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What can a national patient registry tell us about psychiatric disorders and reasons for referral to outpatient services in youth with hearing loss?

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ABSTRACT

Background: Studies of reasons for referral to the Child and Adolescent Mental Health Services (CAMHS) and subsequent psychiatric disorders are missing in youth with Hearing loss (HL).

Aims: To examine the referral reasons to CAMHS and the clinically diagnosed psychiatric disorders in youth with HL among the nationally representative population.

Methods: The study population was a youth with HL referred to CAMHS and registered in the national Norwegian Patient Registry (NPR) during the years 2011–2016. The results were also compared with some data published from CAMHS for the General Youth Population (GenPop).

Results: Among youth with HL, 18.1% had also been referred to CAMHS compared to about 5% in GenPop, at mean age 9.1 years, >70% before age 13 years vs. 46% in the GenPop. Boys with HL comprised 57% and were referred about two years earlier than girls with HL. Compared to the GenPop, youth with HL were referred more frequently for suspected neurodevelopmental- and disruptive disorders, and less frequently for suspected emotional disorders. Girls with HL were referred for suspected Attention-Deficit/Hyperactivity Disorder (ADHD) at about the same rate as boys with HL in the 7–12 year age group. The most frequently registered psychiatric disorders were ADHD: 29.8%, anxiety disorders: 20.4%, and autism spectrum disorders: 11.0%, while disruptive disorders constituted about 5.0%.

Conclusions: Youth with HL were referred to CAMHS more often, but earlier than the GenPop, mostly due to ADHD disorders. Although more rarely referred for suspected anxiety disorders, these were frequently diagnosed, suggesting that anxiety was not recognized at referral in youth with HL.

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Background

The average prevalence of childhood hearing loss (HL) (>20 dB) has been estimated to be 3.1 percent [1]. In general, more emotional and behavioral problems, as rated by questionnaires have been reported among youth with HL compared to those with typically hearing [2–4], as much as 3.7 times more prevalent in a Danish study ($n = 334$) [5]. A review from 2009 reported these problems to be about twice as frequent among youth with HL, and they were not related to the severity of HL [6]. More specifically, a later review reported that youth with HL were consistently more prone to depression, aggression, oppositional defiant disorder, conduct disorder, and psychopathy than their typically hearing peers [7]. Furthermore, levels of anxiety, somatization, delinquency, and symptoms of Attention-Deficit/Hyperactivity Disorder (ADHD) were elevated in some, but not all youth with HL, for reasons such as differences in the distribution of sex and age. Sex differences were in the expected direction, e.g. girls experienced more internalizing symptoms and boys

had more externalizing symptoms, and older age was related to more psychopathology. A meta-analysis from 2015 found differences between youth with HL and typically hearing peers to represent small to moderate effect sizes [8]. However, the author noted that the certainty of these estimates was limited by the heterogeneity between studies, e.g. age, severity of HL, interventions (cochlea implants or conventional hearing aids), and types of controls. Sex differences were not investigated in the mentioned meta-analysis, but no sex differences were found in the author's later longitudinal study of adolescents with HL ($n = 114$) [9].

Studies reporting the prevalence of psychiatric disorders in youth with HL, as rated by standardized diagnostic interviews are scarce. An early seminal British study, using a structured interview with the children ($N = 81$) at mean age 13.5 years and screening questionnaires to parents and teachers, found a high prevalence (50.3%) but the participants were not considered to be representative of the deaf children in the community [10]. Although the study found

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that sex and age were significantly associated with psychiatric disorders on questionnaire scores (higher in boys and older subjects), this was not replicated in the diagnostic assessment. A more representative study administered a structured clinical interview to 95 Austrian pupils with HL and normal non-verbal intelligence at mean child age 11 years [11]. The used interview resulted in a point prevalence of any psychiatric disorder of 32.6% with about the same amount of internalizing- and externalizing disorders (about 20%) but did not include questions about Autism Spectrum Disorders (ASD). Concerning ASD, a prevalence as high as 23.8% was found in a Dutch study ($n = 389$) of youth with HL referred to a national center for child and adolescent psychiatry [12], while a later review estimated that the overall prevalence of ASD was 9.0% [13]. Concerning ADHD, the previously mentioned Austrian study found an 11.6% point prevalence of ADHD [11], while no prevalence of ADHD was reported in the Dutch study [12]. For youth with HL, a concern is whether they get help for psychiatric problems later than others, as one study found them to be older at first referral compared with typically hearing youth (10.8 vs. 9.4 years) [12].

Studies of reasons for referral to CAMHS are rare, and thus far absent for youth with HL, but a Danish study investigated referral patterns in the General Youth Population (GenPop) over the years 2005–2018 [14]. Symptoms related to Behavioral and emotional disorders (ICD-codes F90–98) constituted the largest proportion (39.5%), followed by Developmental disorders (ICD-codes F80–89) with 21.8%. (Within these two groups, the diagnoses ADHD and ASD constituted >90%). Other major referral symptoms were related to affective disorders (11.7%) and anxiety disorders (7.8%), and the girls were significantly older at referral (about 3 years) than the boys. As expected, the sex distribution varied with reasons for referral, but the proportion of girls with suspected ADHD and ASD increased over time. This could indicate improved recognition of these symptoms in girls, but the authors noted that a generally late referral to CAMHS services for these disorders remains an issue. Studies of reasons for a referral might give important information about the problems youth with HL first present with at the General Practitioner's office, and indicate areas of concern to specialists in CAMHS.

The present study presents data on youth (0–18 years) diagnosed with HL, as reported to the nationwide Norwegian Patient Registry (NPR). The study sample (patients in CAMHS) were selected from this population of youth with HL and was obtained to investigate the reasons for referral to – and the subsequent psychiatric disorders reported by CAMHS during the years 2011–2016.

For comparison, the NPR publishes annual reports on the activity in CAMHS for the GenPop [15]. Concerning referral reasons to CAMHS for the GenPop during 2011–2016, four suspected conditions, ADHD, depression, oppositional defiant- and conduct disorders, and anxiety disorders constituted a majority (about 70%). For 20% of the referrals, the term “Other referral reason- not otherwise specified”, was given. Annually, in the same time period, about 55 000 children

were treated in CAMHS, representing 5% of the GenPop. About 46% were referred to CAMHS before age 13 years and boys comprised about 54%. While the majority of boys were referred before age 13 years, the majority of girls were referred \geq age 13 years. The NPR reports described that the most frequent referral reason for both sexes in the youngest age group was “Serious concern for children < age 6 years”. Suspected ADHD was the dominant referral reason for those aged 7–12 years, and about 2.5 as frequent in boys compared to girls. Suspected disruptive disorders and ASD were also frequent in this age group and suspected ASD was substantially more frequent in boys compared to girls. For the oldest age group, suspected depression was the most frequent referral reason, more than twice as frequent in girls compared to boys. Suspected anxiety disorders were also noted as frequent in both sexes, and furthermore, suspected ADHD in boys, and suspected eating disorders (and trauma) in girls.

A strength of register studies is that they reflect the daily clinical work with disorders diagnosed only when associated with impairments in need of referral to CAMHS [16], and the present study adds to the previous literature on youth with HL by being the first to investigate these broad clinical assessments in a nationally representative population.

The aim of the present study was to estimate the proportion of youth with HL who were registered in CAMHS and to examine referral reasons and the subsequent prevalence of psychiatric disorders in youth with HL, as reported to the NPR from CAMHS, including possible sex and age differences. Based on previous research, we hypothesized that reasons for referral to CAMHS for youth with HL would reflect a high number of suspected neurodevelopmental disorders, as well as a high rate of subsequently diagnosed psychiatric disorders, again particularly within the neurodevelopmental domain. Furthermore, we expected that age of referral would be higher than typically found in CAMHS, while sex differences would mirror general findings of more internalizing disorders in girls and more disruptive- and neurodevelopmental disorders in boys.

Methods

Participants

The present sample was selected from all children and adolescents, 0–18 years of age, born between 1993 and 2016 registered with a diagnosis of HL in the Norwegian National Patient Registry (NPR) and includes those who also were registered with at least one diagnosis from CAMHS between January 1, 2011 and December 31, 2016.

The NPR also provided the total number of registered youth with HL, including by sex. In Norway, the health services use the diagnoses “Conductive and sensorineural hearing loss” (code H90) or “Other and unspecified hearing loss” (code H91) hereafter Hearing Loss; HL, from the International Classification of Diseases, 10th edition (ICD-10) [17]. The NPR is a national healthcare registry that receives patient data on medical conditions such as HL reported from somatic

hospitals and reasons for the referral and clinical psychiatric diagnoses from CAMHS, in accordance with the ICD-10 [17].

Measures

The information from NPR on youth with HL in CAMHS included descriptive data, such as sex, age at first referral to CAMHS and age at psychiatric diagnosis, reasons for referrals, and the subsequently diagnosed psychiatric disorders.

The reasons for referrals (referral symptoms) from CAMHS registered in the NPR:

1. Serious concern for children < age 6 years,
2. Suspected ASD,
3. Suspected Oppositional/Conduct disorder (ODD/CD),
4. Suspected ADHD,
5. Suspected Tourette syndrome,
6. School refusal,
7. Suspected anxiety disorder,
8. Suspected eating disorder,
9. Obsessive features-suspected Obsessive Compulsive Disorder
10. Suspected depression,
11. Suspected bipolar disorder,
12. Persistent and severe self-harm,
13. Suspected psychosis
14. Severe psychological reaction after trauma, crises, or catastrophes,
15. Severe psychological symptoms were secondary to somatic disease.
16. Other referral reasons (not otherwise specified).

All the reasons are presented separately, but to compare the prevalence of the most frequent referral reasons in youth with HL to those in GenPop, we also computed the adjusted prevalence of the most frequent referral reasons. This was done by excluding the category "Other referral reasons, not otherwise specified," in line with the presentations in the annual NPR reports (where this category comprises about 20% of the referral reasons) [15].

The psychiatric disorders from CAMHS registered in the NPR:

Following the ICD-10, F-section [17], we calculated the number of psychiatric disorders when present at least once and included: Psychotic disorders (F20–F29), Affective disorders (F30–F39), Anxiety disorders (F40–41, 43–49, F94.0), OCD (F42), Eating disorders (F50), Sleep disorders (F51), Autism Spectrum Disorders (F84), ADHD (F90, F98.8), Conduct disorders (F91), Mixed disorders of conduct and emotions (F92), Emotional disorders with onset specific to childhood (F93), Attachment disorders (F94.1–2), Tics (F95), Elimination disorders (F98.0–1). We also have an "Other" category including diagnoses found in <10 subjects (e.g. substance abuse, organic disorders, and personality disorders).

We did not include ICD codes regarding health status, symptoms/signs, or contact with health services (e.g. R and Z codes), as these observational codes are routinely noted at the time of admission to CAMHS, and not providing clinically

useful information. The number of patients without F-diagnoses in the annual NPR reports was about 30% (specific numbers were only available for years 2015 and 2016) [15].

Ethics

The Regional Committee for Medical Research Ethics approved the present study (REK 17/13774).

Statistics

The characteristics of the participants are given as a number of participants and proportions (%) and means as appropriate. Significant differences were estimated by a statistical calculator (<https://www.medcalc.org/calc/>).

Results

Among the total number of youth (0–18 years of age) who were registered with HL in the NPR ($n = 17\,824$, 54% boys), about one in five ($n = 3\,235$, 18.1%) had also been referred to CAMHS, significantly more than the 5% in the GenPop ($p < .0001$).

Boys comprised 57% of the youth with HL in CAMHS, significantly higher than the 54% boys in CAMHS for the GenPop (Chi-square 11.08, $p = .0009$).

The mean age at first referral to CAMHS for the youth with HL was 9.1 years (SD 4.8). Boys were referred significantly earlier than girls, with mean ages 8.3 years (SD 4.5), and 10.2 years (SD 4.9), respectively ($t = 11.61$, $p < .0001$). Mean age at first psychiatric diagnosis was 10.2 years (SD 4.7), significantly earlier for boys (9.1 years, SD 4.9) than girls (11.4 years, SD 4.7; $t = 11.44$, $p < .0001$). The time lag between age at referral and age at diagnosis was about one year in both boys and girls.

Figure 1 shows the percentages of youth with HL and the GenPop referred to CAMHS divided by sex and age groups. For the youngest age group, there was a larger proportion of boys and girls with HL (23% and 10%) than in GenPop (7% and 4%) with opposite proportions in the oldest age group. In sum, while more than 70% of the youth with HL were referred before age 13, the estimated percentage in GenPop was about 46%. Furthermore, the largest proportion of girls with HL were referred to < age 13 years, in contrast to the GenPop, where the majority of girls were referred ≥ 13 years.

Table 1 presents the reasons for referral to CAMHS for all youth with HL, the percentages of boys, and the mean ages at referral. When excluding "Other referral reasons", the most common reasons were: Suspected ADHD (17%), suspected depression, suspected ODD/CD, suspected ASD, and suspected anxiety disorders (in that order). Boys were generally referred to significantly earlier than girls. Reasons for referral were absent in 14.4% of the cases.

Figure 2 presents the most frequent referral reasons for youth with HL and the GenPop were the six most frequent reasons comprised 88% and 86%, respectively. When compared, youth with HL were referred more frequently for

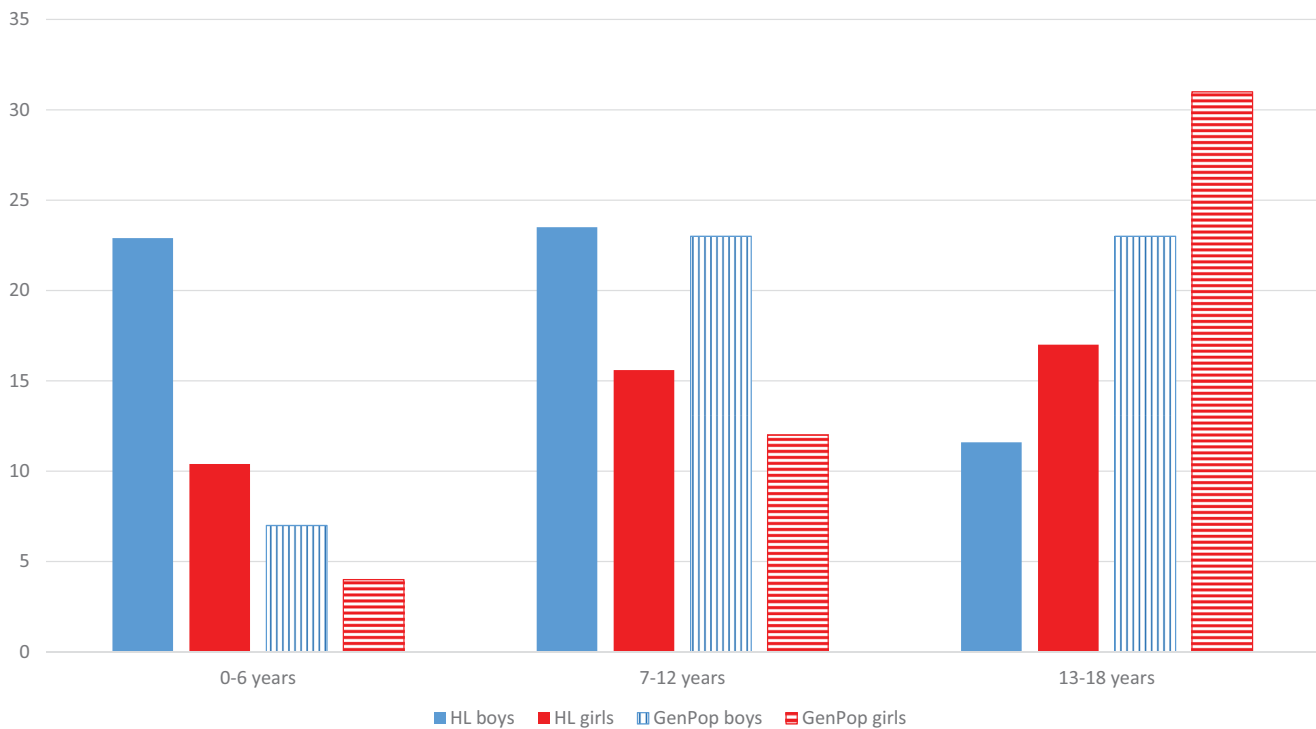


Figure 1. Percentages of youth with HL and the GenPop during 2011–2016 referred to CAMHS divided by age and sex groups.

Table 1. Reasons for referral, percentages of boys, and age at referral in youth with HL.

Child referral reasons (symptoms)	N	%	% boys	Mean age (sd)	Age boys	Age girls
1 Serious concern for children < age 6 years	159	4.9	67**	3.5 (2.2)	3.56 (2.24)	3.40 (2.12)
2 Suspected autism spectrum disorder	203	6.3	73**	5.9 (3.6)	5.46 (3.24)	7.04 (4.13)
3 Suspected oppositional/conduct disorder	263	8.1	67**	8.9 (3.5)	8.86 (3.48)	8.94 (3.57)
4 Suspected attention-deficit/hyperactivity disorder	551	17.0	64**	9.0 (3.4)	8.84 (3.43)	9.38 (3.20)
5 Suspected Tourette syndrome	30	0.9	83**	9.1 (3.2)	9.40 (3.35)	7.60 (1.52)
6 School absenteeism/school refusal	42	1.3	52	11.2 (3.0)	10.64 (2.42)	11.90 (3.55)
7 Suspected anxiety disorder	184	5.7	43*	11.5 (3.8)	10.54 (3.72)	12.25 (3.66)
8 Obsessive features/suspected obsessive compulsive disorder	38	1.2	50	10.6 (3.6)	9.74 (3.33)	10.95 (3.88)
9 Suspected eating disorder	75	2.3	40*	11.3 (5.1)	9.03 (4.86)	12.73 (4.66)
10 Suspected depression	217	6.7	33**	14.0 (3.0)	13.01 (3.43)	14.50 (2.67)
11 Suspected bipolar disorder	7	0.2	43	10.4 (6.3)	6.67 (5.86)	13.25 (5.68)
12 Persistent and severe self-harm (including suicidal)	29	0.9	48	12.2 (3.8)	12.07 (3.81)	12.33 (3.83)
13 Psychotic features/suspected psychosis	18	0.6	67*	14.3 (3.2)	13.58 (3.66)	15.83 (1.17)
14 Severe psychological reactions (due to e.g. trauma)	111	3.4	44	10.5 (4.4)	10.35 (4.26)	10.61 (4.52)
15 Severe psychological symptoms secondary to somatic illness	54	1.7	54	9.3 (5.2)	8.83 (5.05)	9.92 (5.40)
16 Other reasons (not specified)	787	24.3	56**	8.3 (5.2)	7.69 (5.01)	9.16 (5.24)
None or lacking referral symptoms	467	14.4	55			
Total	3235	100				

**<.0001, *<.05.

suspected ADHD, ASD and disruptive disorders, and less frequently for suspected emotional disorders (all p 's < .0001).

Table 2 shows that in the 0–6 year age group, the most frequent referral reason was “Serious concern for children < age 6 years”, followed by suspected ASD and ADHD. Suspected ADHD was by far the most frequent reason in the age group 7–12 years, followed by suspected disruptive disorders, both with relatively even percentages in boys and girls. In the oldest age group, suspected ADHD, suspected depression- and disruptive disorders constituted the majority among boys, while suspected depression, anxiety, and ADHD were most frequent among girls.

Table 3 presents the psychiatric disorders in the youth with HL, the percentages of boys, and the mean ages at diagnosis. The most common diagnoses were ADHD: 29.8%, anxiety disorders: 20.4%, and ASD: 11.0%, while disruptive

disorders (F91, F92) comprised about 5%. Boys comprised the majority of those diagnosed with ASD, ADHD, disruptive disorders, tics, and elimination disorders. A larger proportion of girls were registered with affective- anxiety- and sleep disorders. Registered ICD-10 codes (F-section) were absent in 27% of the cases.

Discussion

The present study addressed the prevalence of referral reasons and subsequent psychiatric disorders from CAMHS in a nationally representative population of youth with HL. We know of no other studies that have investigated reasons for referral in youth with HL and their clinically registered psychiatric diagnoses.

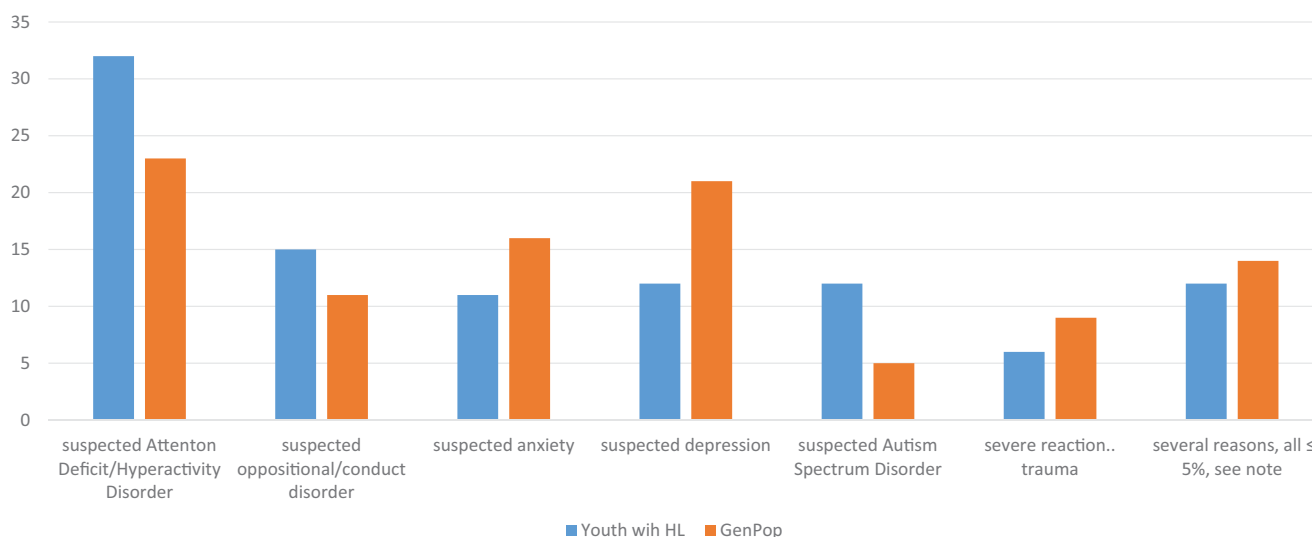


Figure 2. The most frequent reasons for referral to CAMHS for youth with HL and the GenPop during the years 2011–2016. The “several reasons” (all $\leq 5\%$) were comprised by: School absenteeism, suspected eating- and obsessive-compulsive disorder in both populations and “Severe psychological symptoms secondary to somatic disease” in youth with HL and “Serious concern for children < age 6 years” in the GenPop.

Table 2. The most common reasons for referral (%) by age group for all and by sex in youth with HL.

Child referral reasons/symptoms	0–6 years			7–12 years			13–18 years		
	All	Boys	Girls	All	Boys	Girls	All	Boys	Girls
Serious concern for children < age 6 years	17.3	16.8	18.2	–	–	–	–	–	–
Suspected attention-deficit/hyperactivity disorder	15.8	16.6	14.1	30.0	31.1	28.2	12.1	18.5	8.0
Suspected autism spectrum disorder	14.6	16.8	10.0	5.1	6.6	2.8	2.5	3.1	2.1
Suspected oppositional/conduct disorder	9.3	10.2	7.5	13.3	14.3	11.7	6.0	9.4	3.8
Suspected anxiety disorder	1.8	1.7	2.1	7.8	7.0	9.1	10.7	6.9	13.1
Suspected depression	0.7	0.8	0.6	4.9	4.1	6.1	21.8	14.9	26.2
Severe psychological reaction (due to e.g. trauma)	2.0	1.2	3.6	4.5	3.8	5.7	5.9	5.9	5.8
Suspected eating disorder	1.8	1.4	2.5	1.9	1.8	2.2	4.2	2.1	5.5

The six most common reasons are in bold (excluding those lacking reasons and the “Other referral reasons” category, about 40%).

Table 3. Psychiatric disorders in youth with HL in the Norwegian Patient Registry.

Psychiatric disorders (International Classification of Diseases; ICD-10 codes: F-section)	N	%	% boys	Mean age (SD)	Boys	Girls
Psychotic disorders (F20–F29)	13	0.6	46.2	15.1 (1.7)	15.6 (1.4)	14.7 (1.9)
Affective disorders (F30–39)	232	9.9	28.9**	15.7 (2.1)	14.7 (2.6)	16.0 (1.7)
Anxiety disorders (F40–41, F43–49)	481	20.4	39.3**	13.6 (3.7)	12.3 (3.9)	14.3 (3.6)
Obsessive compulsive disorder (F42)	34	1.4	41.2	13.5 (2.9)	13.1 (3.2)	13.8 (2.7)
Eating disorders (F50)	40	1.2	25.0**	13.1 (5.0)	8.5 (6.4)	14.4 (3.6)
Sleep disorders (F51)	10	0.4	20.0*	15.6 (2.4)	14.7 (4.0)	15.9 (1.7)
Autism spectrum disorders (F84)	260	11.0	76.9**	8.3 (4.6)	7.6 (4.2)	10.5 (5.3)
Attention-deficit/hyperactivity disorder (F90, F98.8)	702	29.8	63.5**	10.8 (3.6)	10.3 (3.4)	11.5 (3.6)
Conduct disorders (F91)	77	3.3	70.1**	10.4 (3.7)	9.8 (3.5)	11.8 (3.8)
Mixed disorders of conduct and emotions (F92)	49	2.1	55.1	11.5 (3.7)	10.8 (3.4)	12.4 (3.9)
Emotional disorders... onset childhood (F93)	175	7.4	53.1	10.4 (3.5)	9.9 (3.2)	11.0 (3.8)
Attachment disorders (F94.1–2)	77	3.3	54.5	10.0 (3.7)	9.6 (3.4)	10.5 (4.1)
Tics (F95)	94	4.0	79.8**	10.6 (3.2)	10.7 (3.0)	10.4 (3.9)
Elimination disorders (F98.0–1)	40	1.7	65.0*	9.2 (2.7)	8.8 (2.7)	9.9 (2.5)
Other disorders, with $n < 10$	72	3.1	55.6	12.0 (4.3)	12.0 (4.3)	12.0 (4.3)

** $<.0001$, * $<.05$. The percentages of youth with F diagnoses ($n = 2356$), we did not include other ICD codes (e.g. R and Z codes).

As hypothesized, the proportion of youth with HL registered in CAMHS was significantly higher (18.1%) than the 5% of youth in the GenPop [15]. This is in line with previous studies, estimating higher proportions of emotional and behavioral problems [2–4] and psychiatric disorders [10–12] in this population. Interestingly, we found a 3.5 times higher proportion of youth with HL in CAMHS than among all youth in GenPop, almost identical to a previous Danish study of 334 youth attending schools for youth with HL (3.7 times higher) [5].

In contrast to our hypothesis and a previous study [12], the youth with HL were not referred later than the youth from the GenPop. On the contrary, they were referred to earlier (Figure 1). This is encouraging for youth with HL, but the generally late referrals to CAMHS services (mean age 9 years) is unfortunate, especially for the neurodevelopmental disorders, where early intervention is advised [18,19]. Still, compared to the GenPop, there was more youth in the two youngest age groups (<age 13 years), indicating that parents and health workers may be aware of a vulnerability for psychiatric disorders among youth with HL.

That boys with HL was referred significantly earlier than girls is in line with findings in the GenPop, both in the Norwegian CAMHS [15] and in the relatively large Danish referral study [14]. Reasons for that could partly be due to differences in the presentation of and/or understanding of the symptoms in boys and girls, where boys generally are perceived as more disruptive and therefore more in need of referral for diagnosis and treatment, exemplified in the importance of disruptive symptoms for both an ADHD diagnosis [20] and medication for ADHD [21] in Norway. Such an understanding is in line with the high proportion of referrals for suspected disruptive behavior (where boys constituted a majority) found in the present study (Figure 2), suggesting the importance of disruptive symptoms for referral also in the absence of a similarly high proportion of subsequently diagnosed disruptive disorders (about 5%).

The Danish referral study suggesting increased recognition of ADHD and ASD in girls over the years from 2005 to 2018 [14] could partly explain why the largest proportion of girls with HL were referred before age 13 years, in contrast to ≥ 13 years in the GenPop (Figure 1). Also, that youth with HL were referred more frequently for suspected ADHD and ASD and less frequently for suspected depression (with a generally later onset) compared with the GenPop, could be part of the explanation of this sex difference.

The higher proportion of boys among all the youth with HL found in the present study (54% of 17824), along with the more frequent referral for neurodevelopmental disorders in the youth with HL, and the known overweight of neurodevelopmental disorders in boys [22], may have enhanced the significantly higher proportion of boys among those with HL in CAMHS (57%) compared to the GenPop in CAMHS (54%) [15].

That the mean time lag between age at referral and age at diagnosis was about one year for youth with HL (for ADHD and ASD about two years) shows that it takes considerable time to reach a diagnostic understanding of the youth with HL. This time lag could explain the large number without a registered psychiatric disorder (27%), but as this percentage was about the same as for the GenPop (about 30%) [15], the present study does not support a particular delay for youth with HL.

In the present study, we may assume that the youth were impaired, as they were patients in the CAMHS, and the sex differences mirrored the general findings of more internalizing disorders in girls and more disruptive- and neurodevelopmental disorders in boys. Of note, however, we found a relatively large proportion of girls with HL among those diagnosed with ADHD (about 36%) which is higher than the mean reported proportion of girls (16%) among European youth in the multicenter ADHD study [23]. We have not found an obvious explanation for this relatively large proportion of girls with HL and ADHD in CAMHS, but similar gender findings have been noted in a study on children with functional hearing loss [24]. Although not directly comparable to our study, due to a different study design and a large proportion of girls among participants (70/97), the study by Ashitani *et al* found an even gender ratio (about 50% girls)

among those who were diagnosed with inattention ($n = 35$) using the ADHD-Rating Scale-IV.

While the meta-analysis on youth with HL from 2015 summarized that there still was an unresolved issue whether they showed hyperactivity and inattention [8], the 29.8% prevalence of clinically diagnosed ADHD found in the present study lends strong support to there being a real and substantial increased risk of ADHD among youth with HL.

Although youth with HL were more rarely referred for suspected anxiety disorders (Figure 2), these disorders were very frequently diagnosed (20.4%), suggesting that anxiety symptoms may not have been recognized at the time of referral in this population. The frequent referrals for suspected disruptive disorders were not confirmed in the subsequent diagnoses. This could suggest that disruptive symptoms may be easier to recognize than anxiety during an assumed shorter assessment at referral.

Strengths and limitations

A strength of the present study is the use of a national patient registry, which as far as all data are reported as obliged, includes all Norwegian patients in CAMHS. The NPR provides valuable information about youth with HL and may be considered representative of clinical practice. Our study had several limitations. First, we only included data reported to the NPR as registered by clinicians in CAMHS, and we do not know the validity of the clinically registered diagnoses. However, un-validated registry-based diagnoses have been used in a number of high-quality Scandinavian publications [25,26]. Furthermore, we had no information on possible additional disabilities/physical health conditions known to be frequent and to increase the prevalence of mental disorders in youth with HL [5], but the overall prevalence in our study is in line with the Danish study which included youth with HL who had- or had no additional disabilities. Also, we did not have information about the severity of HL, but a review concluded that severity was not related to the presence of mental health problems. Finally, the available NPR data in our study only included information on youth with HL and could not be directly compared to the GenPop. This limitation was somewhat adjusted for by finding at least some comparisons in the annual NPR reports. We also have another study underway including both populations in the NPR.

Conclusions and clinical implications

This study confirmed a high proportion of youth with HL registered in CAMHS and a particularly high number referred for suspected neurodevelopmental disorders. The relatively younger age at referral in youth with HL suggests that the parents and health workers are aware of the higher vulnerability in this population. However, our findings also point to the particularly weak recognition of anxiety at the time of referral.

Disclosure statement

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Data availability statement

The data that support the findings of this study are available from the NPR, but restrictions apply to the availability of these data, which were used under license for the current study, and so are not publicly available.

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