

# Challenges and pitfalls of antipsychotic prescribing in people with learning disability

### INTRODUCTION

In this opinion piece we highlight the current concerns of prescribing antipsychotics to people with learning disability (PWLD) and propose a system of monitoring of antipsychotic prescribing in general practice that, we argue, will reduce inappropriate antipsychotic use.

Learning disability, synonymous with the term 'intellectual disabilities',<sup>1</sup> affects about 1–2% of the general population<sup>2</sup> and is characterised by significant impairments of both intellectual and adaptive functioning, and an onset before 18 years.<sup>3</sup>

PWLD have high rates of 'challenging behaviour' (CB) — for instance, acts of aggression towards people or property, self-neglect, and self-harm — and risk exploitation.<sup>2</sup> CB is a social construct to enumerate a behavioural or mental pattern that may cause suffering or a poor ability to function in life. It is best understood based on learning theory and the principles of applied behavioural analysis. Mental illness is a structured diagnostic concept that encompasses a large range of recognised emotional and behavioural disorders and its diagnosis requires robust application of the diagnostic schedules. It is reasonable to state that most PWLD with mental illness have CB but the majority of PWLD with CB might not satisfy criteria for mental illness. Therefore, the therapeutic approach to CB can be very different from a diagnostic one. However, there is significant overlap between CB and the presence of mental illnesses, with the latter also being higher in PWLD than in the general population. Deficits in communication, atypical clinical presentations, and differences in diagnostic coding methods mean that mental illness can be under-recorded, particularly in those with severe degrees of learning disability.<sup>1,4</sup> This means that the clinician needs to be aware not just of what is observed behaviourally, but also whether there is something underlying diagnostically. A formulation based on both these elements is central to deciding whether there is a need to prescribe medication.

### PRESCRIBING OF PSYCHOTROPIC MEDICATION

The vast majority of PWLD with CB and/or mental illnesses are seen in primary care. There have been concerns that psychotropic medication is used inappropriately in this group to merely deal with the former.<sup>5</sup> It is

suggested that about 30 000–35 000 PWLD are on antipsychotics or antidepressants, or both, without appropriate indications,<sup>6</sup> and that the proportion of PWLD treated with psychotropic medication exceeds the proportion with recorded mental illness.<sup>7</sup> NHS England has developed a national programme to stop overmedication of PWLD (STOMP).<sup>8</sup> The imperative should be to rationalise clinical practice by carefully balancing the need to stop unnecessary treatment with the possibility of undertreatment that puts the patients or others at risk.<sup>1,4</sup>

Though psychotropic medication can include antipsychotics, antidepressants, mood stabilisers, stimulants, or anxiolytics, particular attention has been focused on antipsychotics. With recent data from secondary care, for instance, from mental health services, suggesting that antipsychotics are not widely used outside of evidence-based indications in PWLD,<sup>9</sup> there is a need to focus particularly on prescribing in primary care.

In general for PWLD, there are three major circumstances in clinical practice that lead to antipsychotic prescribing: the patient has a mental illness with psychotic symptoms; they have CB; or both of the these.

The only acceptable indication is psychosis for the longer-term prescribing of antipsychotics. The rationale for prescribing antipsychotics — either as a definitive diagnosis or as a narrative account of target symptoms — has to be clearly recorded.<sup>4</sup> This recording appears to be problematic in primary care. Although 71% of those PWLD on antipsychotics did not have the diagnosis of a severe mental illness, the comparable figure for the general population, though significantly lower, was still 50%.<sup>7</sup> This suggests that there is a need to improve the recording of the rationale for antipsychotic prescribing across the board. It is pertinent that in population studies, where ascertainment rates were recorded not just through primary care, the inappropriate prescribing rates for antipsychotics were found to be lower.<sup>10</sup>

### GUIDELINES AND AUDIT STANDARDS

The Royal College of Psychiatrists has published practice guidelines and four audit standards for prescribing these drugs in PWLD.<sup>4</sup> This includes clearly documenting the indication for prescribing, recording consent

or best-interests decision-making processes, regularly monitoring treatment response and side effects, and regularly reviewing the need for continuation based on risks and benefits. These four audit standards incorporate the National Institute for Health and Care Excellence (NICE) recommendation<sup>11</sup> that, if antipsychotics are considered for behaviour that challenges, then they should only be used if: psychological or other interventions alone have not produced change within an agreed time; treatment for any coexisting mental or physical health problem has not led to a reduction in the behaviour; or the risk to the person or others is very severe. It also takes account of the NICE guidance, which recommended that prescribers should:<sup>1,12</sup>

- record full details of all medication including the doses, frequency, and purpose;
- record a summary of what information was provided about the medication prescribed to the patient and carers;
- consider reducing or discontinuing antipsychotics for PWLD who are taking antipsychotic drugs and not experiencing psychotic symptoms, and then review their condition;
- annually document the reasons for continuing the prescription if it is not reduced or discontinued; and
- consider referral to a psychiatrist experienced in working with PWLD and mental health problems.

These recommendations and audit standards can pose a number of challenges in primary care. First, there is the difficulty in changing a long-established prescription that may have been the result of an inappropriate need (for example, taking an antipsychotic to manage acute distress), an appropriate but poorly recorded need (for example, psychotic symptoms not recorded in patient notes), an unmet need (for example, chronic social stressors), or resistance from carers, families, and sometimes the patients themselves who may either see the medication as a 'quick fix' or genuinely feel that it has helped. Second, many primary care prescriptions may well have started as part of recommendations from secondary care. However, 'new ways of working', where psychiatrists and mental health teams handle only 'complex' patients while leaving routine follow-up and care to primary care,

have resulted in a large population of PWLD who are on repeat prescriptions without review from, or access to, secondary care services. This group can be described as the 'vulnerable well'. Finally, any effort to change this status quo requires further resources to meet any unmet needs including access to psychological treatments, social care, and other secondary care services.

## STRATEGIES TO ADDRESS THE PROBLEM

A range of views exist from primary care on how this problem needs to be tackled:

- a low threshold be present for referral to specialist teams to manage CB — but this could potentially overburden specialist services;
- the GP if identifying a mental illness initially prescribes and assess outcomes, and then refers if concerns persist — but this could lead to delay in specialised care to a vulnerable adult; and
- if there is concern in the context of uncertain or no obvious comorbid mental illness, to make a referral to a specialist community team — but this could potentially foster diagnostic overshadowing.

To address the practicalities of this issue, there is a need for close working between primary and secondary care services involving GPs, community pharmacists, specialist learning disability teams, and psychiatrists in learning disability. An initiative is under way in Cornwall, UK (pop. 550 000), with a pilot project involving all 64 GP practices, community pharmacists, and specialist learning disability mental health teams to systematically stratify and reduce the level of antipsychotic prescribing. Using a computer program, Eclipse, everyone who has a learning disability but no other recorded mental illness, and who is registered with a GP in Cornwall, has been identified ( $n = 243$ ). They are stratified from low risk to high risk based on the exposure to numbers and types of psychotropics, with those on two antipsychotics being at the top (more information available from authors). Assurance of baseline wellbeing is done using patient/carer-held physical wellbeing records.<sup>13</sup> To ensure the best possibility of success, a STOMP-ID toolkit has been designed to provide assurance of rationalisation and, if necessary, requirement of continuation of medication. Results of this pilot study will clarify the inputs, costs, and efficacy of a programme to address this urgent issue that affects some of the most vulnerable people in society. The likelihood of there being a single way in which this current

burden can be reduced is unlikely. Outcomes from such pilots are best placed to inform how to develop a unified strategy in future.

### Regi T Alexander

Research Lead Consultant, Leicestershire Partnership NHS Trust, Leicester; Consultant Psychiatrist, PIC LD Services, Norfolk; Honorary Senior Lecturer, University of Leicester, Leicester.

### Rohit Shankar

Consultant Neuropsychiatrist, Cornwall Partnership NHS Foundation Trust, Bodmin; Honorary Associate Clinical Professor, Exeter Medical School, Exeter.

### Sally A Cooper

Professor of Learning Disabilities, University of Glasgow, Glasgow; Chair, NICE guidelines on *Mental Health Problems in People with Learning Disabilities*.

### Sabyasachi Bhaumik

Consultant Psychiatrist, Leicestershire Partnership NHS Trust, Leicester; Honorary Chair in Psychiatry, University of Leicester, Leicester.

### Richard Hastings

Professor and Cerebra Chair of Family Research, University of Warwick, Coventry.

### Chaya L Kapugama

Speciality Registrar, Leicestershire Partnership NHS Trust, Leicester.

## ADDRESS FOR CORRESPONDENCE

### Rohit Shankar

Cornwall Partnership NHS Foundation Trust, Chy Govenek, Threemilestone Industrial Estate, Truro TR4 9LD, UK.

E-mail: rohit.shankar@nhs.net

### Samuel J Tromans

Speciality Registrar, Leicestershire Partnership NHS Trust, Leicester.

### Ashok Roy

Consultant Psychiatrist, Coventry and Warwickshire NHS Trust, Coventry; Chair, Faculty of Psychiatry of Intellectual Disability, Royal College of Psychiatrists, London.

## Acknowledgements

We thank the following who contributed to this paper: DM Joy (GP, North Lincolnshire), A Hari (GP, Shropshire), T John (GP, Leicester), A Ranjit (GP Birmingham), K Barnaby (Practice Nurse, North Lincolnshire), J Devapriam (Care Quality Commission), and D Branford (Pharmacist Expert).

## Provenance

Freely submitted; externally peer reviewed.

## Competing interests

The authors have declared no competing interests.

DOI: <https://doi.org/10.3399/bjgp17X692081>

## REFERENCES

1. National Institute for Health and Care Excellence. *Mental health problems in People with Learning Disabilities: prevention, assessment and management*. NG54. London: NICE, 2016. <https://www.nice.org.uk/guidance/ng54> (accessed 20 Jun 2017).
2. Emerson E, Hatton C, Robertson J, *et al*. *People with Learning Disabilities in England 2010*. 2011. [http://wiccare.co.uk/pdf\\_vid\\_9244\\_IHAL2011-02PWLD2010.pdf](http://wiccare.co.uk/pdf_vid_9244_IHAL2011-02PWLD2010.pdf) (accessed 26 Jun 2017).
3. World Health Organization. *The ICD-10 classification of mental and behavioural disorders: clinical descriptions and diagnostic guidelines*. Geneva: WHO, 1992.
4. Royal College of Psychiatrists. *Psychotropic drug prescribing for people with intellectual disability, mental health problems and/or behaviours that challenge: practice guidelines*. 2016. [https://www.rcpsych.ac.uk/pdf/FR\\_ID\\_09\\_for\\_website.pdf](https://www.rcpsych.ac.uk/pdf/FR_ID_09_for_website.pdf) (accessed 20 Jun 2017).
5. Department of Health. *Department of Health review: Winterbourne View Hospital. Interim report*. 2012. [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/141591/Department-of-Health-Review-Winterbourne-View-Hospital-Interim-Report1.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/141591/Department-of-Health-Review-Winterbourne-View-Hospital-Interim-Report1.pdf) (accessed 20 Jun 2017).
6. Public Health England. *Prescribing of psychotropic drugs to People with Learning Disabilities and or autism by general practitioners in England*. 2015. <http://clock.uclan.ac.uk/17970/1/Psychotropic%20medication%20and%20people%20with%20learning%20disabilities%20or%20autism.pdf> (accessed 26 Jun 2017).
7. 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.
8. NHS England. Urgent action pledged on over-medication of people with learning disabilities. 2015. <https://www.england.nhs.uk/2015/07/urgent-pledge/> (accessed 20 Jun 2017).
9. Paton C, Bhatti S, Purandare K, *et al*. Quality of prescribing of antipsychotic medication for people with intellectual disability under the care of UK mental health services: a cross-sectional audit of clinical practice. *BMJ Open* 2016; **6**(12): e013116.
10. Bowring DL, Totsika V, Hastings RP, *et al*. Prevalence of psychotropic medication use and association with challenging behaviour in adults with an intellectual disability. A total population study. *J Intellect Disabil Res* 2017; **61**(6): 604–617.
11. National Institute for Health and Care Excellence. *Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges*. NG11. London: NICE, 2015. <https://www.nice.org.uk/guidance/ng11> (accessed 20 Jun 2017).
12. National Institute for Health and Care Excellence. *Learning disabilities: identifying and managing mental health problems*. QS142. London: NICE, 2017. <https://www.nice.org.uk/guidance/qs142> (accessed 20 Jun 2017).
13. Shankar R, Bradley-Smith G, Brigham P, *et al*. Patient- and carer-held health records: can they improve annual health checks for patients with learning disability? *Br J Gen Pract* 2016; DOI: <https://doi.org/10.3399/bjgp16X684697>.