.8	-			

Note: Bold face indicates percentages over 20%.