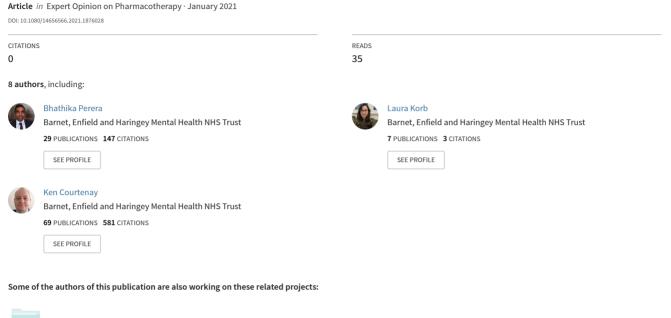
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Patterns of comorbidity and psychopharmacology in adults with intellectual disability and attention-deficit hyperactivity disorder: a UK national cross-sectional audit



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Patterns of comorbidity and psychopharmacology in adults with intellectual disability and attention-deficit hyperactivity disorder: a UK national cross-sectional audit

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ABSTRACT

Background: Attention-deficit hyperactivity disorder (ADHD) is higher in people with intellectual disability (ID) compared to the general population. Available limited evidence suggests this population has increased psychological problems, diagnostic overshadowing and psychotropic prescribing. This audit Identifies and analyzes real-world characteristics, diagnostic practices, treatment, and management of ADHD in adults with ID.

Research Design and Methods: Pooled retrospective case note data for people with ID and ADHD, collected from 30 organizations across the UK, were analyzed. Patients were classified into mild and moderate-profound ID groups. Associated mental health and neurodevelopmental co-morbidity, Demographics, concomitant psychotropics, and mental and behavioral concerns were collected. Group differences were reported using logistic regression models.

Results: Of 445 participants, 73% had co-occurring autism spectrum disorder (ASD) and 65% were prescribed ADHD medications. Those on ADHD medication were less likely to be prescribed antipsychotics (p < 0.001) and antidepressants (p < 0.001). Multiple significant differences were found in ADHD medication response between ID groups and those with/without co-morbid ASD but not associated with challenging behavior reduction.

Conclusions: High levels of neurodevelopmental and psychiatric comorbidity were found. ID severity and the presence of ASD appear to influence the use of certain psychotropic medications. Appropriate use of ADHD medication appears to reduce psychotropic polypharmacy.

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KEYWORDS

Intellectual disability; ADHD; autism spectrum disorder; antipsychotics; antidepressants; stomp

1. Introduction

Attention-Deficit Hyperactivity Disorder (ADHD) has a long history, with the earliest account in 1775 by a German physician, Melchior Adam Weikard, describing signs of ADHD [1]. Over recent decades, the evidence base of ADHD has expanded greatly, but in people with intellectual disability (ID), ADHD still remains understudied and under-recognized [2–5].

ADHD is a neurodevelopmental disorder (NDD) characterized by developmental deficits that produce impairments within personal, social, academic, or occupational functioning [6]. Other neurodevelopmental disorders include intellectual disability (ID), autism spectrum disorder (ASD), dyslexia, dyspraxia, and tic disorders [7]. Even though NDDs frequently coexist, the prevalence of NDDs such as ASD in people with ADHD and ID is not well established. Similarly, evidence on other co-existing mental illnesses in people with ADHD and ID is not well evaluated despite mental health disorders being several times more frequent in people with ID than in those without ID [8,9].

ADHD is estimated to affect approximately 5% of the general population and up to 3% of adults [10–13]. ADHD is 3–10 times more prevalent in people with ID than in the general population and occurs across all age groups [14,15]. Children with ID are more likely to have ADHD than children without ID [16,17]. Adolescents with ID have a higher risk of ADHD than adolescents without ID [18]. Despite this, ADHD continues to be underdiagnosed in people with ID [3]. ADHD is a clinical diagnosis made following a detailed psychiatric and developmental history [6]. The diagnostic criteria are primarily focused on people with normal intellectual functioning. Therefore, there are limitations in applying the diagnostic criteria to people with ID that may account for the under-diagnosis of ADHD in people with ID [19].

Comorbid ADHD in people with ID causes significant functional impairment. Patients suffer from a 'double deficit,' where both disorders affect cognitive functioning [4,5]. In many people, this manifests in severe behavioral difficulties that can impact on social adjustment and functioning [20]. Children with both ID and ADHD diagnoses have more conduct problems than those with ADHD alone [21]. Adults with ID and ADHD have a more severe presentation and less improvement across the lifespan than those without ID [22].

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Q1

Q2 Q3

Q4

Q5 Q6 Thus, there is a compelling argument to understand more about current clinical practices with regards to ADHD in people with ID, to enable accurate diagnosis and management and improve the quality of care delivered. To achieve this, it is necessary to understand the demographics, comorbidities, and impact of pharmacological treatments of ADHD in adults with ID in order to help determine the services and clinical care required for this vulnerable group of people.

a. Aims of the Study

We conducted the first national audit of ADHD in people with ID in the UK, with the aims of assessing the current pharmacological treatment of people with ID, comparing care against national standards, and making recommendations to improve their quality of care.

2. Methodology

2.1. Study design and setting

An online audit of adults with ID and ADHD in the UK was developed by the ADHD Neurodevelopmental Psychiatry Special Interest Group, of the Royal College of Psychiatrists, UK. It was developed through a consultation process by a core team of psychiatrists in ID and academics working in the field of psychiatry of ID. Psychiatrists from ID services across the UK were invited by e-mails to participate in the audit and contribute anonymized data to REDCap platform as part of a national collaborative network [23,24]. Psychiatrists were asked to conduct the audit on all adults (aged 18 years or over) currently under the care of an ID service in the UK with a diagnosis of ADHD. Each site was asked to register with the local Caldicott Guardian and complete a data protection impact assessment (DPIA). The study was reviewed by a research ethics committee in the UK which confirmed that it did not require ethical approval, as the use of the REDCap platform is a well-established methodology for collaborative audits.

2.2. Ethics

The study is a retrospective audit of anonymized data looking at the current clinical practice. This study did not involve any procedures involving human subjects. The NHS Health research authority tool (http://www.hra-decisiontools.org.uk/ research/index.html) was used to confirm that no ethics is needed for this project. It was also confirmed in direct communication with an ethics board. Each participating organization was advised to check and register the project as a local service evaluation/audit and to conduct a Data Protection Impact Assessment (DPIA) or check with the organization Caldecott Guardian and gain organization approval to submit anonymous data to the central REDCap register.

2.3. Data collection

Audit data collected included age, gender, the level of ID (this was divided as per the ICD criteria into two groups, i.e. mild ID

and 'moderate/profound ID based on the rationale in box 1), the presence of neurodevelopmental disorders (ICD10), the presence of comorbid mental illness (ICD10), the presence of challenging behavior, the presence of genetic syndromes, and current ADHD and psychotropic medication regimens. Audit tool had drop-down menus to choose different options except for genetic syndromes which was an open field. No patient identifiable data were collected. Each psychiatrist then entered their local data to the Research Electronic Data Capture (REDCap) tool which is a secure, web-based application designed to support data capture for similar national audits providing an intuitive interface for validated data entry and audit trails for tracking data manipulation and export procedures [25].

2.4. Data analysis

Data on demographics, challenging behavior and medication use were analyzed using SPSS software. The risks of challenging behavior were compared between people prescribed ADHD medication and those not prescribed ADHD medication using logistic regression models. In the base model, adjustment was made for age, gender and, ID status (mild v moderate to profound). Differences in effects of ADHD medication use for people with mild or moderate to profound ID were explored with an appropriate interaction term. The model was further extended by adjustment for ASD status. Similar analyses were conducted to assess the associations between the use of ADHD medication and other psychotropic medications.

3. Results

3.1. Study sample

During the study period, anonymized data for 445 people with ID and a confirmed diagnosis of ADHD were entered to the REDCap database [Table 1] by 47 collaborators from 30 partner organizations in the UK. The majority of people were male (n = 352, 79%) and the remainder female (n = 93, 21%), representing a male to female ratio of 3.8:1. The ages of people ranged from 18 to 68 years where most were at the younger end of the age range. The mean age was 27 years. Seventy-five percent were aged 18 to 29 years. The severity of ID was grouped into two categories, mild ID (n = 200, 45%) and moderate to profound (n = 245, 55%).

3.2. Comorbid mental disorders

Nearly three-fourth of those with ADHD and ID also had a diagnosis of autism spectrum disorder (n = 325, 73%). Other recorded diagnoses of neurodevelopmental disorders were tic disorder (n = 31, 7%), and dyspraxia (n = 13, 3%). Anxiety disorders were the commonest mental disorder reported (n = 65, 15%) followed by depression (n = 43, 10%), psychotic disorders (n = 27, 6%), personality disorders (n = 23, 5%), bipolar affective disorder (n = 22, 5%), obsessivecompulsive disorder (n = 14, 3%), and trauma/stress disorder (n = 10, 2%). Irrespective of the presence of comorbid Table 1. Characteristics of adults with ID and ADHD. Profile of ID severity, age distribution, and comorbid ASD diagnosis, stratified by gender. Note: missing age data for one female patient. **Box 1: Rationale of having two groups -mild and moderate- profound ID** 1.Each of the 3 sub-groups of ICD 10 moderate (F71), severe (F72) and profound ID (F73) have a low prevalence (9% moderate ID, 4% severe ID, and about 2% profound) and together they would combine to form 15% of the total ID population (King et.al 2009). Taken individually it would be difficult to achieve satisfactory power to deliver meaningful conclusions. 2.Moderate, Severe and profound ID is difficult to assess and classify which causes significant issues with accuracy of specific diagnosis of degree of ID.

	Male (n = 352)	Female (n = 93)	Both $(n = 445)$
Severity of ID	157 (45%)	43 (46%)	200 (45%)
Mild	195 (55%)	50 (54%)	245 (55%)
Moderate-Profound			
Age	65 (18%)	20 (22%)	85 (19%)
18–20	207 (59%)	55 (60%)	262 (59%)
21-30	57 (16%)	8 (9%)	65 (15%)
31–40	13 (4%)	6 (7%)	19 (4%)
41–50	9 (3%)	3 (3%)	12 (3%)
51–60	1 (0%)	0 (0%)	1 (0%)
61–70			
Diagnosis of ASD	262 (74%)	63 (68%)	325 (73%)

disorders, the majority exhibited challenging behavior (n = 301, 68%).

3.3. Genetic syndromes

Genetic disorder was found in 52 people (12%). More than 20 different genetic syndromes were represented in the group. The three most common were Down syndrome (trisomy 21), Smith-Magenis syndrome (chromosome 17p deletion), and Di George syndrome (chromosome 22q11.2 deletion).

3.4. ADHD medication use

Patient characteristics depending on the use of ADHD medications are provided in Table 2. Approximately two-third (n = 285, 65%) of the participants were using prescribed ADHD medication. Methylphenidate was the most commonly used (n = 156, 54% of users). The next most commonly used ADHD medication was atomoxetine (n = 112, 39% of users). The rest of the patients were on lisdexamfetamine, clonidine, guanfacine, and dexamfetamine. Various reasons were recorded for people not prescribed ADHD medication that included not having active symptoms; behavior controlled without medication; behavior controlled with other medications such as antipsychotics; medication options still being explored; medication tried previously but ineffective or made behavior worse; medication had intolerable side effects, such as agitation, aggression, or poor sleep; medication had undesirable interactions with other medications such as antiepileptics; noncompliance with medication; noncompliance with necessary medical investigations; medical contraindications, such as long QT interval; and disagreement with medication by patients, parents, or carers.

3.5. Antipsychotic medication use

Antipsychotic medications were frequently prescribed in this group, in 263 patients (59%). Of those on antipsychotics, 226 (86%) were using one type of antipsychotic, 24 (9%) using two,

Table 2. Patient characteristics depending on the use of ADHD medications. Profile of gender distribution, ID severity, age distribution, stratified by use of ADHD medications. Profile of types of ADHD medications used. Note: missing medication usage data for two male patients and age data for one female patient.

	On ADHD medications (n = 285)	Not on ADHD medications (n = 158)
Gender	225 (79%)	125 (79%)
Male	60 (21%)	33 (21%)
Female		
ID	139 (49%)	60 (38%)
Mild	146 (51%)	98 (62%)
Moderate-Profound		
Age	51 (18%)	34 (22%)
18–20	174 (61%)	87 (55%)
21–30	42 (15%)	22 (14%)
31–40	9 (3%)	10 (6%)
41–50	9 (3%)	3 (2%)
51–60	0 (0%)	1 (1%)
61–70		
Type of ADHD medication	156 (55%)	N/A
Methylphenidate	16 (6%)	N/A
preparations	112 (39%)	N/A
Dexamfetamine	10 (4%)	N/A
preparations	5 (2%)	N/A
Atomoxetine		
Clonidine		
Guanfacine		

6 (2%) using three, and 7 (3%) using four or more. Of those on antipsychotics, 197 (75%) displayed challenging behavior. It is possible that antipsychotics were prescribed to manage challenging behavior, as a slightly higher proportion of those on antipsychotics had challenging behavior compared to the overall rate (68%). Of those on antipsychotics, however, only a small proportion of people (n = 91, 35%) had an underlying mental illness that warranted antipsychotic use: 26 (9%) had a known psychotic disorder, 20 (8%) had bipolar affective disorder, and 45 (17%) had anxiety disorders.

There were associations between using ADHD and antipsychotic medications. Of the 285 using ADHD medications, 149 (52%) were using antipsychotics. Of the 158 people not using ADHD medications, 114 (72%) were using antipsychotics. Two hundred sixty-three people were using antipsychotics and of them 149 (57%) were using ADHD medications in addition. Of the 180 people not using antipsychotics, 136 (76%) were using ADHD medication. Using ADHD medications was therefore associated with a lower usage of antipsychotics.

3.6. Other psychotropic medication use

Various other psychotropic medications were frequently prescribed of which the most common were antidepressants of all classes (n = 120, 27%). People with moderate to profound ID were less likely to use antidepressants compared to people with mild ID (OR 0.60, 95% CI 0.38–0.94, p = 0.03;Table 4a). Analysis of antidepressant use among people with ID and ADHD showed that people using ADHD medications were less likely to use antidepressants compared to people with ID not using ADHD medications (OR 0.32, 95% CI 0.20–0.50, p < 0.001;Table 4a). Use of other medications included benzodiazepines (n = 96, 22%), melatonin (n = 81, 18%), antiepileptics (n = 65, 15%), and mood stabilizers (n = 61, 14%). Less commonly used medications were z-drugs (n = 16, 4%), pregabalin or gabapentin (n = 13, 3%), anticholinergics (n = 12, 3%), propranolol (n = 7, 2%), and antihistamines (n = 5, 1%).

3.7. ADHD medications and challenging behavior

There was no statistically significant difference in challenging behavior between those using ADHD medication and those not (OR 1.26, 95% CI 0.82–1.95, p = 0.30;Table 5). The moderate to profound ID group was more likely to show challenging behavior than the mild ID group (OR 2.45, 95% CI 1.61–3.73, p < 0.001;Table5) irrespective of ADHD medications use (p = 0.71 for interaction term).

The analysis of sedative usage in the group did not reveal a statistically significant difference (p = 0.75; Table 4b) whether using ADHD medications or not. A sub-analysis of sedative use relative to severity of ID showed a statistically significant increase in the use of these drugs in people with moderate to profound ID (OR 2.25, 95% CI 1.50–3.39, p < 0.001;Table4b) compared with people with mild ID irrespective of their use of ADHD medications (p = 0.50 for interaction term).

Using ADHD medications did not make a statistically significant difference to the use of mood stabilizers or not (p = 0.49; Table 4c) but people with moderate to profound ID group were more likely to use mood stabilizers (OR 3.05, 95% CI 1.94–4.82, p < 0.0001;Table4c) compared to the mild ID group irrespective of the use of ADHD medication (p = 0.75 for interaction term).

3.8. Use of ADHD medications and use of antipsychotics

Those prescribed ADHD medications were significantly less likely to use antipsychotic medications compared to those not using them (OR 0.45, 95% CI 0.29–0.69, p < 0.001; Table 2d). People with moderate to profound ID, irrespective of their use of ADHD medications were more likely to be prescribed antipsychotic medications compared to people with mild ID (OR 1.79, 95% CI 1.20 to 2.66, p < 0.004;Table 4d)

3.9. People with ADHD and ASD

People with ADHD and ASD had similar levels of challenging behavior compared to people without ASD after accounting for ID status (OR 1.25, 95% CI 0.78–1.99, p = 0.35). There were no statistically significant differences in their use of antidepressants (OR 1.23, 95% CI 0.73–2.08, p = 0.44), and mood stabilizers (OR 0.98, 95% CI 0.59–1.63, p = 0.94) between ASD and non-ASD groups, after accounting for ID status. People with ASD were more likely to use antipsychotic medications (OR 2.58, 95% CI 1.63–4.07, p < 0.001) and sedatives (OR 2.66, 95% CI 1.59–4.47, p < 0.001) compared to people without ASD, after accounting for ID status.

4. Discussion

Greater awareness of ADHD among clinicians and availability of treatments have led to the need to understand ADHD in people with ID and improve current practice in caring for them. This study was based on the national ADHD in ID crosssectional audit in the UK. It is the only large-scale study capturing data on demographics, comorbidities, and treatments of adults with ADHD and ID that we are aware of.

4.1. Characteristics of people with ADHD and ID

The characteristics of people with ID and ADHD in a large sample such as this have not been reported before. The male to female ratio was nearly 4:1 that is higher than reported in children (2.3:1) and adults (1.5:1) in the general population [26,27]. Three-quarters of the group were between the ages of 18 to 30 years, suggesting that the diagnosis of ADHD in ID is commoner in younger people with ID, likely reflecting that clinicians are considering ADHD diagnosis more in younger people. This raises the question of whether the diagnosis of ADHD is missed in older people with ID, as it is a diagnosis that was made less frequently in previous decades. Finding that a larger percentage of people with ID and ADHD (55%) were in the moderate to profound ID group was interesting. This could be due to various reasons such as some ID services do not accept people with milder ID and people with mild ID and ADHD may access ADHD treatment through generic non-ID ADHD services. There is also a possibility that this could be due to diagnostic challenges when separating symptoms of inattentive from lower intellectual functioning in the milder ID group.

4.2. ADHD medications

In this study, methylphenidate was the most commonly used ADHD medication (54%) followed by atomoxetine (39%). This fits in with the NICE guideline recommendation that methylphenidate and dexamfetamine preparations as the first line of pharmacological treatment in ADHD. The usage of atomoxetine needs to be explored further since NICE guidelines recommend it as a second line of ADHD medication. Anecdotal evidence from clinicians suggests that atomoxetine is also used for ADHD in people with ID given its 24-hour control of symptoms.

4.3. Antipsychotic and other psychotropic medication usage

Patient characteristics depending on the use of antipsychotic medications are outlined in Table 3. The finding that antipsychotic use was significantly lower in people on ADHD medications compared to those who were not on ADHD medications needs further exploration. It is possible that antipsychotics are inappropriately used to manage ADHD symptoms without a strong evidence base for their effectiveness. This is consistent with existing evidence that many people use antipsychotics in the absence of severe mental illness [28]. The correct use of ADHD medications control symptoms more effectively

and may reduce the use of antipsychotics and their associated side effects [29]

Significantly low use of antidepressants among people with ID on ADHD medication is another interesting finding. This may be due to reduced anxiety associated with ADHD symptom control. Low use of antidepressants, but high use of sedatives, mood stabilizers and antipsychotics in people with moderate to profound ID, has not been reported before. High use of mood stabilizers, mainly antiepileptics, was likely to be linked to high prevalence of epilepsy in moderate to profound ID group. This study did not separate whether antiepileptics were used for mood disorders or epilepsy. High rate of challenging behavior reported in this study in more moderate to profound ID group may explain the high use of antipsychotics and sedatives.

Table 3. Patient characteristics depending on the use of antipsychotic medications. Profile of gender distribution, ID severity, comorbid ASD diagnosis, and use of ADHD medications, stratified by the use of antipsychotic medications. Note: missing medication usage data for two male patients.

	On antipsychotics (n = 263)	Not on antipsychotics (n = 180)
Gender	208 (79%)	142 (79%)
Male	55 (21%)	38 (21%)
Female		
Severity of ID	102 (39%)	97 (54%)
Mild	161 (61%)	83 (46%)
Moderate-Profound		
Diagnosis of ASD	214 (81%)	110 (61%)
ADHD medications	149 (57%)	136 (76%)
On ADHD medications	114 (43%)	44 (24%)
Not on ADHD medications		

Table 4. Multivariable logistic regression models for factors associated with the use of psychotropic medications Table 4a. – Odds ratios for use of anti-depressants.

Characteristic	Odds ratio	95% CI	p-value	
Age				
<30	1.00			
30–39	1.36	0.76 to 2.43	0.301	
40+	2.99	1.40 to 6.39	0.005	
Sex				
Female	1.00			
Male	0.52	0.31 to 0.87	0.013	
ID				
Mild	1.00			
Moderate-Profound	0.60	0.38 to 0.94	0.025	
ADHD medication				
No	1.00			
Yes	0.32	0.20 to 0.50	< 0.001	

Table 4b. Odds ratios for use of sedatives.

Characteristic	Odds ratio	95% CI	p-value
Age			
<30	1.00		
30–39	0.72	0.41 to 1.25	0.244
40+	1.47	0.71 to 3.07	0.302
Sex			
Female	1.00		
Male	0.74	0.46 to 1.21	0.230
ID			
Mild	1.00		
Moderate- Profound	2.25	1.50 to 3.39	< 0.001
ADHD medication			
No	1.00		
Yes	0.94	0.62 to 1.42	0.751

Table 4c.	Odds	ratios	for	use	of	mood	stabilizers.
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Characteristic	Odds ratio	95% CI	p-value
Age			
<30	1.00		
30–39	1.73	0.99 to 3.00	0.053
40+	2.63	1.24 to 5.57	0.012
Sex			
Female	1.00		
Male	0.89	0.52 to 1.50	0.656
ID			
Mild	1.00		
Moderate-Profound	3.05	1.94 to 4.82	< 0.001
ADHD medication			
No	1.00		
Yes	1.17	0.75 to 1.84	0.491

Table 4d. Odds ratios for use of anti-psychotics.

Characteristic	Odds ratio	95% CI	p-value	
Age				
<30	1.00			
30–39	2.36	1.33 to 4.18	0.003	
40+	2.45	1.05 to 5.72	0.038	
Sex				
Female	1.00			
Male	0.97	0.60 to 1.58	0.905	
ID				
Mild	1.00			
Moderate- Profound	1.79	1.20 to 2.66	0.004	
ADHD medication				
No	1.00			
Yes	0.45	0.29 to 0.69	< 0.001	

Table 5. Logistic regression model for factors associated with challenging behavior.

Characteristic	Odds ratio	95% CI	p-value	
Age				
<30	1.00			
30–39	2.14	1.15 to 4.00	0.017	
40+	1.61	0.69 to 3.75	0.267	
Sex				
Female	1.00			
Male	1.29	0.78 to 2.12	0.321	
ID				
Mild	1.00			
Moderate- Profound	2.45	1.61 to 3.73	< 0.001	
ADHD medication				
No	1.00			
Yes	1.26	0.82 to 1.95	0.297	

The presence of comorbid mental illnesses in people with ID raises challenges in treatment. In this study, the prevalence of autism in people with ID and ADHD was 73%, supporting previous findings [30]. The high prevalence of comorbidities may relate to shared etiology based in genetic abnormalities and neurobiological mechanisms in neurodevelopmental disorders [31]. This may also be due to the data collection method in this audit; hence, a larger number of people with ASD and ID were captured. Larger population-representative studies are needed to establish whether there is a higher prevalence of ASD when there are two existing NDDs (ID and ADHD) [32].

The presence of comorbid disorders may affect ADHD treatment. For example, in children with ADHD, stimulants are tolerated less by those with comorbid ID or autism [33]. At present, there is limited evidence on how clinical

management is altered in the context of multiple neurodevelopmental comorbidities [7].

4.4. Challenging behavior and ADHD

In this audit, 68% of those with ID and ADHD were reported to display challenging behavior which is significantly higher compared to 18% in those with ID alone reported in other studies [34]. This raises a clinically relevant suggestion whether ADHD should be considered in people who present with behavioral challenges especially given that the accurate diagnosis and effective treatment of ADHD in ID can considerably reduce the functional and psychosocial burden and improve a wide range of long-term outcomes [3,35].

4.5. Strengths and limitations

A strength of the audit is that individual audits done in different organizations were added together to get a picture of current care of people with ID and ADHD at a national level. As far as we are aware, this is the largest study on ADHD in adults with ID. Data in this audit allow us to understand psychiatric comorbidities, pattern of medication use, and the interactions between these. The study is limited in not having comparative data on other groups, such as adults with ID but not ADHD, or adults with ADHD but not ID, however, this is not within the remits of an audit.

There are no data on how many psychiatrists were approached and whether those who responded entered data for all their patients with ID and ADHD leading to a selection bias in this sample. Furthermore, there was no agreement on how ADHD was diagnosed in adults with ID by participating psychiatrists in this audit. This may have caused some degree of heterogeneity in the audit sample. As a cross-sectional audit, we analyzed the patterns of ADHD and antipsychotic medication use but are not able to draw definite causative associations. We do not have information to stratify our participants by socio-economic measures and therefore cannot assess the influence of social context on ADHD in ID.

Additional studies are needed to further our understanding of ADHD in people with ID. Clarifying the prevalence and developmental trajectory of ADHD in adults with ID is important since, given the debate about the nature of adult ADHD and its relationship to childhood ADHD, there is a need for detailed longitudinal characterization of ID across ages to examine its patterns of origin and persistence throughout the lifespan [7]. Future research is needed into multimorbidity in neurodevelopmental disorders because people with ID and ADHD frequently have comorbid autism and other mental disorders. We speculate that many people with ID and challenging behavior may have undiagnosed ADHD. Current strategies for assessment and treatment typically focus on a single disorder, yet treatment needs might be altered in the presence of other disorders. There is a risk of approaching disorders too rigidly and failing to recognize comorbidities or symptoms beyond the primary diagnosis of interest [7].

ADHD may present differently in people with ID and responses to treatment may vary [3]. Criteria that are normally used to diagnose ADHD may need to be adapted according to the presence and severity of ID [19]. Currently, screening and assessment for ADHD are difficult because of the absence of validated diagnostic tools for ADHD in those with ID [2]. Understanding what treatment options are effective for ADHD in adults with ID is essential [5]. We suspect that using ADHD medication reduces the usage of antipsychotics but randomized controlled trials are required to confirm this. It is important to characterize how social context contributes to impairments and long-term outcomes of ID and ADHD [7]. Previous studies demonstrate that socio-economic deprivation confers an increased risk of physical and mental disorders on people with ID [19]. Social context may have a major influence on the prevalence, severity, and characteristics of ADHD in people with ID. It is important to highlight the very high levels of ASD co-morbid with ADHD in the study sample (73%). This could be due to the sample selection being from specialist care where complexity and co-morbidity would be an obvious confounder. Given the significantly high proportion (nearly 3 out of 4) presence of comorbid ASD, it was not considered suitable to adjust for the ASD especially as many in this population would have had a clinical diagnosis as opposed to established validated diagnostic testing. Findings of this audit cannot be generalized due to clear limitations in the methodology; however, it provides some indications for clinicians when managing people with ID and ADHD.

5. Conclusions

In conclusion, ADHD is a chronically impairing condition that is prevalent yet frequently neglected in adults with ID. The diagnosis of ADHD can be difficult but is important since there is a strong evidence base for effective management. This national study of ADHD in adults with ID provides insights into the variety of psychiatric comorbidities and the complexities of medication use. Further understanding of the clinical characteristics of ADHD in ID, together with increasing knowledge about their underlying neurobiology, should guide our progress toward the most effective treatment for this vulnerable group of people.

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Author contributions

BP, JC, LK, AB, KC, St, WH and RS conceptualized, analyzed, designed, and wrote up the study. All authors contributed significantly. All authors are in agreement to be accountable for all aspects of the work.

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References

Papers of special note have been highlighted as either of interest (•) or of considerable interest (••) to readers.

- Ollendick TH, Jarrett MA, Grills-Taquechel AE, et al. Comorbidity as a predictor and moderator of treatment outcome in youth with anxiety, affective, attention deficit/hyperactivity disorder, and oppositional/conduct disorders. Clin Psychol Rev. 2008;28 (8):1447–1471.
- Barkley RA, Peters H. The earliest reference to ADHD in the medical literature? Melchior Adam Weikard's description in 1775 of "attention deficit" (mangel der Aufmerksamkeit, Attentio Volubilis). J Atten Disord. 2012;16(8):623–630.
- Perera B, Courtenay K. ADHD and challenging behaviour in people with intellectual disability: should we screen for ADHD? Psychiatr Danub. 2017;29(Suppl 3):562–564.
- Perera B. Attention deficit hyperactivity disorder in people with intellectual disability. Ir J Psychol Med. 2018;35(3):213–219.
- 5. Rose E, Bramham J, Young S, et al. Neuropsychological characteristics of adults with comorbid ADHD and borderline/mild intellectual disability. Res Dev Disabil. 2009;30(3):496–502.
- Al-Khudairi R, Perera B, Solomou S, et al. Adults with intellectual disability and attention deficit hyperactivity disorder: clinical characteristics and medication profiles. Br J Lear Disabil. 2019;47(2): 145–152.
- Thisclinic-based study shows the high use of antipsychotic medications among people with intellectual disability and ADHD not taking ADHD medications
- American Psychiatric Association. Diagnostic and statistical manual of mental disorders: DSM-5. Arlington: American Psychiatric Publishing; 2013.
- 8. Thapar A, Cooper M, Rutter M. Neurodevelopmental disorders. Lancet Psychiatry. 2017;4(4):339–346.
- 9. Cooper SA, Smiley E, Morrison J, et al. Mental ill-health in adults with intellectual disabilities: prevalence and associated factors. Br J Psychiatry. 2007;190(1):27–35.
- Hughes-McCormack LA, Rydzewska E, Henderson A, et al. Prevalence of mental health conditions and relationship with general health in a whole-country population of people with

intellectual disabilities compared with the general population. BJPsych Open. 2017;3(5):243–248.

- Polanczyk G, Rohde LA. Epidemiology of attention-deficit/hyperactivity disorder across the lifespan. Curr Opin Psychiatry. 2007;20 (4):386–392.
- Simon V, Czobor P, Bálint S, et al. Prevalence and correlates of adult attention-deficit hyperactivity disorder: meta-analysis. Br J Psychiatry. 2009;194(3):204–211.
- Polanczyk G, De Lima MS, Horta BL, et al. The worldwide prevalence of ADHD: A systematic review and metaregression analysis. Am J Psychiatry. 2007;164(6):942–948.
- Fayyad J, De Graaf R, Kessler R, et al. Cross-national prevalence and correlates of adult attention-deficit hyperactivity disorder. Br J Psychiatry. 2007;190(5):402–409.
- Emerson E. Prevalence of psychiatric disorders in children and adolescents with and without intellectual disability. J Intellect Disabil Res. 2003;47(1):51–58.
- Simonoff E, Pickles A, Wood N, et al. ADHD symptoms in children with mild intellectual disability. J Am Acad Child Adolesc Psychiatry. 2007;46(5):591–600.
- Voigt RG, Barbaresi WJ, Colligan RC, et al. Developmental dissociation, deviance, and delay: occurrence of attention-deficit-hyperactivity disorder in individuals with and without borderline-tomild intellectual disability. Dev Med Child Neurol. 2006;48 (10):831–835.
- Baker BL, Neece CL, Fenning RM, et al. Mental disorders in five-year-old children with or without developmental delay: focus on ADHD. J Clin Child Adolesc Psychol. 2010;39(4):492–505.
- Neece CL, Baker BL, Crnic K, et al. Examining the validity of ADHD as a diagnosis for adolescents with intellectual disabilities: clinical presentation. J Abnorm Child Psychol. 2013;41 (4):597–612.
- 20. Perera B, Audi S, Solomou S, et al. Mental and physical health conditions in people with intellectual disabilities: comparing local and national data. Br J Learn Disabil. 2020;48(1):19–27.
- This study using national data highlights the prevalence of multimorbidity amongst people with intellectual disability
- Lowe K, Allen D, Jones E, et al. Challenging behaviours: prevalence and topographies. J Intellect Disabil Res. 2007;51(8):625–636.
- Ahuja A, Martin J, Langley K, et al. Intellectual disability in children with attention deficit hyperactivity disorder. J Pediatr. 2013;163 (3):890–895.
- 23. Xenitidis K, Paliokosta E, Rose E, et al. ADHD symptom presentation and trajectory in adults with borderline and mild intellectual disability. J Intellect Disabil Res. 2010;54(7):668–677.
- 24. Kolias AG, Cowie CJ, Tarnaris A, et al. Proposal for a British neurosurgical trainee research collaborative. Br J Neurosurg. 2012;26(3):434–435.
- 25. Dowswell G, Bartlett DC, Futaba K, et al. How to set up and manage a trainee-led research collaborative. BMC Med Educ. 2014;14(1):1–6.
- Harris PA, Taylor R, Thielke R, et al. Research electronic data capture (REDCap)—a metadata-driven methodology and workflow process for providing translational research informatics support. J Biomed Inform. 2009;42(2):377–381.
- Willcutt EG. The prevalence of DSM-IV attention-deficit/hyperactivity disorder: a meta-analytic review. Neurotherapeutics. 2012;9 (3):490–499.
- Fayyad J, Sampson NA, Hwang I, et al. The descriptive epidemiology of DSM-IV adult ADHD in the world health organization world mental health surveys. ADHD Atten Def Hyp Disord. 2017;9(1):47–65.
- Sheehan R, Hassiotis A, Walters K, et al. Mental illness, challenging behaviour, and psychotropic drug prescribing in people with intellectual disability: UK population based cohort study. BMJ. 2015;351:h4326.
- McQuire C, Hassiotis A, Harrison B, et al. Pharmacological interventions for challenging behaviour in children with intellectual disabilities: a systematic review and meta-analysis. BMC Psychiatry. 2015;15(1):303.

- Clark T, Feehan C, Tinline C, et al. Autistic symptoms in children with attention deficit-hyperactivity disorder. Eur Child Adolesc Psychiatry. 1999;8(1):50–55.
- Williams NM, Zaharieva I, Martin A, et al. Rare chromosomal deletions and duplications in attention-deficit hyperactivity disorder: a genome-wide analysis. Lancet. 2010;376 (9750):1401–1408.
- 33. Reichow B, Volkmar FR, Bloch MH. Systematic review and meta-analysis of pharmacological treatment of the symptoms of

attention-deficit/hyperactivity disorder in children with pervasive developmental disorders. J Autism Dev Disord. 2013;43 (10):2435–2441.

- Bowring DL, Totsika V, Hastings RP, et al. Challenging behaviours in adults with an intellectual disability: a total population study and exploration of risk indices. Br J Clin Psychol. 2017;56(1):16–32.
- 35. Shaw M, Hodgkins P, Caci H, et al. A systematic review and analysis of long-term outcomes in attention deficit hyperactivity disorder: effects of treatment and non-treatment. BMC Med. 2012;10:99.