Prevalence of psychotropic medication use and association with challenging behaviour in adults with an intellectual disability. A total population study.

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Abstract

Background

There is a high prevalence of psychotropic medication use in adults with Intellectual Disabilities (ID), often in the absence of psychiatric disorder, also associated with challenging behaviour. Previous research has focused on specific sample frames or data from primary care providers. There is also a lack of consistency in the definition of challenging behaviour used.

Methods

We adopted a total population sampling method. Medication data on 265 adults with ID were classified according to the Anatomical Therapeutic Chemical classification system. The Behavior Problems Inventory – short form classified challenging behaviours. We examined the association between challenging behaviour and the use of psychotropic medication, and whether any association would still be present after accounting for sociodemographic and clinical characteristics.

Results

70.57% of adults with ID were prescribed at least one class of any medication (mean per person = 2.62; range 0-14). Psychotropic medications were used by 37.73% of participants with antipsychotics the commonest type used by 21.89% of individuals. Polypharmacy and high dosages were common. Generalised Linear Models indicated significant associations between psychotropic medication and the presence of a psychiatric diagnosis, challenging behaviour, older age and type of residence. Male gender was additionally associated with antipsychotic medication.

Conclusions

The use of a total population sample identified via multiple routes is less likely to overestimate prevalence rates of medication use. Current challenging behaviour was a predictor of medication use after controlling for other variables. Data indicate that there may be differences in prescribing patterns associated with different topographies of challenging behaviours.

Keywords Psychotropic medication, antipsychotic, challenging behaviour, intellectual disability, Behavior Problems Inventory.

Introduction

Psychotropic medication, and in particular antipsychotic medication, is overused in people with intellectual disabilities (ID) (Deb & Fraser, 1994; Sheehan *et al*. 2015). Studies have reported varied prevalence and patterns of prescribing. For example, UK estimates vary from 49% (Sheehan *et al*. 2015) to 89% (Deb *et al.* 2014) with some variation subject to residence or setting of the sample cohort (Robertson *et al*. 2000; Tsiouris *et al*. 2013). Antipsychotics have been reported to be the most common type of medication prescribed to individuals with ID (Holden & Gitlesen, 2004; Deb & Unwin, 2007; Matson & Neal, 2009; Singh & Matson, 2009; Henderson *et al*. 2015; Sheehan *et al*. 2015). Up to 62% of adults with ID who receive psychotropic medication receive multiple psychotropic medications (Lott *et al.* 2004) often in high dosages (Cullen, 1999; McGillivary & McCabe, 2004; Deb *et al*. 2009; Taylor, 2010). A high prevalence of psychiatric problems in adults with ID may explain some increased medication use (Chaplin, 2004; Cooper *et al*. 2007; Morgan *et al*. 2008; Buckles *et al*. 2013). However, prescribing rates are typically higher than reported rates of mental health problems (Henderson *et al.* 2015; Sheehan *et al*. 2015) and prescribing is also associated with the presence of challenging behaviour (Gothelf *et al*. 2008; Matson & Neal, 2009; Henderson *et al*. 2015; Sheehan *et al.* 2015).

In studies that have used convenience or small samples recruited from clinical services, estimates of the prevalence of the use of psychotropic medication have been high. For example, in a community based sample of adults with ID and aggressive behaviour, from ten psychiatric clinics in the West Midlands, UK, 89% were prescribed psychotropic medication (Deb *et al*. 2014). Similarly, 72% of adults with ID at a Psychiatry Department in Salford, UK, were prescribed antipsychotics (Griffiths *et al*. 2012). Data from such samples are likely to be associated with a

range of biases and total population or population representative samples are needed. Henderson *et al*. (2015) focused on a prospective cohort sample of 1023 adults aged ≥16 years with ID known to local services including primary care (general practitioners - GPs) in Scotland. Sheehan *et al*. (2015) identified 32306 adults aged ≥18 years with ID from 3.7 million active patients on The Health Improvement Network (THIN) where records from 571 General Practices were examined. Henderson *et al*. (2015) found a 49.1% prevalence rate of psychotropic medication use with a prevalence rate of antipsychotic drug use of 23.2%. Similarly, Sheehan *et al.* (2015) found a 49% prevalence of psychotropic medication use with 21% of participants prescribed antipsychotic medication. These studies used population-based samples, but identified their participants from primary care services.

Some studies have found that adults with challenging behaviour are prescribed more psychotropic medications than those without challenging behaviour (Holden & Gitlesen, 2003; Aman & Ramadan, 2007; Crossley & Withers, 2009; Doan *et al.* 2013; Scheifes *et al.* 2015). In the Henderson *et al.* (2015) study, 32% of those prescribed antipsychotics had no mental health problems at the time of assessment. Sheehan *et al*. (2015) reported that 47% of participants with a record of challenging behaviour received antipsychotics but only 12% had a record of mental illness. There remains no convincing evidence of positive treatment effects of these medications on challenging behaviour (Emerson & Baines, 2010; Tsiouris, 2010; Paton *et al.* 2011; Wilner, 2014). The underlying aetiological factors for challenging behaviour are complex and varied (Hastings *et al*. 2013) so treatment with medication alone is unlikely to resolve the issue. Under current UK best practice guidelines (NICE, 2015; RCP, 2016) if adults with ID and challenging behaviour have no evidence of mental

illness then there may be no role for prescribing, other than in the very short term to address risk whilst other psycho-social interventions are implemented.

Socio-demographic factors associated with higher prevalence rates of psychotropic medication are male gender (McGillivray & McCabe, 2006; Delafon *et al*. 2013; Doan *et al*. 2014) and older age (Holden & Gitlesen, 2004; Singh & Matson, 2009; Deb *et al*. 2014; Sheehan *et al*. 2015). Kiernan *et al*. (1995) found different prevalence rates in different districts of the UK and hypothesised that this may be due to different organisation in psychiatric services for people with ID. Variation in prevalence rates by residential setting has also been identified with highest prevalence rates in hospitals, lower in community residential services, and lowest in family homes (Clarke *et al*. 1990; Kiernan *et al*. 1995; Robertson *et al*. 2000; Tsiouris *et al*. 2013).

Further research is thus required for several reasons. First, obtaining accurate prevalence rates of psychotropic drug use has been problematic given many existing studies have focused on small, highly selective convenience samples with a lack of population wide estimates (Sheehan *et al.* 2015). The number of population-based studies is small with participants recruited predominantly from primary care. One of the limitations of the Sheehan *et al.* (2015) study was the potential under-recording by GPs of people with mild ID. This may have overestimated the prevalence of prescribing given potentially lower levels of challenging behaviour (Bowring *et al*. 2016) and psychiatric problems (Whitaker & Read, 2006) in this sub-group. One disadvantage of using data from primary care is the lack of reliable and consistent identification of adults with an ID. Second, there has been variation in results due to a lack of standardised medication rating systems, preventing comparisons between studies. For example, some researchers have included antiepileptics for epilepsy as

psychotropic medications (Holden & Gitlesen, 2004; Henderson *et al*. 2015), whereas other researchers have classed them as somatic medication (Scheifes *et al.* 2013; Doan *et al*. 2014).Third, researchers have used varied definitions of challenging behaviour to examine its putative association with medication use. Sheehan *et al*. (2015) used a 200 long list of behaviours, including sleep disturbance, which primary care providers coded against records. This system was not externally validated, it was not clear if all behaviours would be reported to GPs, and did not identify if the problem was historical or current. Sheehan *et al*. (2015) reported that 36% of participants had a record of challenging behaviour with the majority of codes featuring generic labels such as ‘behaviour problem’ or ‘behaviour disorder’ with few specific topographical codes used. This rate of challenging behaviour is considerably higher than reported in other recent population studies (Bowring *et al*. 2016: 18.1%; Jones *et al.* 2008: 18.7%-22.5%; Lundqvist, 2013: 18.7%). Behaviour may be more accurately assessed through a direct individual assessment utilising a psychometrically evaluated behaviour rating scale with clear definitions of what constitutes challenging behaviour taking into account temporal and intensity factors.

The main aim of the present study was to address these limitations in existing studies by investigating the prevalence of medication use, particularly psychotropic medication, in the total administrative population of adults with ID (identified through multiple methods) in Jersey, Channel Islands. We determined the prevalence of psychotropic medication using an internationally recognised coding system (the World Health Organisation Anatomic Therapeutic Classification Scheme - WHO, 2014; WHOCC – ATC/DDD, 2014) and examined associations with challenging behaviour, and specific sub-types of challenging behaviour, identified by a rating tool

with good psychometric properties (the Behavior Problems Inventory – short form; Rojahn *et al.* 2012a). We also explored whether any association between medication prescription and challenging behaviour would be present after accounting for other sociodemographic and clinical characteristics.

Method

Participants

Participants were 265 persons ≥ 18 years of age administratively defined as having ID (i.e., who were receiving, or had received, support from services in Jersey). Participants were identified from multiple sources including the Health and Social Services (H&SS) administrative database, in Jersey, FACE (Functional Analysis of Care Environments, http://www.face.eu.com). FACE is a database used by the local community multi-disciplinary ID service which includes social work, occupational therapy, community nursing, positive behaviour support service and physiotherapy. Records were cross-referenced with current Education Department Record of Needs, and records of individuals maintained by local service providers from the voluntary sector and employment support services. The population ascertainment process and more detail on the procedure is provided in a previous paper (Bowring *et al*. 2016).

This identified 311 potential participants. Surveys were completed with 265 participants which is equivalent to 97% of eligible and traceable participants (N=274; 9 declined consent) or 85% of eligible people (N=311; 11 were traced but did not reciprocate contact, and we were unable to trace 26). Informed consent was

obtained from 162 adults. For 103 adults who did not have capacity to provide independent consent consultees gave consent. Given that surveys were completed on 85% of eligible participants results are a robust representation of the Jersey population in receipt of ID services.

Procedure

The study was approved by XXX University ethics committee, and by the States of Jersey, Health and Social Services ethics committee. The authors assert that all procedures contributing to this work comply with the ethical standards of the relevant national and institutional committees on human experimentation and with the Helsinki Declaration of 1975, as revised in 2008.

Researchers completed two surveys for each participant in face-to-face meetings with a proxy informant. Informants were either family members or key workers within a supporting organisation. Informants were judged to be in a good position to provide information about the participant if they had a minimum of regular weekly contact and had known the participant for at least one year. All data were collected over a period of 12 months (2013-2014). There were no missing data.

Measures

1. Medication data

The first survey tool was adapted from the Individual Schedule of the Challenging Behaviour Survey (Alborz *et al*. 1994) and the Wessex Scale (Kushlick *et al*. 1973;

Palmer & Jenkins, 1982) to collect socio-demographic information and clinical characteristics including medication use. Definitions for degree of ID were taken from the UK Department for Work and Pensions Guidance (2012). This definition categorises degree of ID based on IQ score (mild: 50-69; Moderate: 35-49; severe: 20-34; profound: less than 20) and describes typical daily living skills and support needs associated with each category. Whilst there was a reliance on proxy information, all responses were checked where possible against records stored on FACE.

Medication data collected included name of medication and corresponding dosage. For adults living in paid and congregate care settings (n=132) data were taken directly from individual Medication Administration Record (MAR). For adults who lived independently or with family, medication use data were provided by proxy informants (n=133).

The system for coding medication use (WHO, 2014; WHOCC – ATC/DDD, 2014) has been used in other studies of medication use in individuals with ID (Scheifes *et al*. 2013; Doan *et al*. 2014). The ATC system groups medications into 14 categories according to the organs or system on which they act or their chemical, pharmacological or therapeutic characteristics (Doan *et al*. 2014). Medication was independently coded by an Intellectual Disability Nurse, with research experience, who was an independent and supplementary prescriber (v300 Qualification). Psychotropic medications were defined as medical agents for the nervous system, excluding analgesics and antiepileptics prescribed for epilepsy (Doan *et al*. 2014). Psychotropic medications included anticholinergic agents, antipsychotics, anxiolytics, hypnotics and sedatives, antidepressants, psychostimulants and antiepileptics used as mood stabilisers.

There were several cases where there were different codes for particular medicines depending on their purpose of pharmacology. In 11 cases the research team had to return to proxy informants, or the health service database (FACE), to establish medical history and the pharmacological purpose of the medicine. Of the 68 people who were using antiepileptics, 15 did not have a diagnosis of epilepsy or history of seizures when checked against the demographic data. Further research established 7 were prescribed antiepileptics as mood stabilisers so were classified in the psychotropic drug category as per previous studies (Scheifes *et al*. 2013). The other 7 people were prescribed antiepileptics for absence seizures (and suspected epilepsy) or pain and were categorised under the appropriate somatic label.

For each medication, the ATC also provides a defined daily dose (DDD) which is in effect an average daily dosage for its main indication. Dosage was investigated for medication which affected the nervous system (N-coded) which included psychotropic medication. We recorded dosage against the listed DDD as below the DDD, equivalent to the DDD, or above the DDD. There were 3 medication entries within the nervous system category which researchers could not code due to the individual way dosage is calculated (Lithium x2) and due to brand differences (Nicotine patches x1).

The numbers of people prescribed PRN (as required) medication was very small (N=15) and so we did not include this as an analysis variable (cf. Schiefes *et al*. 2013; Sheehan *et al*. 2015).

All coded medication data were then independently checked by another researcher. There were two (from 694) data entry errors, which were amended. Prevalence was then calculated for all medications. The independent coder then

categorised all medication within the four digit ATC code to create a table of prevalence according to the class of the medication (see Table 2).

2. Challenging behaviour data

Researchers also completed the Behavior Problems Inventory - short form (BPI-S) (Rojahn *et al.* 2012ab; Mascitelli *et al*. 2015) to measure challenging behaviour during the previous six months as reported by proxy informants. BPI-S data were coded against the following definition (Bowring *et al.* 2016):

a) SIB: any item of self-injurious behaviour is “challenging” if either it is rated as severe and occurs at least weekly, or is rated as moderate but occurs at least daily. Any other occurrence of behaviour is not rated as challenging.
b) ADB: any item of aggressive destructive behaviour is “challenging” if either it is rated as severe and occurs at least weekly, or is rated as moderate but occurs at least daily. Any other occurrence of behaviour is not rated as challenging.
c) SB: any item of stereotyped behaviour is “challenging” if it occurs at the highest rated frequency (hourly). Any other occurrence of behaviour is not rated as challenging.
d) CB: Overall challenging behaviour is defined by the presence of a least one behaviour defined as “challenging” in the above categories.

The overall prevalence of challenging behaviour was 18.1% (95% CI: 13.94%-23.19%; n=48), self-injurious behaviour was 7.5% (95% CI: 4.94%-11.37%; n=20), aggressive and destructive behaviour 8.3% (95% CI: 5.54%-12.25%; n=22), and stereotyped behaviour 10.9% (95% CI: 7.73%-15.27%; n=29) (Bowring *et al*. 2016).

Statistical Analysis

Data were analysed using Statistical Package for the Social Sciences Version 21 (SPSS, Inc., Chicago, Il, USA). Descriptive statistics were used to summarise the overall prevalence of medication use in the sample. We then investigated the association between challenging behaviour (total challenging behaviour, aggressive and destructive behaviour, self-injury and stereotypy) and medication using Chi Square associations, additionally estimating unadjusted Relative Risks (RR). Finally, we adjusted for other variables using multivariable Generalised Linear Models (GLM) to further explore the association between medication use and challenging behaviour.

Results

Table 1 summarises participant characteristics. Of the 265 participants 50.6% (n=134) were male and 49.4% (n=131) female with a mean age of 41.44 (range 18-85). The majority lived in either congregate care (40.8%) or with family (34.3%). Over a quarter of adults (26.4%) had a psychiatric condition.

+++INSERT TABLE 1+++

Medication prevalence

+++INSERT TABLE 2+++

Table 2 shows the prevalence of medication use within this sample. A total of 70.57% (n=187) of adults with ID were prescribed at least one medication (mean=2.62; range 0-14). Under the ATC system the largest group of medications used were those coded to treat the nervous system used by 52.07% (n=138), followed by those for alimentary tract and metabolism used by 31.32% (n=83), followed by drugs for the cardiovascular system used by 15.69% (n=40).

Within the total sample 37.73% (n=100; mean=.68; range 0-5) used a psychotropic medication. The largest group of psychotropic medications used were antipsychotic medications used by 21.89% (n=58; mean=.27; range 0-3). Most commonly used were second generation (atypical) antipsychotics used by 15.09% (n=40). Of these the most common medications were Risperidone (n=16) and Olanzapine (n=13). Of the first generation (typical) antipsychotics used by 7.92% (n=21), the most common drug used was Haloperidol (n=10). The second largest group of psychotropic medications was antidepressants used by 17.38% (n=46; mean number=.18; range 0-2). The majority of these were selective serotonin reuptake inhibitors (SSRI) antidepressants used by 12.83% (n=34). The most common SSRI drugs used were Citalopram (n=10), Paroxetine (n=7) and Fluoxetine (n=6).

Dosage and polypharmacy

Nearly one-third of participants who were prescribed medication for the nervous system were prescribed at a level above the DDD: 30.43% (n=42) used at least one

medication above the DDD (35 people took one medication above DDD, 6 people 2 medications above DDD, 1 person 3 medications above DDD).

Among those prescribed medication for the nervous system (n=138) 41.31% were prescribed just one medication, while 58.69% were prescribed 2+ medications (mean =3.20; range 2-5). Polypharmacy was also common with psychotropic medication. Among those prescribed psychotropic medication (n=100), 51% were prescribed just one medication, while 49% were prescribed 2+ medications (mean=3.69; range 2-5).

Bivariate Analysis of the challenging behaviour-psychotropic medication association

+++INSERT TABLE 3+++

Chi-square tests were used to explore the association between challenging behaviour (total challenging behaviour, aggressive and destructive behaviour, self-injury and stereotypy) and medication use. Table 3 summarises these associations by detailing the percentage in the challenging behaviour and no challenging behaviour groups prescribed medication. Where associations were statistically significant at $p<.05$ we supplemented the chi-square results with a Relative Risk (RR) described below.

Adults with challenging behaviour were nearly twice as likely to be prescribed psychotropic medication compared to adults who did not present challenging behaviour (RR=1.921, 95% CI: 1.328 to 2.781). Similarly, adults who displayed

aggressive and destructive behaviour were nearly two times more likely to have been prescribed psychotropic medication (RR=1.891; 95% CI: 1.207 to 2.965). The adults with self-injurious behaviour were more than two and a half times as likely to have psychotropic medications prescribed (RR=2.606; 95% CI=1.741 to 3.902). There was no significant association between stereotyped behaviour and psychotropic medication use.

Adults with challenging behaviour were nearly three times as likely to have been prescribed antipsychotic medication compared with adults who did not present challenging behaviour (RR=2.99; 95%CI: 1.524 to 5.869). Similarly, adults with stereotyped behaviour were nearly two and a half times as likely to use antipsychotic medication (RR=2.457; 95%CI: 1.087 to 5.553). Adults with self-injurious behaviour were more than four times as likely to use antipsychotic medication (RR=4.104; 95%CI: 1.617 to 10.418). There was no association between aggressive destructive behaviour and antipsychotic drug use.

There was no association between antidepressant medication use and any topography of challenging behaviour.

Multivariate analysis of the challenging behaviour-psychotropic medication association

In the final analyses, we wanted to explore whether the associations between challenging behaviour and medication use remained after accounting for potential correlates of medication use. To identify correlates, we first ran a simple generalised linear model (GLM) to obtain an unadjusted RR between the potential correlate (sociodemographic and other clinical characteristics) and the use of medication

variables. Variables considered were largely those identified in previous studies such as psychiatric diagnosis, age, gender, type of residence (living in paid/congregate care versus other), degree of ID (severe/profound versus mild/moderate), low communication skills (non-verbal or no clear speech and limited receptive understanding) and sensory impairments (sight or hearing impairment). All correlates significantly associated with medication use were then fitted into a multivariable GLM to examine all potentially relevant correlates alongside challenging behaviour.

GLMs were used to explore the association with the number of psychotropic medications used (0,1,2,3+) fitted to follow a Poisson distribution with robust standard errors (Knoll *et al*. 2012). For a number of antipsychotic medications (defined as 0 and 1+) we fitted a logistic GLM. Results are presented in tables 4 and 5.

+++INSERT TABLE 4+++

+++INSERT TABLE 5+++

Results from GLM Poisson regression models showed that those with a psychiatric diagnosis had a 4.22 RR (95% CI 3.007 to 5.92; p<.001) of being prescribed psychotropic medication (Table 4). Those living in paid or congregate care had a 2.015 RR (95% CI 1.378 to 2.946; p<.001); those who presented challenging behaviour a 1.921 RR (95% CI 1.328 to 2.781; p<.001); adults with a severe profound ID a 1.475 RR (95% CI 1.009 to 2.155; p=.045); and (older) age gave a 1.034 RR (95% CI 1.025 to 1.044; p<.001). There were no significant associations between gender, sensory impairment or low communication skills and the use of psychotropic medication. When all significantly associated variables were

entered in the GLM model together (Table 5), severe-profound ID was no longer significantly associated with psychotropic use. Significant correlates remaining included psychiatric disorder (RR=3.725; 95% CI 2.68 to 5.178; p<.001), challenging behaviour (RR=1.565; 95% CI 1.074 to 2.282; p=.02), living in paid/congregate care (RR=1.542; 95% CI 1.082 to 2.196; p=.016) and (older) age (RR=1.023; 95% CI 1.013 to 1.034; p<.001).

Using GLM loglink regression models we found that those with a psychiatric diagnosis had a 7.478 RR (95% CI 3.945 to 14.174; p<.001) of using antipsychotic medication (Table 4). Those who presented with challenging behaviour had a 2.99 RR (95% CI 1.524 to 5.869; p=.001); those living in paid / congregate care a 2.516 RR (95% CI 1.363 to 4.644; p=.003); males had a 2.42 RR (95% CI 1.311 to 4.466; p=.005); those with a severe/profound ID a 2.099 RR (95% CI 1.096 to 4.019; p=.025); and (older) age a 1.05 RR (95% CI 1.03 to 1.071; p<.001). There was no significant association between sensory impairments and low communication skills and antipsychotic medication use. When all significant correlates were entered into the model together (Table 5), living in paid/congregate care and severe/profound ID were no longer significant. Significant correlates remaining were psychiatric disorder (RR=9.124; 95% CI 4.151 to 20.058; p<.001), male gender (RR=3.35; 95% CI 1.573 to 7.134; p=.002), challenging behaviour (RR=2.968; 95% CI 1.131 to 7.79; p=.027) and (older) age (RR=1.043; 95% CI 1.018 to 1.069; p=.001).

Discussion

Among the total administrative population of adults with ID in Jersey, nearly 4 in 10 were in receipt of at least one psychotropic medication (37.73%, n=100) and

30.43%, (n=42) were prescribed a medication which acts on the nervous system above the indicated daily dose. Nearly half of all adults prescribed psychotropic medications (49%, n=49) were in receipt of more than one of these medications. Thus, the use of psychotropic medication, at high doses and polypharmacy were common supporting previous evidence (Deb *et al*. 2014; Henderson *et al*. 2015; Sheehan *et al.* 2015).

The most prevalent group of medications was antipsychotics, prescribed to 21.89% of people. This confirms the preference for this type of medication by prescribers as seen in other studies (Holden & Gitlesen, 2004; Deb & Unwin, 2007; Matson & Neal, 2009; Singh & Matson, 2009). Second generation antipsychotics were used by 15.09% of the sample which confirms a shift in prescribing patterns to second generation antipsychotics and SSRIs (Spreat *et al*. 2004; Matson & Neal, 2009; Paton *et al*. 2011).

The prevalence of psychotropic drug use is lower in our sample than those reported from other recent studies in the UK (e.g. Henderson *et al.* 2015, 49.1%; Sheehan *et al*. 2015, 49%). There are a number of potential reasons for this. First, one strength of this population study was that it did not recruit from a particular clinical route such as participants in contact with general practitioners and psychiatrists (e.g. Henderson *et al.* 2015; Sheehan *et al*. 2015). Sheehan et al. (2015) indicate they may have over-estimated prevalence of prescribing due to difficulties identifying adults with mild ID from GP records. The total population ascertainment process in this study used multiple routes. There may be potentially lower prevalence estimates in studies that consider total population samples and not just primary care records or records from specialised challenging behaviour, residential, or hospital services. In a county in Norway, adults with ID known to

services (N=300) and living in the community, had a similar prevalence of psychotropic prescribing (37.4%) to the current study (Holden & Gitlesen, 2004)

Second, our total population study did not recruit from one specific clinical setting like other studies with high prevalence rates (e.g. Griffiths *et al*. 2012, 72%; Deb *et al.* 2014, 89%) but from multiple routes. We found prevalence of antipsychotics by residence was only 11% for those residing in family homes, 21.4% in independent living and much higher at 29.5% in paid/congregate care. Studies that have considered differing prescribing patterns by including community samples may lead to lower prevalence estimates.

Third, previous studies have identified regional variations in prevalence rates between districts of origins in the UK (Kiernan *et al*. 1995). This has been explained by the fact that prescribing professionals, practices and samples will vary by region. There appears to be less use of certain medications in Jersey. Sheehan *et al*. (2015) reported a 21% prevalence of antipsychotics and 20% prevalence of antidepressants which was similar to the present sample (21.89% and 17.36%), but a higher prevalence of mood stabilisers (20%) and anxiolytics/hypnotics (22%) compared to the present sample (2.64% and 10.57%). The Jersey General Hospital Formulary (States of Jersey, 2016) lists medications licenced to be prescribed in Jersey. This may detail a slightly different set of medications to other authorities/countries and identifies some medications that GPs cannot prescribe.

In Jersey, all adults with ID and challenging behaviour are open to the ID psychiatrist. Some evidence has suggested a reduced level of prescribing from psychiatrists compared to GPs (Holden & Gitlesen, 2004). We found that 39.7% of adults with ID in receipt of antipsychotic medication did not have a psychiatric disorder. This rate is lower than that reported in other recent studies (50-71%:

Tsiouris, 2010, Paton *et al*. 2011; Marston *et al*. 2014; Sheehan *et al*. 2015). This may have contributed to lower rates of prescribing. Further investigations are required into regional variations and what influences prescribing patterns of individual medications at a prescriber level.

Our data also suggested that psychotropic medication prescribed in the absence of a psychiatric diagnosis may be related to the presence of challenging behaviour. Ascertainment of the presence of challenging behaviour was a strength of the current study through the BPI-S. Our data extended previous findings (Brylewski & Duggan, 2004; Tsiouris, 2010; Henderson *et al.* 2015; Sheehan *et al*. 2015) by indicating different patterns of association with specific topographies of challenging behaviour. Psychotropic medication use was associated with aggressive/destructive behaviour and self-injurious behaviour, but not stereotyped behaviour. Antipsychotic medication use was associated with self-injurious behaviour and stereotyped behaviour, but not aggressive/destructive behaviour. Adults with SIB in particular may be a priority for psychosocial interventions and medication reviews. It is of interest that antipsychotic use was associated with behaviours that could be considered inner-directed (self-injury and stereotypy), but not outward-directed such as aggression/destruction. In the presence of aggression/destruction the relative risk of using hypnotics/sedatives was over 200% and 700% for using antiepileptics as mood stabilisers. Mood stabilisers for aggression have been documented in other studies (Deb *et al*. 2014; Wilner, 2014: Tsiouris *et al*. 2015). Overall, our data indicate that differences in prescribing patterns may be associated with specific challenging behaviours, or the features associated with those behaviours which requires further investigation.

Factors other than challenging behaviour and psychiatric diagnosis were also independently associated with medication use. Psychotropic medication use was additionally associated with living in paid/congregate care and increased age. Antipsychotic medication was similarly associated with increased age and also male gender. Associations between psychotropic medication use, older age, and type of residence have been seen consistently in other studies (Aman *et al*. 1995; Kiernan *et al*. 1995; Singh *et al.* 1997; Robertson *et al*. 2000; Holden & Gitlesen, 2004; Sheehan *et al.* 2015). The increased likelihood of receiving antipsychotic medication for males compared to females has also been reported in other studies and requires further exploration to consider why this is (McGillivray & McCabe, 2006; Delafon *et al*. 2013; Doan *et al.* 2014).

A limitation of the present study is that findings apply only to the administratively defined ID population in Jersey while there may also be adults with ID < 70 not known to services who were not included. However, findings from this study are likely useful in practice since specialised support (such as for medication reviews) might be best planned on the basis of a population of people with ID already known to services. The sample size was also relatively small compared to other recent studies. A second limitation was the reliance on proxy informants to report medication use for those living in family or independent settings (133 participants) where there is a possibility of misreporting as these informants are not clinically trained. However, potential inaccuracy was limited as proxy informants often showed researchers the medication with listed name and dosage; where they were unsure they made further enquiries and researchers contacted them again. Follow up checks were also made on the FACE database as initial assessments, care plans and nursing plans listed on FACE usually contained information on

medication use. PRN medication use was rare, but future studies with larger samples could also consider separate analysis of these medications.

Implications for policy and practice

Despite the lower prevalence in this sample, prescribing levels of psychotropic medication are still too high and often related to challenging behaviour with no evidence this practice is effective (Matson & Neal, 2009). Studies on withdrawing medication suggest many adults with ID can do so successfully (Ahmed *et al.* 2000). Health organisations should complete audits to ascertain psychotropic prescribing levels and identify adults requiring a psychiatric review of their medication. The involvement of specialist prescribers, rather than GPs, is essential as there is evidence prescribing rates are lower where psychiatrists lead prescribing (Holden & Gitlesen, 2004).

Although requiring future replication, we found that different topographies of behaviour related to different patterns of prescribing, with those with SIB being a particularly high risk group. Efforts should be made to reduce prescribing in high risk populations by prioritising them for medication reviews (RCP, 2016) and alternative psychosocial interventions.

We also found that general medication use is high in adults with ID (for example, 31.32% were in receipt of medication for the alimentary tract and metabolism) and future research needs to investigate the high prevalence of all types of medication prescribed and whether these are indicated by an underlying health need.

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Table 1. Baseline Characteristics of the study population (N=265)

Characteristic	N (%)
Mean age	41.44 years (SD: 16.278)
Gender	Male: 134 (50.6%)
	Female: 131 (49.4%)
Type of accommodation	Congregate care: 108 (40.8%)
	Paid carer: 24 (9.1%)
	Family carer: 91 (34.3%)
	Independent living: 42 (15.8%)
Time in setting	Less than 1 year: 32 (12.1%)
	1-5 years: 60 (22.6%)
	6-10 years: 62 (23.4%)
	11-20 years: 53 (20%)
	21 years plus: 58 (21.9%)
Degree of intellectual disability	Profound: 26 (9.8%)
	Severe: 32 (12.1%)
	Moderate: 83 (31.3%)
	Mild: 124 (46.8%)
Other diagnoses (include)	Autism: 31
	Down Syndrome: 36
	Cerebral Palsy: 15
	ADHD: 2
	Fragile X: 2
	Soto syndrome: 2
	Other: 11
Daytime engagement	Paid work: 37 (14%)
	Voluntary work: 39 (14.7%)
	Vocational training: 22 (8.3%)
	Education: 5 (1.9%)
	Day service: 60 (22.6%)
	No daytime engagement: 102 (38.5%)
Epilepsy	57 (21.5%)
Psychiatric condition	70 (26.4%) including:
	Depression: 31 (11.7%)
	Schizophrenia: 18 (6.8%)
	Affective Disorder 10 (3.8%)
	Psychotic condition 8 (3%)
	Neurosis 3 (1.1%)

Table 2.The prevalence of medication use in the study population by ATC category (N=265).

ATC section Category	ATC four digit category	N = Number of participants (range)	% of participants
N - Nervous System		138 (0-5)	52.07
	Psychotropic Medication	100 (0-5)	37.73
	Anticholinergic agents N04A	25 (0-1)	9.43
	AntiPsychotic N05A	58 (0-3)	21.89
	First generation Antipsychotic	21 (0-3)	7.92
	Second generation Antipsychotic	40 (0-1)	15.09
	Drugs for mania and hypomania Anti-psychotic	5 (0-1)	1.89
	Anxiolytics N05B	11 (0-1)	4.15
	Hypnotics and sedatives N05C	17 (0-1)	6.42
	AntiDepressants N06A	46 (0-2)	17.36
	SSRI AntiDepressants	34 (0-2)	12.83
	Tricyclic Antidepressants	5 (0-1)	1.89
	Other Antidepressants	9 (0-1)	3.40
	Psychostimulants N06B	1 (0-1)	0.38
	Antiepileptic's as Mood stabilisers N03A	7 (0-1)	2.64
	Analgesia N02A/B/C	14 (0-2)	5.28
	Antiepileptics for nerve pain N03A	3 (0-1)	1.13
	Antiepileptics for epilepsy N03A	57 (0-4)	21.51
	Dopaminergic agents N04B	2 (0-2)	0.75
	Anti-dementia drugs N06D	3 (0-1)	1.13
	Drugs used in Nicotine dependence N07B	1 (0-1)	0.38
A - Alimentary tract and metabolism		83 (0-5)	31.32
B- Blood and blood forming organs		26 (0-3)	9.81
C- Cardiovascular system		40 (0-4)	15.09
D - Dermatologicals		16 (0-2)	6.04
G - Genito-urinary system and sex hormones		30 (0-2)	11.32
H - Systemic hormonal preparations		24 (0-2)	9.06
J - Antiinfectives for systemic use		16 (0-1)	6.04
L - Antineoplastic and immunomodulating agents		2 (0-1)	0.75
M - Musculo-skeletal system		20 (0-2)	7.55
R - Respiratory System		24 (0-4)	9.06
S - Sensory organs		5 (0-1)	1.89
V - Various		6 (0-1)	2.26
	Total medication use	187 (0-14)	70.6

* No participant was using P – Antiparasitic products, insecticides and repellents

Table 3. Association between challenging behaviour and medication use (N=265).

	Psychotropic Medication	Antipsychotic Medication	Antidepressant Medication
Challenging Behaviour (%):	56.3	39.6	18.8
No Challenging behaviour (%):	33.6	18	17.1
Chi Square:	$\chi^2(1)=8.55,p=.003$	$\chi^2(1)=10.74,p=.001$	$\chi^2(1)=0.08,p=.778$
Aggressive Destructive Behaviour (%):	63.6	36.4	27.3
No Aggressive Destructive Behaviour (%):	35.4	20.6	16.5
Chi Square:	$\chi^2(1)=6.85,p=.009$	$\chi^2(1)=2.94,\ p=.086$	$\chi^2(1)=1.64,p=.200$
Self-injurious Behaviour (%):	70	50	25
No Self-injurious Behaviour (%):	35.1	19.6	16.7
Chi Square:	$\chi^2(1)=9.58,p=.002$	$\chi^2(1)=10.00,p=.002$	$\chi^2(1)=0.88,p=.348$
Stereotypical Behaviour (%):	48.3	37.9	6.9
No Stereotypical Behaviour (%):	36.4	19.9	18.6
Chi Square:	$\chi^2(1)=1.54,p=.215$	$\chi^2(1)=4.90,p=.027$	$\chi^2(1)=2.48,p=.115$

Table 4. Association of medication use with sociodemographic and clinical characteristics: Unadjusted Relative Risk.

Psychotropic medication	
	Unadjusted RR (95% CI; p=)
Challenging behaviour (N=48)	1.921 (1.328 to 2.781; p=.001)
Psychiatric disorder (N=70)	4.22 (3.007 to 5.92; p<.001)
Male gender (N=134)	1.312 (.91 to 1.892; p=.145)
Paid / congregate care (N=132)	2.015 (1.378 to 2.946; p<.001)
Severe / profound ID (N=58)	1.475 (1.009 to 2.155; p=.045)
Age (N=265)	1.034 (1.025 to 1.044; p<.001)
Sensory impairment (N=38)	1.134 (.696 to 1.848; p=.615)
Low communication skills (N=33)	.984 (.581 to 1.668; p=.953)
Antipsychotic medication	
	Unadjusted RR (95% CI; p=)
Challenging behaviour (N=48)	2.99 (1.524 to 5.869; p=.001)
Psychiatric disorder (N=70)	7.478 (3.945 to 14.174; p<.001)
Male gender (N=134)	2.42 (1.311 to 4.466; p=.005)
Paid / congregate care (N=132)	2.516 (1.363 to 4.644; p=.003)
Severe / profound ID (N=58)	2.099 (1.096 to 4.019; p=.025)
Age (N=265)	1.05 (1.03 to 1.071; p<.001)
Sensory impairment (N=38)	1.127 (.501 to 2.539; p=.772)
Low communication skills (N=33)	.956 (.392 to 2.328; p=.920)

Table 5. Association of medication use with sociodemographic and clinical characteristics: Adjusted Relative Risk.

Psychotropic medication	
	Adjusted RR (95% CI; p=)
Challenging behaviour (N=48)	1.565 (1.074 to 2.282; p=.02)
Psychiatric disorder (N=70)	3.725 (2.68 to 5.178; p<.001)
Paid / congregate care (N=132)	1.542 (1.082 to 2.196; p=.016)
Severe / profound ID (N=58)	.926 (.627 to 1.367; p=.699)
Age (N=265)	1.023 (1.013 to 1.034; p<.001)
Antipsychotic medication	
	Adjusted RR (95% CI; p=)
Challenging behaviour (N=48)	2.968 (1.131 to 7.79; p=.027)
Psychiatric disorder (N=70)	9.124 (4.151 to 20.058; p<.001)
Male gender (N=134)	3.35 (1.573 to 7.134; p=.002)
Paid / congregate care (N=132)	1.096 (.774 to 4.698; p=.161)
Severe / profound ID (N=58)	1.131 (.427 to 2.998; p=.804)
Age (N=265)	1.043 (1.018 to 1.069; p=.001)