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STUDY ON THE USE OF ANTIPSYCHOTIC MEDICATION IN AN INTELLECTUAL DISABILITY (ID) COMMUNITY CASELOAD

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SUMMARY

Background: *People with intellectual disabilities (ID) are prescribed antipsychotic medications for different reasons; sometimes this is for a mental illness such as psychotic or affective symptoms, however antipsychotics are also used to improve behaviours that challenge, which are common in people with intellectual disabilities (ID) or autism or both.*

Antipsychotic medications can have many unwanted side effects and these should be monitored for. Guidelines also indicate that reductions in medication should be considered at psychiatry reviews and alternative interventions should be trialled.

Methodology: *Using national recommendations on antipsychotic prescribing and monitoring and also on reducing antipsychotics in people with intellectual disabilities (ID), audit standards were determined.*

Results: *The Bedford caseload included 192 service users; of these 2 were new referrals and had yet to be seen so were not included. 70 of the remaining 190 were not on an antipsychotic medication. 120 patients were on an antipsychotic medication. Medical records of 60 of these were audited against the identified standards. The records over the previous year were observed to see either how an antipsychotic was started or an existing antipsychotic was monitored compared to the standards.*

Key words: *intellectual disabilities (ID) – antipsychotic - side effects*

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INTRODUCTION

People with Intellectual Disabilities (ID) (previously referred to as Learning Disabilities) are as likely, or more likely, than the general population to experience mental health problems, including mental disorders such as depression and psychotic disorders. However, a significant proportion of people with Intellectual Disability display 'behaviours that challenge'. It covers a wide range of presentations and can be related to communication difficulties, environmental stressors, physical health problems, psychiatric disorders or, in many cases, a combination of these. A careful assessment of the presentation is therefore required before making decisions about treatment, particularly prescribing.

The most common reason for the prescription of antipsychotic medication to people with Intellectual Disabilities is the management of behavioural problems/ challenging behaviours (Wressell et al. 1990, Molyneaux et al. 2000). The most common types of challenging behaviour reported are physical aggression, self-injury, destructiveness, verbal aggression, sexually inappropriate behaviour etc. The effectiveness of antipsychotic drugs in reducing maladaptive behaviour is questionable (Brylewski & Duggan 1998). Concerns about side-effects and dubious efficacy have led to litigation in the USA, where prescription rates have fallen (Briggs 1989, Poindexter, 1989). This contrasts with the apparent increase found in a longitudinal cohort in England (Emerson et al. 1997). In addition, it has been found that many individuals can be taken off antipsychotic drugs completely with positive results or at least no deterioration. It has also been noted that a deterioration in behaviour problems leads to the reinstatement of medication (Fielding et al. 1980, Briggs 1989). A number of drug withdrawal studies have investigated predictors of successful withdrawal (Luchins et al. 1993, Branford 1996).

A study by Public Health England showed that 1 in 6 adults with an Intellectual Disability is being prescribed anti-psychotic drugs by their GP that are normally used to treat major mental illnesses. Over half of these adults do not have a recorded diagnosis of a condition they are designed to treat. (Prescribing of psychotropic drugs to people with Intellectual Disabilities and/or autism by general practitioners in England, 2015). The report also reveals that:

- 17% of adults with a Intellectual Disability known to their GP were being prescribed an antipsychotic
- over half (58.1%) did not have a diagnosis in their GP record of a condition which they are designed to treat, including psychosis, bipolar disorder, depression and anxiety
- at any time, between 30,000 and 35,000 people with Intellectual Disabilities are prescribed an antipsychotic, an antidepressant or both by their GP without having the conditions for which the drugs were designed to treat and have been shown to be effective (this is 1 in every 6 people known to their GP as having a learning disability)
- Services are overstretched and care is demanding.

Antipsychotic medications can have many unwanted side effects and these should be monitored for. Studies have also shown an increase in the risk of irreversible tardive dyskinesia (Baumeister et al. 1998). The harm from Antipsychotic medication can range from time limited symptoms to life threatening either in the short

or the long term. Guidelines also indicate that reductions in medication should be considered at psychiatry reviews and alternative interventions should be trialled.

The use of antipsychotic drugs in people with Intellectual Disabilities is currently receiving intensified scrutiny and attempts are being made to reduce it. The use of psychotropic medication to manage mental disorders and challenging behaviour in people with Intellectual Disabilities has been highlighted as an area for development under the Transforming Care Programme. The Royal College of Psychiatrists pledges to work with its partners to promote the campaign in leading to a reduction in the use of psychotropic medication in people with Intellectual Disabilities.

Aims

The aims of the study were to sample patients in a Bedford community Intellectual Disability service receiving Antipsychotic medication and to examine prescribing practice and to develop recommendations to address any limitations identified.

METHODOLOGY

Using national recommendations on antipsychotic prescribing and monitoring and also on reducing antipsychotics in people with Intellectual Disabilities, audit standards were determined and agreed. The source of data was the Electronic RiO case records used by the Trust. The Bedford caseload included 192 service users; of these 2 were new referrals and had yet to be seen so were not included. 70 of the remaining 190 were not on an Antipsychotic medication. 120 patients were on an antipsychotic medication. Medical records of 60 of these were audited against the identified standards. The records over the previous year were observed to see either how an antipsychotic was started or an existing antipsychotic was monitored compared to the standards. The notes of 60 patients were selected and analysed.

RESULTS

Demographics

Of the 60 people, 55 had been on antipsychotic medication for over a year, 5 had commenced it with in the last year.

The range in ages of this group of patients was 19–67 years. The mean age was 38.4, the median age was 37.5 and the modal age was 21 years. There were 39 males in the group and 21 females (Figure 1).

Degree of Intellectual Disability

The degree of Intellectual Disability in the group were: 33 people (55%) had a mild ID, 13 people (21.7%) had a moderate ID and 14 people (23.3%) had a severe ID. No one was classed as having a borderline or profound ID (Figure 2).

Indications of Antipsychotic Usage

The indications for which the people we prescribed antipsychotics were: 36 had challenging behaviours, 11 had psychosis, 4 had both challenging behaviour & psychosis, 2 were prescribed it as a mood stabiliser, another 2 were prescribed them for augmentation of another medication, 1 person had challenging behaviour & required a mood stabiliser, 1 was prescribed it for challenging behaviour &augmentation of another medication & 1 person was prescribed it for anxiety. In 2 cases, there was no indication for the antipsychotic listed (Figure 3).

Figure 1. Gender Distribution

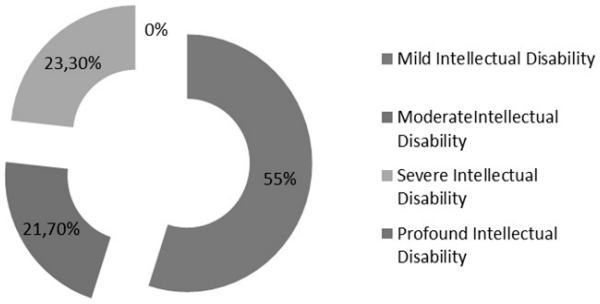

Figure 2. Degree of Intellectual Disability

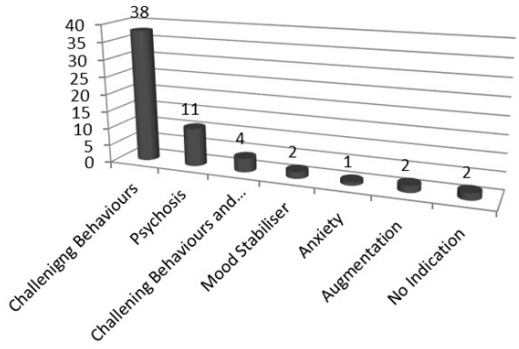

Figure 3. Indications of Antipsychotic Usage

Range of Medications Used

The medications given included 8 different antipsychotics alone and for 4 people a combination of 2 antipsychotics (Figure 4).

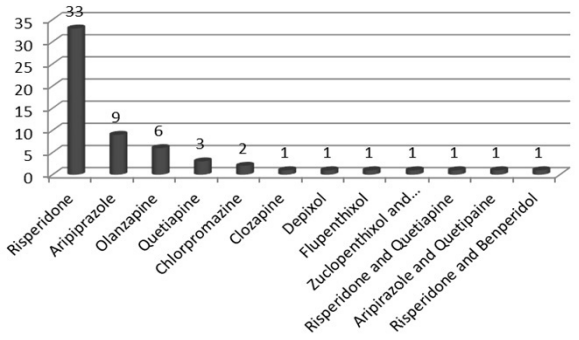

Figure 4. Range of Medications Used

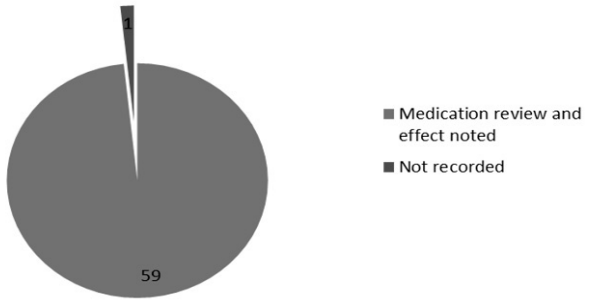

Figure 5. Medication review taken place

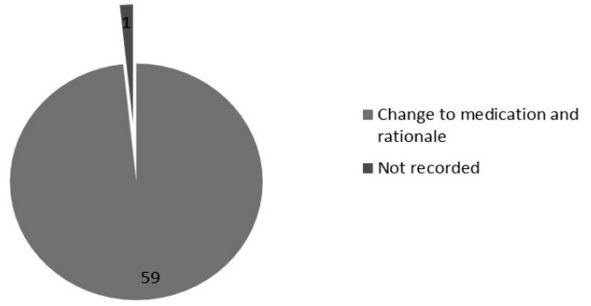

Figure 6. Change to medication and rational documented

Medication Review

For all people apart from 1 who had only recently commenced an antipsychotic, a medication review had occurred and an effect noted (Figure 5).

Changes to Medication Documented

In all but 1 case, whether there was any change or not to the medication at the review was clearly documented, as was a rationale for the decision (Figure 6).

Side Effects

For 55 patients, an assessment for side effects of the antipsychotic was carried out and 22 were experiencing side effects. The side effects experienced were: weight gain by 13 people, sedation in 7 people, hypersalivation in 3 people, Extrapyramidal side effects in 2 people, Hyperprolactinemia in 2 people, Hypertension in 1 person, tremor in 1 person, Hypercholesterolaemia in 1 person and 1 person experienced lower limb oedema. 6 people had more than 1 side effect documented (Figure 7, 8, 9).

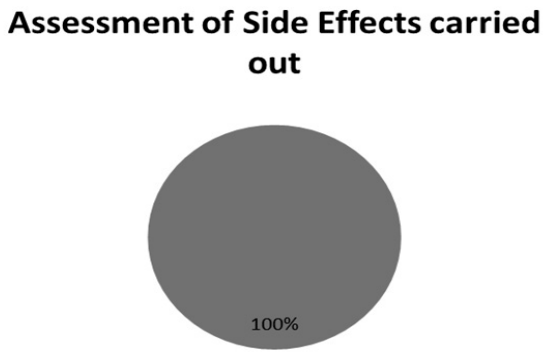

Figure 7. Assessment of Side Effects carried out

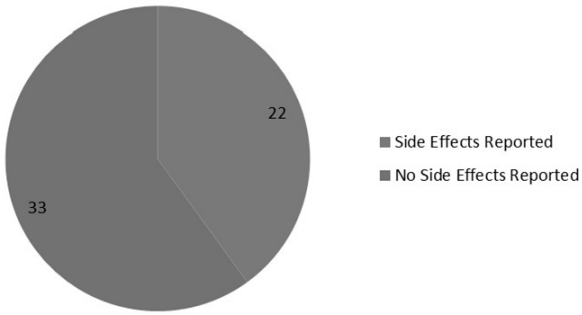

Figure 8. Side effects reported

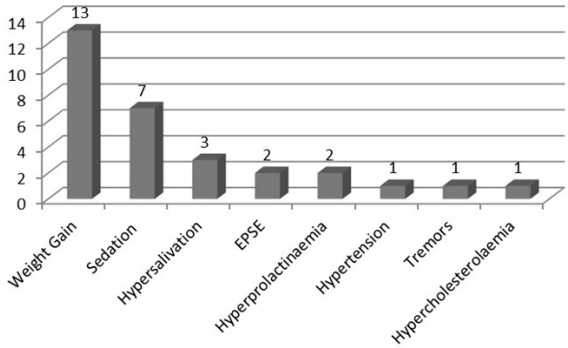

Figure 9. Range of Side effects reported

Medication commenced in the last year

For the 5 people where medication was started in last year, 3 also had other interventions trialled when the medication was commenced. In 1, there was too high a risk of aggression to themselves and others to try another intervention and in 1 it was not documented.

3 of the 5 who started an Antipsychotic in the last year had no capacity to consent to it, 1 did have capacity, and in one capacity was not documented.

In 3 cases, verbal information on the medication was given to the patient and their carer and in 2 cases; there was no documentation of this.

Baseline investigations when an antipsychotic was commenced in 5 cases:

- Weight done in 3 out of 5
- Waist circumference done in no patients
- Pulse recorded in 3

- Blood pressure recorded in 3
- Glucose / HbA1c was done in 3 and requested at 3 months in another
- Assessment of movement disorder was done in 1
- Nutritional status and physical activity was documented in 2 cases
- An ECG was done on 4 people
- A lipid profile was done in 3 and requested at 3 months in another
- Prolactin level was taken in 1 and requested at 3 months in another

In people who had been on Antipsychotics for over a year or when Antipsychotics were started and reviewed within the last year (59 / 60 people):

Review of baseline investigations

- Weight done in 39
- Waist circumference done in 2
- Pulse recorded in 22
- Blood pressure recorded in 23
- Glucose / HbA1c was done in 27, requested for GP to do for 4 and attempted in 1
- Assessment of movement disorder was done in 27
- Nutritional status and physical activity was documented in 38
- An ECG was done on 25
- A lipid profile was done in 28, requested of the GP in 3 and attempted in 1
- Prolactin level was taken in 25, requested of GP in 2 and attempted in 1

Consideration of Antipsychotic medication reduction in last 12 months for all patients

Of the 60 people, 1 had recently started the Antipsychotic, so consideration of a reduction was not applicable. In 4, it was not documented as considered, although other psychotropic medication was reduced in 2 of these patients. In 28 cases, a reduction was considered but it was not possible to reduce it due to symptoms or concerns about deterioration, however in 2 of these other psychotropic medications were reduced. In 6 cases, a reduction was trialled but was unsuccessful. In 18 cases, a reduction in antipsychotics occurred successfully.

DISCUSSION

Research suggests that 12–17% of people with an Intellectual Disability will display challenging behaviour (Kiernan & Alboraz 1996), 25% of people with a Intellectual Disabilities requiring services regularly receive antipsychotic drugs (Branford 1994) and 48% of people with a Intellectual Disabilities and challenging behaviour receive antipsychotic medication (Kiernan et al, 1995) and polypharmacy is common. Antipsychotic medication is frequently used to control behaviour in other specialties too, particularly in elderly patients with Dementia. This practice has recently come under the spotlight because of concerns about the increased risk of stroke associated with atypical antipsychotics. The report Valuing People (Department of Health 2001) expresses concern that 'too often this medication is used as an alternative to adequate staffing'.

There are a number of reasons why Intellectual Disability Psychiatrists prescribe medication for challenging behaviour. Potential reasons for this include limited resources, lack of clinical psychology input, inability to change environment meaningfully, lack of suitably trained staff to manage private residential homes, pressure from nursing staff and other professionals for immediate resolution of problems, lack of meaningful employment or day care opportunities' (Bhaumik & Michael 2004).

There is also evidence that long-term antipsychotic therapy can be successfully withdrawn in a significant proportion of patients (Ahmed et al. 2000). It is likely that this proportion can be increased if favourable clinical approaches and environmental conditions can be made more common.

There is a need to demonstrate well-considered prescribing characterized by describing behaviour well, considering alternative approaches, using outcome measures, discussing risks with clients and carers and monitoring for side-effects.

Recommendations

The authors have reviewed the findings and reviewed the available literature and present recommendations to review the usage of Antipsychotic medication in people with Intellectual Disabilities to include:

- All patients for whom prescribing is considered should have a full diagnostic evaluation that covers: the degree of intellectual disability, the cause of intellectual disability, including syndromes, behavioural phenotypes, etc., other developmental disorders, any mental illnesses, personality disorders, disorders related to substance misuse or dependence, physical disorders, psychosocial stressors, types of behaviours that challenge.
- A clear description of the challenging behaviour, including severity and frequency should be documented.
- Consideration of the other modes of intervention offered and the response to this.
- There should be a clear statement of indications, risks and rationale including off-label use as well as the documentation of capacity and consent to treatment.
- Prescribers to collaborate with professional colleagues, families, paid carers, and service-users to develop a personalized care plan.
- In clinical practice, decisions on using psychotropic medication as part of a treatment plan will adhere to Mental Capacity legislation (Mental Capacity Act 2005; Adults with Incapacity (Scotland) Act 2000). For people who cannot consent to their treatment, clinicians will follow the legislation and Codes of

Practice in making decisions under the 'Best Interests' framework.

- Patients should preferably not be receiving drugs in dosages exceeding British National Formulary (BNF) limits; patients who are should be appropriately monitored.
- Ideally, no patient should be taking more than one regular drug for challenging behaviour, without clear justification and approval of a senior psychiatrist and should only have one regular medication to be started at a time.
- Regular reviews of medication, benefit and response, side effects and discussion around reducing/ discontinuing antipsychotic medication as appropriate, preferably 3 months or less, at a minimum of 6 months.
- Consider the use of a case register of patients on Antipsychotic medication to aid with regular review and future studies.
- Locally, services could consider the use of structured templates formats with prompts for some of the baseline / repeat monitoring parameters to increase completion of these investigations.

Role of wider organizations

- Engage in in POMH-UK audit on prescribing practices to monitor trends over time.
- Royal College of Psychiatrists are already working collaboratively with the Royal College of General Practitioners, Royal Pharmaceutical Society and Royal College of Nursing on developing training materials that could be disseminated through the Royal Colleges for use in local services.
- Clinical diagnoses should be supported by, and consistent with a recognised classification system for example, ICD 10, DSM 5, DM-ID2 to ensure treatable mental illness as cause of challenging behaviour is identified and treated using evidence-based, effective treatments. Diagnoses should be subject to on-going review with reference to the recognised diagnostic frameworks.
- Quality monitoring of medication reviews should be a part of the Quality monitoring frameworks and use psychotropic medication as an important Quality Improvement initiative within their local organisations. RCPsych can support with Quality Improvement methodology and specific tools to enhance appropriate prescribing practice.
- The Royal College of Psychiatrists to promote the gaining of skills and competencies in the assessment of Neurodevelopmental Disorders by making them learning objectives for higher trainees in Psychiatry of ID.
- Resources on psychotropic medication to be available in accessible format for use by practitioners with families.
- The Royal College of Psychiatrists to support the development of strategic approaches by provider organisations to ensure consistent, system-wide approaches to manage behaviour that challenges.

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Contribution of individual authors:

Madhusudan Deepak Thalitaya: Data collection and writing the paper;

Claire Reynolds: Audit design, data collection and analysis;

Imadeldin Hassan Ismail: Data Collection.

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