Attention Deficit Hyperactivity Disorder in people with Intellectual Disability

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Two case reports of people with severe intellectual disability (ID), Autism and challenging behaviour are discussed here to describe the presentation of attention-deficit hyperactivity disorder (ADHD) in people with ID. Both cases highlight how the diagnosis of ADHD can be missed and the behaviours attributed to ID and autism, which could lead to using ineffective treatment strategies. The case reports illustrate the importance of the diagnosis and treatment of ADHD in people with ID and how it can make a difference to their clinical presentation and quality of life.

Attention-deficit hyperactivity disorder (ADHD) and intellectual disability (ID) are categorised as neuro-developmental disorders in Diagnosis and Statistical Manual of Mental Disorders 5th Edition (DSM V). ADHD is a characterised by a persistent pattern of inattention and/or hyperactivity-impulsivity that interferes with functioning or development. ID is defined as a disorder with onset during the developmental period that includes both intellectual and adaptive functioning deficits in conceptual, social and practical domains (American Psychiatric Association, 2013).

The prevalence of ADHD in general population is estimated to be (approximately) 5.3% (Polanczyk *et al.* 2007). Most studies related to the ID population are done in children. Research shows that children with ID are at least three times more likely to have ADHD compared with children without ID (Dekker *et al.* 2002; Voigt *et al.* 2006; Baker *et al.* 2010). Adolescents with ID continue to have a higher risk of ADHD (risk ratio: 3.38:1) compared to their peers without ID (Neece *et al.* 2013). Given the trajectory of ADHD in childhood, it is likely that most individuals with ID and ADHD continue to experience ADHD symptoms into adulthood (Pearson *et al.* 2000) but the evidence on ADHD in adults with ID is limited.

Autism is another neurodevelopmental disorder that is seen among people with ID. Around a third of people who have learning disabilities (IQ less than 70) do have autism, according to research published by Emerson and Baines, in 2010. ADHD is commonly seen among people with Autism. Studies in children have shown that 28% of children with autism has a diagnosis of

ADHD (Simonoff *et al.* 2008). Given ADHD has high prevalence rate in people with ID and also in people with autism, presence of ADHD in people with both ID and Autism can be hypothesised to be even higher.

Clinical experience suggests that adults with ADHD and ID are under-diagnosed for various reasons. Research shows that ADHD is often under-diagnosed and under-treated, even in non-ID populations (Ginsberg *et al.* 2014). Attention deficit is a core symptom of ADHD and is a symptom that people with ID experience. Melnyk and Das (1992) reported that attention deficit is 'characteristic of individuals with mental retardation' that may have dissuaded clinicians from considering ADHD as a diagnosis in people with ID. Separating out attention deficits due to ID from ADHD in an individual with both ID and ADHD can be challenging and controversial. Some of the main manifestations of ADHD, such as poor organisation, forgetfulness and time management, are not likely to be clearly evident in people with ID as their functional needs are met by their carers. Some people with ID do not have necessary cognitive and communication skills to reflect on their difficulties and give a detailed description of symptoms they experience such as inattention and impulsivity. Furthermore, not all of the diagnostic criteria in DSM V are applicable to people with ID. For example, criterion 6 'often talks excessively' and criterion 7 'often gives the answer before questions have been completed' cannot be applied in individuals with ID and non-verbal skills. In addition, attention-deficit symptom criteria are difficult to apply in people who have severe ID and do not engage in activities that require the ability to pay and sustain attention, which are the main criteria under the attention domain (American Psychiatric Association, 2013).

ADHD in the non-ID population remains one of the most researched disorders in medicine (Spencer *et al.* 2000). There is growing evidence that ADHD is a valid

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diagnosis even in people with ID (Neece *et al.* 2013) and data on the validity of ADHD is more compelling than for many other medical conditions (Spencer *et al*. 2000).

Case report

Case 1

A 50-year-old woman with severe ID, Autism and without verbal communication skills presented with challenging behaviour since early childhood. She had lived in residential care placements for most of her life with deprivation of her liberty to keep her safe due to the challenging nature of her behaviour. Carers often described her as restless. The behavioural difficulties included stripping-off her clothes, screaming, urinating inappropriately and physical aggression towards staff members and residents. There was no clear pattern to the onset of the behaviours. Staff described how she would exit her room and target a specific staff member or residents. She would remain agitated for many hours thereafter. There was no history to suggest severe mental illness except signs of anxiety. These difficulties go back to early childhood. She had regularly been prescribed various psychotropic medications, including antipsychotic (clopixol) and anxiolytic (sertraline) medication to manage her behaviour. Various behavioural and psychological assessments were carried out without any significant reduction in challenging behaviour or carer stress. Psychotropic medications did not make a significant improvement in her behaviour but attempts to reduce her medication led to a worsening of her behaviour.

A clinical interview with her carers revealed symptoms such as 'been fidgety most of the time', 'not able to sit in one place for long', 'appear restless', 'constantly moving around', 'not been able to engage in leisure activities', 'often on the go as driven by a motor', 'difficulty waiting for her turn' and 'often interrupts and intrude others' which have always been present as far as carers were able to recall. History from current carers goes back to last 10 years. Family members are not in touch to get a childhood history. Above symptoms met the hyperactivity/impulsivity criteria for a diagnosis of ADHD according to DSM V. It was difficult to consider diagnostic criteria for 'Inattention' except for the 'easily distractible' criteria, which she exhibited. These symptoms were reported to go back to her childhood in her clinical records. A diagnosis of ADHD was made and she was commenced on a non-stimulant (atomoxetine 18 mg OD). The dose was titrated up to 60 mg without significant change in her presentation, following which atomoxetine was stopped and a long-acting methylphenidate preparation was commenced. There was no change in her presentation with the starting dose but with increments in dose, a clear improvement in her behaviour which can be considered as hyperactivity/ impulsivity symptoms of ADHD became evident. There was a clearly observable reduction in the stripping-off of her clothes, screaming or wetting herself. Staff described her mood as 'relaxed, settled and pleasant'. She was able to sit in one place and engage in activities that she enjoyed such as listening to music.

Case 2

A 55-year old man with severe ID, autism and without verbal communication presented to services with challenging behaviour since early childhood. He had always lived in residential care placements as his parents could not manage his behaviour. Childhood reports described him as 'overactive', 'screaming most of the time', 'throwing things that he can get hold of' and 'keeping everyone up at night'. Even as an adult, he was hyperactive and always wandered around his placement. The challenging behaviour included pulling people along with him and being unable to sit and engage in activities. He had been prescribed an antipsychotic (risperidone) and anxiolytic (citalopram) to manage his anxiety.

His presentation again included 'being fidgety most of the time', 'not able to sit in one place for long', 'feeling restless', 'constantly moving around', 'not able to engage in leisure activities', 'often on the go, as if driven by a motor', 'difficulty waiting for his turn' and 'often interrupts and intrude others'. These symptoms go back to his childhood. Adult ADHD was diagnosed as per DSM V criteria, following an interview with his carers. He was commenced on Atomoxetine, resulting in a clear improvement in his presentation at a dose of 60 mg. Staff described him sitting in one place and watching TV, engaging in social activities for the first time in his life. Staff described his mood as calm and relaxed.

Both patients were followed up for nearly 3 months from the point of observing benefits.

Discussion

Diagnosis

The cases described were regarded as two individuals with severe ID and autism with challenging behaviour dating back to childhood. Such patients are often regularly in contact with mental health and ID services. Behavioural and psychological strategies were not effective in managing their behaviours and reducing risks to themselves. Psychotropic medications, including antipsychotics, had been used for a long time as part of their treatment due to the severity of nature of the challenging behaviour. One could argue that the use of psychotropic medications is to manage underlying

anxiety symptoms which is one of the commonest mental disorders in people with ID (Emerson, 2003). It is not uncommon in the United Kingdom to prescribe psychotropic medications for challenging behaviour in the absence of a documented underlying mental illness (Sheehan *et al*. 2015).

ADHD diagnostic assessment includes a detailed psychiatric history to rule out comorbid mental disorders and structured ADHD questionnaires to explore symptoms of inattention, hyperactivity and impulsivity (Pettersson *et al*. 2015; Ramos-Quiroga *et al*. 2016). Diagnostic Manual- Intellectual Disability (Fletcher 2007) and Diagnostic criteria for Psychiatric Disorders for Adults with Learning disabilities have adopted DSM IV and International Classification of Diseases 10 criteria to be applicable in ID population to make the diagnosis of ADHD. There are no validated structured questionnaires for ADHD in ID. This makes such diagnosis challenging for clinicians. Some screening tools for ADHD are shown to be less specific and less sensitive even in the non-ID population (Pettersson *et al*. 2015). Therefore, at present, ADHD diagnosis in ID is often made by clinicians who have undergone special training on diagnosing ADHD with some adaptations to existing structured questionnaires.

Symptoms such as hyperactivity can lead to inner tension and restlessness, which is often misdiagnosed as anxiety (Kooij *et al*. 2010). Patients with intellectual disabilities are less likely to be able to explain their inner feelings, which can further lead to manifestation of such symptoms as behavioural difficulties and miss- or over diagnosis of anxiety disorders and agitation. Under recognition of ADHD is also partly due to the belief that ADHD is a childhood disorder and does not persist into adulthood (Ginsberg *et al*. 2014). Neece *et al*. (2011) followed a group of children with ID for 8 years. They showed that children in the ID group exhibited higher rates of ADHD (over three times as high) consistently. This shows that when adults with ID present to mental health services, a high degree of suspicion should be used to look for underlying ADHD symptoms.

The relationship between autism and ADHD can affect the diagnosis. Mayes *et al*. (2012) discussed if autism is misdiagnosed as ADHD given the non-significant differences found between children with autism and ADHD on neuropsychological tests including measures of attention, working memory, processing speed and graphomotor skills. Further studies have shown that deficits in attention and working memory do not appear to be distinctive in discriminating autism from ADHD, however, response-inhibition was observed only in the ADHD group (Craig *et al*. 2016). Both conditions are considered as additive impairments rather than two distinct conditions. This adds to the complexity of diagnosing ADHD in a person with both ID and autism.

ADHD symptoms presentation

Both individuals in this case report consistently presented with hyperactivity and impulsivity but ADHD as a diagnosis appeared not to have been considered. This is due to the fact that carers often tend to report results of ADHD such as 'stripping clothes' as that's the most distressing and stressful symptom for the person and carers. As a result, symptoms of hyperactivity and impulsivity in both cases which were manifested as 'being fidgety, constantly moving around, not able to engage in leisure activities, on the go, difficulty waiting for turn' were not given much attention or possibly considered as part of ID and autism. These symptoms met the DSM V criteria for hyperactivity/impulsivity domain. Criteria for inattention was not met in both patients. However, diagnosis of adult ADHD can be made by only meeting criteria for hyperactivity/impulsivity domain. Challenging task for clinicians working with people with ID is to make a judgement whether the severity of hyperactivity, impulsivity and inattentive symptoms are more than what is expected for the specific individual's level of ID. In these two cases, author considered both individuals experienced symptoms of hyperactivity and impulsivity more than what is expected from someone with severe ID.

Treatment of ADHD in ID

We observed in these cases that prescribing medication for ADHD made a significant difference to the patients' behaviour and mental state, with an improvement in their level of hyperactivity and impulsivity, which in turn led to a reduction in their challenging behaviour. The two people were considered by their carers to never be able to sit in one place for an appreciable period of time or to enjoy activities, such as watching TV. Once established on medication they were able to engage in and enjoy community activities.

Guidelines recommend using medication in the treatment of moderate to severe ADHD [National Institute for Health and Clinical Excellence (NICE), 2008]. The severity of ADHD is assessed on the level of functional impairment, which is based on the impact of ADHD on various aspects of life, such as academic achievement, relationships, family, work and emotional well-being. In people with ID these criteria need to be adapted as the functional impairment manifests in different ways compared with people without ID. In the ID population, functional impairment can lead to challenging behaviour that results in deprivation of liberty and therefore people not achieving their maximum potential in life. There are no structured tools available to aid clinicians to assess the severity of functional impairment for people with ID. This makes the treatment decisions more challenging and subjective.

Medication

ADHD medications have been shown to be superior to placebo in managing the core symptoms of ADHD (Michelson *et al.* 2001; Wolraich *et al.* 2001; Biederman *et al.* 2002; Michelson *et al.* 2003). Stimulant and non-stimulant medications are recommended to treat ADHD (National Institute for Health and Care Excellence, 2008). Stimulant medications include different preparations of methylphenidate and dexamfetamine. These are present in immediate-release as well as prolonged-release preparations. Non-stimulant medication preparations that are commonly used include atomxoetine, clonidine, guanfancine and modafinil, which have been shown to be effective in the treatment of ADHD (Rugino & Copley, 2001; Sallee *et al.* 2009; Aman *et al.* 2014).

ADHD medications are significantly more effective when compared with other psychotropic medications. The Number Needed to Treat (NNT) is around 4–5 for most ADHD medications (Banaschewski *et al.* 2006). In comparison, most psychotropic drugs have a higher NNT (Leucht *et al.* 1999). For this reason it is important for clinicians to consider and assess for treatable disorders such as ADHD where treatments are highly effective. However, response to ADHD medication has been shown to be less than non-ID populations. Courtenay and Elstner (2016) reviewed current studies on ADHD medication for people with ID. There were few studies on pharmacological treatment in ADHD for people with ID. Response rate for stimulant medications for people with ID were in the range of 45–66% compared to 65–75% for the non-ID population (Greenhill *et al.* 2001). Similarly, a lower response rate was found for atomoxetine for people with ID. Further studies are needed to clarify the reasons behind the lower response rate, however, the use of low doses of ADHD medications and comorbidity have been suggested as possible reasons (Aman *et al.* 2003).

These case studies show the response to ADHD medication can vary. It highlights how one person responded to a stimulant medication and the other responded to a non-stimulant. Stimulants are preferred as first-line treatment (Banaschewski *et al.* 2006; NICE, 2008). However, whether to use a stimulant or a non-stimulant depends on various factors, such as the duration of control of symptoms, side effect profile and risk of substance abuse. For example, where 24-hour control of symptoms is desired, non-stimulants are preferred given their mechanism of action. Therefore in people with ID, ADHD and challenging behaviours, careful consideration need to be given to expected outcomes when deciding between different ADHD medications. In both cases, single-dosing non-stimulant medication (atomoxetine) was considered first in both patients, as ADHD symptom control was needed throughout the day. One patient's medication had to be switched from a non-stimulant to stimulant due to non-responsiveness.

People with ID tend to experience more adverse events compared to the general population when prescribed psychotropic medications (Matson & Mahan, 2010). Therefore, medications are often used in low doses in people with ID. It is recommended that psychotropic medications are prescribed in low doses and dose titrated up slowly to minimise adverse events and increase tolerability (Ji & Findling, 2016). Similarly, ADHD medications were started in lower doses and gradually titrated up in these two cases. Both patients tolerated ADHD medications without any significant adverse events.

Deb *et al.* (2015) showed that psychotropic medications are commonly prescribed in community based ID clinics for aggression. They also showed that high-dose antipsychotic use was positively correlated with severe aggressive behaviour and self-injurious behaviour. Therefore, use of antipsychotics in both patients in this case report is likely to be to manage aggression. There was no evidence for psychosis or bipolar disorder observed by carers. Antipsychotics are used to control anxiety symptoms in psychiatric practice which could explain the reasons why both patients were on antipsychotics along with Selective Serotonin Reuptake Inhibitors. If the hypothesis is that antipsychotics are given for aggression, this poses the challenge of reducing/withdrawing antipsychotic medications once the patient is stabilised on ADHD medications. Author's opinion is that a slow and gradual reduction of antipsychotic medication can be trialled with close monitoring.

Quality of life

In terms of treatment outcomes, ADHD medications reduce hyperactivity, impulsivity and inattention, which are core symptoms of ADHD but the benefits of ADHD treatment extend beyond symptom control. They have a positive impact on quality of life and daily functioning (Banaschewski *et al.* 2013). In the two case reports, both patients were able to sit in one place for longer and were less challenging in their behaviour as a result of reduced hyperactivity and impulsivity. The ability of both cases to start to enjoy community activities and have fewer restrictions on their daily life indicate the positive impact on quality of life and improvement in their daily functioning.

Limitations

There are inherent limitations to using evidence from case reports. Findings from case reports cannot be generalised as cases were not selected from a representative

sample. There is a selection bias with choosing case reports for publication. Findings from these two case reports may have a limited value in similar presentations. Both patients were followed up for nearly three months from the point of observing benefits. A longer follow-up would have helped to rule out other factors which could have led to improvements in their presentations. The diagnosis of ADHD was made using a clinical impression rather than structured diagnostic interviews. Treatment response and improved quality of life were assessed subjectively rather than using rating scales.

However, case reports have been an integral part of medical research for centuries and have helped to raise awareness and increase research into areas which have not been looked in to. For example, Shell Shock Syndrome was first introduced through case studies in The Lancet after World War 1 (Myers, 1915).

Conclusion

These two case reports highlight the potential for ADHD to be missed or under-diagnosed in people with ID. They show how ADHD treatment can significantly improve the quality of life of people with ID and ADHD. There are many barriers to diagnosing ADHD in people with ID. DSM V criteria need to be adapted when applied to people with ID. The clinical impression of clinicians is more important in the diagnosis of ADHD in ID than the strict application of diagnostic criteria. Treatment response can vary from one person to another and therefore a lack of response to one ADHD medication should not stop clinicians from considering another class of ADHD medications. These two case reports may bring awareness to the presentation of ADHD in people with ID to readers and help to detect similar cases.

Further research is needed to explore how ADHD symptoms are present in adults with ID compared to adults without ID and how the responses to treatment vary. Structured diagnostic tools are needed to help the diagnosis of ADHD in people with ID. Awareness need to be raised as ADHD can often be an under-diagnosed and undertreated debilitating condition, which is often associated with comorbidity as it is in the non-ID population.

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Ethical Standards

The authors assert that all procedures contributing to this work comply with the ethical standards of the relevant national and institutional committee on human experimentation with the Helsinki Declaration of 1975, as revised in 2008. The authors assert that ethical approval for publication of this audit was not required by their local REC. The two patients described above did not have capacity to consent due to their ID, therefore assent was taken from paid carers who look after both clients. Due care was taken to ensure anonymity of both patients when writing up the case study.

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Conflicts of Interest

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