A STOMP-focused evaluation of prescribing practices in one assessment and treatment unit for people with intellectual disabilities

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Jon Painter, Winola Chio, Liam Black and David Newman

Abstract

Purpose – *This study aims to understand whether psychotropic prescribing practices for people with intellectual disabilities are in keeping with best practice guidelines.*

Design/methodology/approach – *This service evaluation project was a retrospective analysis of routinely collected data from the care records of all 36 people with intellectual disability discharged from an intellectual disability assessment and treatment unit during the first five years of the Stop Over medicating People with Intellectual Disabilities and/or autistic people (STOMP) initiative. Data were gathered at four time points (pre-admission, discharge, 6- and 12-month follow-up) before being analysed to understand whether psychotropic prescribing differed among people with different clinical characteristics/traits/diagnoses. Changes over time were also explored to ascertain whether and how prescribing altered from admission to discharge, and over the subsequent year of community living.*

Findings – *Most people with intellectual disabilities left the assessment and treatment unit on fewer regular psychotropic medications and at lower doses than at admission. These optimised regimes were still apparent 12 months post-discharge, suggesting effective discharge planning and community care packages. Inpatients with severe intellectual disabilities generally received more anxiolytics and hypnotics, at higher doses. Autistic people tended to receive more psychotropics in total and at higher cumulative doses, a pattern that persisted post discharge. A third of the sample were admitted on regular anti-psychotic medications despite having no corresponding psychotic diagnosis, a proportion that remained relatively stable through discharge and into the community.*

Originality/value – *This study highlights subsets of the intellectual disability population at particular risk of receiving high doses of psychotropics and a feasible template for providers intending to undertake STOMP-focused evaluations.*

Keywords *Psychotropic, Medication, Prescribing, Intellectual disability, STOMP, Anti-psychotic*

Paper type *Research paper*

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Background

Mental health (MH) problems are more common in people with intellectual disabilities than the general population (Buckles *et al.*, 2013; Cooper *et al.*, 2007; Hemmings *et al.*, 2013). Medication can form a helpful aspect of MH care [National Institute for Health and Care Excellence (NICE), 2015, p. 23] however, even when prescribed according to best practice, psychotropic medications carry significant risks including cardiovascular disease (Mwebe and Roberts, 2019) and metabolic abnormalities (Mazereel *et al.*, 2020). Given the already elevated prevalence of these physical comorbidities in people with intellectual disabilities (Cooper *et al.*, 2015), this is cause for concern, particularly because these

individuals are prescribed psychotropics more frequently, at higher doses, and for longer than the norm (Bowring *et al.*, 2017; Glover and Williams, 2015; McMahon *et al.*, 2020). Finally, in 2015, in England alone, 30,000–35,000 people with intellectual disabilities received these drugs each day, despite having no psychiatric diagnoses to warrant the prescription (Glover and Williams, 2015). There are a limited number of legitimate, short-term scenarios (NICE, 2015; de Kuijper and Lenderink, 2021); however, as people with intellectual disabilities are also more likely to be prescribed antipsychotics if they exhibit behaviours of concern (Bowring *et al.*, 2017), it is likely that this is an inappropriate/off-licence form of behaviour management (Royal College of Psychiatrists, 2021; de Kuijper and Lenderink, 2021; Sheehan *et al.*, 2015).

In 2015, responding to this situation, and the Winterbourne View scandal (Department of Health, 2012a, 2012b), NHS England launched a national campaign. Its aim was to raise awareness of the issue, promote non-pharmacological interventions and increase the number of people with intellectual disabilities engaged in regular medication reviews, to "Stop Over-Medicating People with a learning disability, autism or both with psychotropic medicines" (STOMP), ultimately improving the quality of life (NHS England, 2022). By 2019, Branford *et al.* argued national awareness of these issues had improved, however, overall patterns of prescribing remained unclear. More latterly, Rauf *et al.* (2021) indicated that the awareness-raising has led to tangible reductions in over-medicating people with intellectual disabilities. Reductions in prescribing are also noted by Mehta and Glover (2019) though with more caution about causality. However, identification of local exemplars (Branford *et al.*, 2019), by definition, suggests variation and the continued existence of areas of poor prescribing practice (Kiernan *et al.*,1995). These national uncertainties necessitate ongoing local scrutiny of psychotropic medication use in people with intellectual disabilities to ensure quality of life is optimised (Bowring *et al.*, 2017; da Costa *et al.*, 2021).

Therefore, the aim of this study was to understand whether local prescribing adhered to best practice guidelines by examining:

- the needs, characteristics, traits and diagnoses of the people with intellectual disabilities admitted to one assessment and treatment unit (ATU) and prescribed psychotropics;
- how psychotropic prescribing altered between admission, discharge and the following 12 months of community living; and
- whether psychotropic prescribing differed among individuals with different clinical characteristics/traits/diagnoses.

Method

Participants

Data were gathered from the care records of all people with intellectual disabilities discharged from an ATU (n = 36) during the first five years of STOMP. Twenty-one (58.3%) were male; 30 (83.3%) were white British and half were aged 18–30. Pre-admission accommodation was recorded for 31 (86.1%) of individuals with 13 (36.1%) admitted from their family home; 8 (22.2%) from supported living; 6 (16.7%) from residential accommodation; 2 (5.6%) from other hospitals; 1 (2.8%) from their own house and 1 (2.8%) from a friend's. The mean number of significant life events pre-admission as per the Mini PAS-ADD (Prosser *et al.*, 1998) was 1.22 (SD 1.10); the most common being; contact with the police (n = 9), serious illness/injury (n = 7), bereavement (n = 7), moving residence (n = 5), and sexual abuse (n = 5). At admission, levels of intellectual disability (ID) were skewed towards mild/moderate levels and over 40% were autistic. Half had at least one psychiatric diagnosis of which psychosis was the most common (Table 1). Median length of stay was 147 days (range 19–754).

Table 1 Levels of ID, presence of autism and psychiatric diagnoses

Level of ID and presence of ASD		*Autistic*	*Not autistic*	*Total*
ID diagnosis				
Mild	At admission	7	6	13
	At discharge	3	9	12
Mod	At admission	1	9	10
	At discharge	3	9	12
Severe	At admission	4	3	7
	At discharge	7	2	9
ID (level unspecified)	At admission	3	2	5
	At discharge	1	0	1
Missing data	At admission	0	1	1
	At discharge	2	0	2
Psychiatric diagnoses		Yes	No	Total
At least one psychiatric diagnosis	At admission	18	18	36
	At discharge	28	8	36
Psychotic disorder	At admission	11	25	36
	At discharge	14	22	36
Anxiety disorder	At admission	5	31	36
	At discharge	6	30	36
Mood disorder	At admission	9	27	36
	At discharge	10	26	36
Psychiatric diagnoses other	At admission	4	32	36
	At discharge	8	28	36

Note: ASD: autism spectrum disorder

Pre-admission, social services funded the care packages of 18 individuals at a median annual rate of £33,101 (range £11,321–£177,280). At discharge, 29 individuals were funded at a median annual rate of £112,603 (range £10,579–£274,189), a level which remained relatively stable for 12 months.

Procedure

With reference to the project's goals, a bespoke data set was developed. At admission, this included demographic information, significant life events, diagnoses, community care packages and psychotropic medication. At discharge, this comprised diagnoses, care packages and psychotropics. At 6- and 12-months post-discharge, care packages and psychotropics were recorded. Staff gathered these data from the records of all ATU discharges during the first five years of STOMP (December 2015 to April 2020).

Following pseudonymisation and secure electronic transfer, data were exported into SPSS version-24 (IBM, 2016), during which, it was noted that one female had three admissions and three males each had two. The remaining 32 people with intellectual disabilities each had one admission. Consequently, to create a final data set of unique patient records (n = 36), only the earliest stays were retained. The impact of this data cleansing on participants' characteristics (above) was negligible.

This project was registered by the relevant NHS Trust as service evaluation and ethically approved by Sheffield Hallam University (ID:ER25221337).

Analysis

For each of the four timepoints, regularly prescribed psychotropics were grouped under four British National Formulary (BNF) [Joint Formulary Committee (JFC), 2021] categories. These were antipsychotics; mood stabilisers/anti-manics; anxiolytics and hypnotics; and

antidepressants; plus, a final "other regular psychotropics" category (ultimately comprising procyclidine alone). For each category, the number of medications and total percentage of maximum BNF doses were calculated. Here, the method mirrored one typically used to define high-dose antipsychotic therapy (Royal College of psychiatrists, 2014), meaning figures over 100% were possible for individuals prescribed multiple medications from the same BNF group. These category totals were subsequently summed to create overall figures for regular psychotropics. Finally, although actual usage of Pro Re Nata (PRN) psychotropics was not captured, the number prescribed at each timepoint was recorded.

To identify statistically significant differences between timepoints, descriptive statistics for each of these variables were calculated (Table 2), together with repeated measures ANOVAs with Greenhouse–Geisser correction. Where apparent, post hoc analyses with Bonferroni adjustment revealed more about the differences.

To examine prescribing differences between different diagnostic categories, one-way ANOVAs with Tukey post hoc tests were performed. Statistically significant differences in inpatient prescribing were identified on the basis of ID level, autism and psychiatric diagnoses recorded at admission. In light of improved data quality, and the dynamic nature of MH, analyses of differences in community prescribing used level of ID, autism and psychiatric diagnoses recorded at discharge. Finally, because of particular concerns regarding over-prescribing of antipsychotics, a cross-check for diagnostic indications was undertaken.

Results

Prescribing patterns over time

Table 2 shows prescribing patterns for the seven medication groupings, across timepoints. Four statistically significant changes were identified.

The mean number of regularly prescribed mood-stabilisers decreased during admission, then remained constant post discharge. A repeated measures ANOVA with Greenhouse–Geisser correction determined the differences were statistically significantly between timepoints [$F(1.928, 57.841) = 4.163$, $p = 0.022$]. However, post hoc analysis did not identify any significantly different pairwise comparisons.

The mean number of regularly prescribed anxiolytics and hypnotics decreased over time. With the 12-month post-discharge mean being less than half the pre-admission mean. The mean differed significantly between timepoints [$F(2.304, 69.107) = 3.697$, $p = 0.025$]. Post hoc analysis with Bonferroni adjustment revealed differences were only statistically significant between admission and 12 months [0.452(95% CI, 0.001 to 0.902), $p = 0.049$].

The mean total percentage of maximum BNF doses of "other" psychotropics (i.e. procyclidine) halved during hospitalisation, before increasing slightly post discharge. These means differed significantly between timepoints [$F(1.037, 29.044) = 19.822$, $p = <0.001$]. Post hoc analysis revealed the 12-month mean differed significantly from admission: T1[85.817(95% CI, 30.80 to 140.834), $p = 0.001$]; discharge: T2[86.966(95% CI, 32.550 to 141.382), $p = 0.001$]; and 6 months: T3[86.966 (95% CI, 31.907 to 142.025), $p = 0.001$], respectively.

Finally, the mean number of PRN medications rose between admission and discharge, fell to six months post-discharge, then stabilised. These means differed significantly between timepoints [$F(2.565, 74.392) = 3.604$, $p = 0.022$]. Post hoc analysis revealed that the decrease was only significant from discharge to six months [0.367(95% CI, 0.049 to 0.685), $p = 0.017$].

Prescribing by diagnosis

The total number of anxiolytics and hypnotics prescribed to inpatients differed significantly by level of ID, as determined by a one-way ANOVA [$F(3, 30) = 4.984$, $p = 0.006$]. Tukey

Table 2 Prescribing patterns across four timepoints

BNF category	*Variable*	*Timepoint*	*N*	*Min.*	*Max.*	*Mean*	*SD*	*Statistically significant changes**	*Statistically significant pairwise comparisons***
Total regularly prescribed medications	Number of medications	T1 (Admission)	36	0	7	2.6	1.9		
		T2 (Discharge)	36	0	6	2.3	1.4		
		T3 (6 months post-discharge)	36	0	5	1.9	1.3		
		T4 (12 months post-discharge)	32	0	4	1.7	1.3		
	Total % of BNF maximum doses	T1 (Admission)	35	0	378.3	127.1	98.9		
		T2 (Discharge)	36	0	387.5	121.2	97		
		T3 (6 months post-discharge)	35	0	307.1	101.4	80.2		
		T4 (12 months post-discharge)	30	0	350	90.1	102.9		
Regularly prescribed antipsychotic medications	Number of medications	T1 (Admission)	35	0	3	0.7	0.8		
		T2 (Discharge)	36	0	2	0.8	0.6		
		T3 (6 months post-discharge)	35	0	2	0.8	0.6		
		T4 (12 months post-discharge)	32	0	2	0.8	0.7		
	Total % of BNF maximum doses	T1 (Admission)	35	0	168.8	27.1	41.8		
		T2 (Discharge)	36	0	143.3	38.9	37.6		
		T3 (6 months post-discharge)	35	0	141.7	33.5	37.3		
		T4 (12 months post-discharge)	32	0	140	31.7	37.9		
Regularly prescribed mood stabilising medications	Number of medications	T1 (Admission)	35	0	2	0.3	0.6	$F(1.928, 57.841) = 4.163$, $p = 0.022$	
		T2 (Discharge)	36	0	2	0.1	0.4		
		T3 (6 months post-discharge)	35	0	2	0.1	0.4		
		T4 (12 months post-discharge)	32	0	1	0.1	0.2		
	Total % of BNF maximum doses	T1 (Admission)	35	0	100	8.1	21.9		
		T2 (Discharge)	36	0	136	5	23.1		
		T3 (6 months post-discharge)	35	0	136	7.5	26.6		
		T4 (12 months post-discharge)	32	0	80	3.3	14.7		
Regularly prescribed antidepressant medications	Number of medications	T1 (Admission)	35	0	1	0.6	0.5		
		T2 (Discharge)	36	0	1	0.4	0.5		
		T3 (6 months post-discharge)	35	0	1	0.4	0.5		
		T4 (12 months post-discharge)	32	0	1	0.4	0.5		
	Total % of BNF maximum doses	T1 (Admission)	35	0	100	29.3	34.7		
		T2 (Discharge)	36	0	100	27.8	38.7		
		T3 (6 months post-discharge)	35	0	100	28.8	40.9		
		T4 (12 months post-discharge)	31	0	100	23.9	37.9		
Regularly prescribed anxiolytic and hypnotic medications	Number of medications	T1 (Admission)	35	0	2	0.9	0.8	$F(2.304, 69.107) = 3.697$, $p = 0.025$	T1-T4 0.452 (95% CI, 0.001 to 0.902), $p = 0.049$
		T2 (Discharge)	36	0	3	0.8	0.9		
		T3 (6 months post-discharge)	35	0	2	0.6	0.7		
		T4 (12 months post-discharge)	32	0	2	0.4	0.7		
	Total % of BNF maximum doses	T1 (Admission)	35	0	150	51.9	56.1		
		T2 (Discharge)	36	0	237.5	46.7	65.2		
		T3 (6 months post-discharge)	35	0	150	28.7	44		

(*continued*)

Table 2

BNF category	*Variable*	*Timepoint*	*N*	*Min.*	*Max.*	*Mean*	*SD*	*Statistically significant changes**	*Statistically significant pairwise comparisons***
		T4 (12 months post-discharge)	32	0	200	27.9	55.8		
Other regularly prescribed psychotropic medications	Number of medications	T1 (Admission)	35	0	1	0.2	0.4		
		T2 (Discharge)	36	0	1	0.1	0.3		
		T3 (6 months post-discharge)	35	0	1	0.1	0.3		
		T4 (12 months post-discharge)	32	0	1	0.1	0.3		
	Total % of BNF maximum doses	T1 (Admission)	35	0	50	5.2	12.6	$F(1.037, 29.044) = 19.822$, $p < 0.001$	T1-T4 85.817 (95% CI, 30.80 to 140.834), $p = 0.001$
		T2 (Discharge)	36	0	33.3	2.8	8.5		T2-T4 86.966 (95% CI, 32.550 to 141.382), $p = 0.001$
		T3 (6 months post-discharge)	35	0	50	2.9	10.3		T3-T4 86.966 (95% CI, 31.907 to 142.025), $p = 0.001$
		T4 (12 months post-discharge)	31	0	50	3.2	10.9		
Pro Re Nate (PRN) medications	Number of medications	T1 (Admission)	35	0	2	0.6	0.7	$F(2.565, 74.392) = 3.604$, $p = 0.022$	T2-T3 0.367 (95% CI, 0.049 to 0.685), $p = 0.017$
		T2 (Discharge)	35	0	3	0.8	0.8		
		T3 (6 months post-discharge)	35	0	2	0.4	0.7		
		T4 (12 months post-discharge)	32	0	2	0.4	0.7		

Notes: *Repeated measures ANOVA with Greenhouse–Geisser correction. **Post hoc analysis with Bonferroni adjustment

post hoc testing revealed the number of these medications prescribed at admission was higher for people with severe ID (1.67 ± 0.516) than mild (0.69 ± 0.855, p = 0.049) or moderate (0.40 ± 0.516, p = 0.010). Similarly, the total percentage of maximum BNF doses of anxiolytics and hypnotics prescribed at admission also differed significantly [F(3, 30) = 4.756, p = 0.008]. Post hoc testing revealed means were significantly higher for people with severe ID (87.97%±36.64%) than moderate (7.79%±12.23, p = 0.016).

The total percentage of maximum BNF doses of all psychotropics regularly prescribed to people with/without an autism diagnosis at admission also differed significantly [F(1, 32) = 5.432, p = 0.026]. Here, the autism mean was 175.68% versus 98.25% for those without. Post hoc tests were not possible.

The total number of regularly prescribed psychotropics at discharge also differed significantly by autism diagnosis [F(1, 33) = 9.247, p = 0.005]. The autism mean was 3.07 versus 1.71 for those without.

As regards post-discharge prescribing by the specialist team, differences for autistic people continued. Firstly, the total percentage of maximum BNF doses of all regularly prescribed psychotropics at discharge differed significantly [F(1, 33) = 4.395, p = 0.044). The autism mean was 158.68% versus 91.57% for those without. Secondly, the total number of PRN psychotropics at six months also varied significantly [F(1, 32) = 4.163, p = 0.050]. Here, the autism mean was 0.64 versus 0.20 for those without. Finally, the total percentage of BNF maximum doses of all regularly prescribed psychotropics at 12 months was significantly different [F(1, 27) = 4.360, p = 0.046]. The mean autism percentage was 121.23% versus 52.78% for those without.

Antipsychotic prescribing

Table 3 shows antipsychotic prescribing with/without diagnostic indication.

At admission, 26 people with intellectual disabilities (72.25%) had no psychotic diagnoses. Nonetheless, 12 were prescribed antipsychotics. This represents almost half this subset and one-third of the study's sample, a figure that remains reasonably constant across timepoints.

Considering MH more broadly, at admission, half the people with intellectual disabilities (n = 18) had no psychiatric diagnosis whatsoever but 11 (61.1%) were still prescribed antipsychotics. This equates to 30.55% of the sample. More positively, by discharge this had roughly halved (n = 6) before stabilising for the subsequent year.

Table 3 Antipsychotic prescribing by diagnosis

Diagnostic group	*Antipsychotic medication status*	*Admission*	*Discharge*	*Timepoint 6 months post-discharge*	*12-months post-discharge*
At least one psychotic diagnosis recorded	Prescribed	7	13	10	9
	Not prescribed	3	1	3	3
	Missing data	0	0	1	2
No psychotic diagnoses recorded	*Prescribed*	*12(5)*	*13(7)*	*14(12)*	*12(6)*
	Not prescribed	13	9	8	8
	Missing data	1	0	0	2
At least one psychiatric diagnosis recorded	Prescribed	8	20	17	15
	Not prescribed	10	8	10	10
	Missing data	0	0	1	3
No psychiatric diagnoses recorded	*Prescribed*	*11(4)*	*6(3)*	*7(5)*	*6(4)*
	Not prescribed	6	2	1	1
	Missing data	1	0	0	1

Note: NB Bracketed figures are individuals with an intellectual disability who are also autistic

Around half of individuals admitted on antipsychotics without diagnostic indication were autistic. This proportion was similar at discharge and 12 months but, at 6 months post-discharge it was notably higher.

Discussion

Reassuringly, when considering change over time, most people with intellectual disabilities were discharged on fewer regular psychotropic medications and at lower doses than at admission. Arguably, this demonstrates the value of nurses, psychiatrists, psychologists, pharmacists, physician associates, speech and language therapists and occupational therapists working as a coordinated multi-disciplinary team to deliver positive behaviour support (PBS) interventions. Although we did not seek to definitively attribute reductions to PBS, in other studies (Gerrard *et al.*, 2019) these interventions resulted in successful discontinuation of psychotropics in 60%–92% of participants. The government's bed closure programme is undoubtedly laudable; however, progress has been slow and ATUs are likely to remain for some time (Devine, 2019; Painter *et al.*, 2017). When these types of interventions are eventually routinely delivered in the community, it will be important to ensure this level of coordinated PBS is retained. It is also encouraging to see that, in general, medication reductions were maintained over the subsequent 12 months of community living. In conjunction with the increased number and costs of care packages instigated at discharge, this suggests collaborative discharge planning was effective. This is important as, community transitions that are effectively facilitated by professionals can positively impact people's quality of life (Lennard *et al.*, 2020).

Examining differences in prescribing patterns among sub-groups, inpatients with more severe ID tended to receive more anxiolytics and hypnotics, and at higher doses. Given that this group are less likely to be given a psychiatric diagnosis than the mild and moderate groups (Deutsch and Burket, 2021) this is somewhat counterintuitive; however, there are well-recognised complexities around diagnostic overshadowing that may be at play here. Additionally, autistic inpatients were prescribed more psychotropics in total and at higher cumulative doses. Given that no medications are marketed to "treat" autism (Murray *et al.*, 2014) this again appears anomalous but, could, in part, be related to the higher rate of comorbid MH problems in autistic people (Mannion and Leader, 2013).

Post discharge, for these autistic individuals, the difference in the mean number of psychotropic medications disappeared by 12 months; however, they continued to receive higher cumulative doses than their neurotypical counterparts and (perhaps as a consequence) be prescribed more PRN psychotropics.

Finally, considering antipsychotic prescribing specifically, there was a slight increase across time which was not statistically significance but of course may still be clinically significant. Furthermore, mirroring other studies (Perry *et al.*, 2018), a concerning proportion of people with intellectual disabilities were admitted on antipsychotics without diagnostic indication, thus being exposed to potentially serious and unnecessary side effects (Mwebe and Roberts, 2019). Post discharge, this picture improved for individuals with no psychiatric diagnoses but remained stubbornly constant for those with non-psychotic psychiatric diagnoses (a phenomena worthy of future investigation). Also of note was the six-month post-discharge spike in the proportion of non-psychotic individuals prescribed antipsychotics who were autistic. Individual reasons were not captured; however, this is clinically intuitive given autistic people struggle to adapt to change (Alhuzimi, 2021); often exhibit behaviours of concern when stressed (Bowring *et al.*, 2019); and are typically prescribed antipsychotics ahead of PBS (Bowring *et al.*, 2017). The service is, therefore, currently remodelling its community provision and seeking increased resources for enhanced post-discharge MH and PBS.

As ever, there are limitations to these findings. The convenience sample was relatively small, from a single ATU and with varying levels of data completeness/quality which limit the generalisability of findings. The dose calculation method did not capture nuanced prescribing decisions, e.g. medications given for multiple reasons or reasons other than their primary indication. Analyses were statistically robust, but some data (e.g. prescription duration, use of PRN psychotropics and individuals' subjective experiences) were not captured. That said, all completed inpatient spells were included and findings chime with other studies.

Conclusion

STOMP has now been subsumed into the Department of Health's (2012a, 2012b) Transforming Care Programme (Branford *et al.*, 2019) with a range of deliverables. Unfortunately, progress with some aspects of this wider transformation initiative, e.g. bed closures have not matched the rhetoric (Devine, 2019; Painter *et al.*, 2017). Continued uncertainty about STOMP's national impact and geographical variations (Branford *et al.*, 2019; Mehta and Glover, 2019) makes local initiatives, such as this project, valuable primarily to provide an accurate picture of local psychotropic prescribing practices with this high-risk group, but also as a template for other providers to use when evaluating their services. Finally, it provides foundations upon which to build local understanding of user (and staff) experience as it identifies areas that warrant qualitative investigation.

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