Off-label use of antipsychotic medication in people with intellectual disabilities

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CHAPTER 2

Adherence of clinicians to guidelines for the prescription of antipsychotic drugs to people with intellectual disabilities

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Abstract

Purpose

Antipsychotic drugs are frequently prescribed to people with intellectual disabilities to ameliorate psychotic symptoms and behavioural symptoms with and without mental condition. Guidelines recommend systematic evaluation of treatment effects and adverse effects, and limiting the treatment duration. Studies have shown that adherence to prescription guidelines is beneficial for clients' outcomes. Therefore, we set up a study to investigate the adherence to antipsychotic drug prescription guidelines in two treatment settings.

Methods

A checklist, based on existing antipsychotic drug prescription guidelines, was used to evaluate the adherence of prescribers to guidelines in two settings in the Netherlands, i.e., in specialized Intellectual disability care organizations and mental health care organizations. Data from medical records of clients who used antipsychotic drugs (N=299) were compared to the items of the checklist.

Findings

Treatment effects were measured with validated scales in both settings in only 2.7%. Prescriptions were for problem behaviour in absence of a psychotic disorder or psychotic symptoms in 90% (specialized Intellectual disability care) and in 79% (mental health care) of cases. In specialized Intellectual disability care pipamperone (31.9%) and in mental health care risperidone (48.5%) was most often prescribed. Adverse effects were monitored more frequently in specialized ID care.

Value

The adherence to guidelines for prescribing antipsychotic drug to people with intellectual disabilities is insufficient in the Netherlands, because of shortcomings in the evaluation of treatment and adverse effects.

Introduction

Antipsychotic drugs are indicated and licensed for the treatment of psychotic disorders and episodes of psychotic symptoms, and some for the short-term treatment of aggressive behaviour in people with intellectual disabilities, in addition to psychosocial interventions (National Institute for Health and Care Excellence (NICE), 2015; NICE, 2017). In general, there are three groups of people with intellectual disability that use antipsychotic drugs: those with a diagnosis of a psychotic disorder or schizophrenia, those with a diagnosis of a non-psychotic mental condition and comorbid problem behaviour, and those with problem behaviour without a diagnosis of a mental condition (NICE, 2016).

The evidence for the effectiveness of antipsychotic drugs for the treatment of behavioural symptoms and problem behaviour is not clear, however (Brylewski & Duggan, 2004; de Kuijper, Evenhuis, Minderaa, & Hoekstra, 2014; Deb & Unwin, 2007; Tyrer et al., 2008). Moreover, antipsychotic drugs' adverse effects, i.e., neurological, metabolic and hormonal adverse events occur frequently (Bhuvaneswar, Baldessarini, Harsh, & Alpert, 2009; Haddad & Dursun, 2008; Matson & Mahan, 2010). These adverse effects may harm health and negatively influence the quality of life of users. Unfortunately, many people with intellectual disabilities are not able to effectively communicate discomfort caused by adverse effects (Reiss & Aman, 1997) while support professionals often do not recognize symptoms (Fretwell & Felce, 2007). Clinicians should therefore balance the benefits of ongoing treatment with antipsychotic drugs versus the risks of the occurrence of adverse events, by carefully monitoring treatment effects as well as adverse effects.

There are several national and international guidelines that provide recommendations on prescribing antipsychotic drugs in people with intellectual disability. These guidelines all provide similar recommendations on when and how long to prescribe antipsychotic drugs, how to measure treatment effects, when additional psychological and psychosocial treatments are needed, how to monitor adverse effects and when to discontinue the pharmaceutical treatment (Cahn et al., 2008; de Leon, Greenlee, Barber, Sabaawi, & Singh, 2009; Deb et al., 2009; Dieleman, Dierckx, & Hofstra, 2011; NICE, 2014; NICE, 2015; NICE, 2016; NICE, 2017; (Dutch General Practice Organization, NHG), 2006; Nederlandse Vereniging van Artsen Somatisch voor de Psychiatrie (Dutch society for physicians somatic in psychiatry, NVASP), 2006; Nederlandse Vereniging van Artsen voor Verstandelijk Gehandicapten (Dutch society for Intellectual Disability Physicians, NVAVG), 2007; NVAVG, 2016).

Previous studies concluded that the successful implementation of clinical guidelines into mainstream mental health care improved treatment outcomes (van Dijk, Oosterbaan, Verbraak, & van Balkom, 2013), led to lower relapse rates (Melfi et al., 1998), greater treatment satisfaction (van Dijk et al., 2013) and improved quality of care (Bauer, 2002). However, studies on adherence to guidelines in people with intellectual disability have pointed to insufficient monitoring of adverse effects (Cleary et al., 2012; Griffiths, Halder, & Chaudhry, 2012; Marshall, 2004; Paton, Bhatti, Purandare, Roy, & Barnes, 2016; Paton et al., 2011; Teeluckdharry et al., 2013; Thalitaya, Udu, Nicholls, Clark, & Prasher, 2011; Walter et al., 2008) and limited evaluation of the need for on-going treatment and related discontinuation (Paton et al., 2011; Thalitaya et al., 2011).

Adherence to treatment guidelines may be different across treatment settings. In the Netherlands, there are two main settings in which antipsychotic drugs are prescribed to people with an intellectual disability: specialized intellectual disability care, which mostly offer care through Intellectual Disability (ID) physicians or sometimes specialized general practitioners; and mental health care that provide care through mostly psychiatrists and sometimes specialized ID physicians. Therefore, we set up a study to investigate adherence to prescription guidelines of antipsychotic drugs in these two care settings for people with intellectual disabilities, including the monitoring of treatment effects and adverse effects.

Methods

Study design, settings and sample

We studied randomly selected pharmaceutical and medical records of clients with intellectual disabilities who had been prescribed antipsychotic drugs from two types of settings: (1) Three organizations providing specialized Intellectual Disabilities (ID) health care and (2) two organizations providing mental health care (a specialized outpatient clinic for mental health care and an outpatient clinic for child and adolescent psychiatry). Mental health care in these two types of settings was provided by various professionals: in specialized ID care by intellectual disabilities physicians, general practitioners, nurses and behavioural scientists; in mental health care organizations by psychiatrists, behavioural scientists and/or ID physicians and nurses.

In this study 299 medical records were included (Figure 1). We took a random sample from the 378 available records from the specialized ID organizations (N=113) and included all available records from the mental health care organizations (N=186).

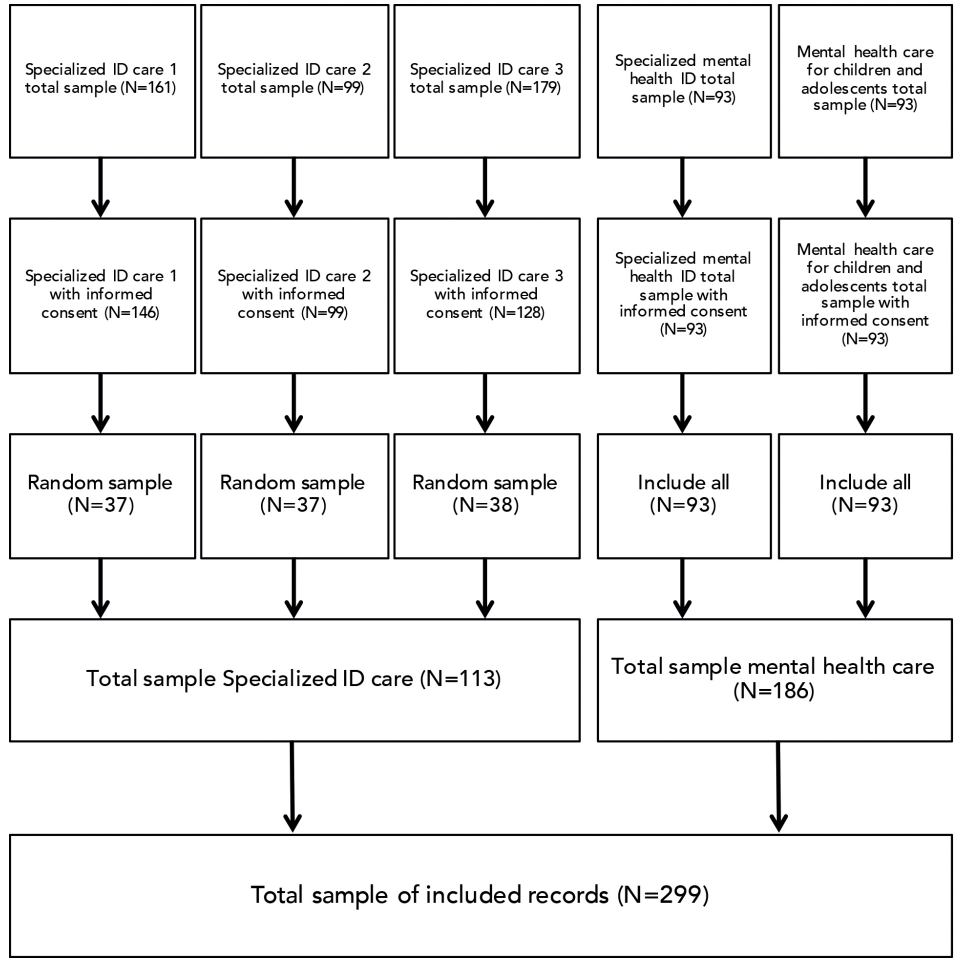

Figure 1. Inclusion and sampling process.

Selection criteria

Medical records were selected if:

- The client used at least one antipsychotic drug at the time of the study.
- The client had an intellectual disability (IQ<70) based on medical records.
- The client was aged six years or older.
- The client and/or legal representative provided informed consent.

The use of other medication, including other psychotropic drugs, was no reasons for exclusion.

Table 1. Domains of the antipsychotic drug prescription checklist. Items were rated as follows: monitored yes/no; aberrant yes/no; if 'yes' action taken yes/no; if yes change in dose and/or type of AP drug (for full checklist see appendix 1).

Domain	Subdomain	Items
Domain 1 Patient characteristics	Demographic characteristics (NVAVG)	Sex, age, living situation, severity of intellectual disability, aetiology of intellectual disability
	Comorbid mental and physical conditions (NICE, NVAVG)	Comorbid mental and physical conditions and mobility
Domain 2 Prescription history & reason for prescribing	Reason for prescription and/or target symptoms (NICE, NVAVG, NHG)	Reason for prescription, including target symptoms
	History of antipsychotic drug use	Previously used antipsychotic drugs
	History of treatment with other medication (including psychotropic drugs) and of psycho-social interventions (NVAVG)	Use of other pharmaceutical and non-pharmaceutical treatments, daily care, living facilities, social environment and personal and family medical history
	Contra-indications (NVAVG)	Medication use
	Type of antipsychotic drug (NVAVG)	Type of antipsychotic drugs
	Duration of use (NICE, NVAVG, NHG, NVASP)	Duration of use
	Dosage (NVAVG)	Dosage (in Defined Daily Dose; DDD)
Domain 3 Treatment evaluation	Treatment evaluation with use of validated instruments (NVAVG)	Use of validated scales for the monitoring of treatment effects
	Reassessment of reason of prescription (NICE, DeLeon et al. 2009, NVAVG)	Change in dosage and reason for change, change in type and reason for change, attempted discontinuations and/or attempted lowering of dosage
	Monitoring of adverse effects (NVAVG, Cahn et al. 2008, NVASP)	- Neurologic symptoms (extrapyramidal symptoms, Central Nervous System symptoms, autonomic symptoms) - Cardio vascular symptoms (pulse, blood pressure) - Metabolic symptoms (weight, waist circumference) - Laboratory parameters (fasting plasma glucose, fasting total cholesterol, LDL, HDL and triglycerides, plasma levels of prolactin, liver and renal parameters)

Instrument

We constructed a checklist based on national and international guidelines (Cahn et al., 2008; de Leon et al., 2009; Deb et al., 2009; Dieleman et al., 2011; NICE, 2014; NICE, 2015; NICE, 2016; NICE, 2017; NHG, 2006; NVAVG, 2007; NVAVG, 2016; van Alphen et al., 2012), covering three different domains (Table 1): (1) Patient characteristics, (2) Prescription history and reasons for prescription;

and (3) Treatment evaluation, including monitoring of adverse effects. Table 1 contains the various items of the three domains. Medical records were investigated by comparing the items of checklist to the corresponding items as noted in the medical files.

Statistical analysis

Descriptive statistics included means and standard deviations for age and Defined Daily Dose (DDD). All other items from the checklist (Table 1) were categorical variables, for which frequencies were calculated. Differences between the two treatment settings were tested by chi square test for the categorical items or Mann Whitney U tests for age and DDD. The association between severity of intellectual disability and diagnosis of a mental condition was tested with a chi square test. Significant differences were defined as $p<0.05$.

Results

Domain 1: patient characteristics

Clients from specialized ID care were significantly older than clients from mental health care. Furthermore, clients from mental health care more often lived independently or with their parents, while clients from ID care often lived in residential facilities of the organizations (Table 2). In specialized ID care organizations, clients presented with greater severity level of the intellectual disability and more frequent comorbid somatic conditions. In the mental health care settings, significantly more clients had comorbid mental conditions. There was a significant association between severity of intellectual disability and having a diagnosis of mental health condition (Pearson $\chi 2$ (4) =32.4, $p<0.001$), indicating that people with more severe intellectual disability are less likely to have a diagnosis of a mental condition.

Table 2. Patient characteristics.

	Total	Service providers for people with ID (n=113)	Mental health care for people with ID (n=186)	Significance
Age (mean (SD))[a]	34.58 (18.62)	47.78 (15.86)	26.38 (15.21)	$p<0.001$
Sex (n (%))[a]				
Male	196 (65.5)	74 (65.5)	122 (65.6)	NS
Female	103 (34.4)	39 (34.5)	64 (34.4))	NS
Living accommodation aimed at (n (%))[a]				
Nursing and care	9 (3.0)	9 (8.0)	0 (0)	$p<0.001$
Care and support	62 (20.7)	50 (44.2)	12 (6.5)	$p<0.001$
Support	74 (24.7)	41 (36.3)	33 (17.7)	$p<0.001$
Independent living	42 (14.0)	2 (1.8)	40 (21.5)	$p<0.001$
With parent/relatives	81 (27.1)	0 (0)	81 (43.5)	$p<0.001$
Unknown	31 (10.4)	11 (9.7)	20 (10.8)	NS
Severity of intellectual disability (n (%))[a]				
Mild	166 (55.5)	11 (9.7)	155 (83.3)	$p<0.001$
Moderate	53 (17.7)	30 (26.5)	23 (12.4)	$p=0.002$
Severe	40 (13.4)	38 (33.6)	2 (2.2)	$p<0.001$
Profound	14 (4.7)	14 (12.4)	0 (0)	$p<0.001$
Unknown	26 (8.7)	20 (17.7)	6 (3.2)	$p<0.001$
Comorbid somatic conditions (n (%))[a]				
None	157 (52.5)	18 (15.9)	58 (62.4)	$p<0.001$
Cardio vascular	18 (6.0)	13 (11.5)	5 (2.7)	$P=0.002$
Pulmonary	13 (4.4)	4 (3.5)	9 (4.8)	NS
Gastrointestinal and liver	36 (12.0)	30 (26.5)	6 (3.2)	$p<0.001$
Renal disorders and urinary tract	1 (0.3)	0 (0)	1 (0.5)	NS
Sensory	27 (9.0)	21 (18.6)	6 (3.2)	$p<0.001$
Musculoskeletal	48 (16.1)	37 (32.7)	11 (5.9)	$p<0.001$
Neurologic	47 (15.7)	35 (31.0)	12 (6.5)	$p<0.001$
Metabolic	22(8.7)	13 (11.5)	13 (7.0)	NS
Endocrine	23 (7.7)	23 (20.4)	0 (0)	$p<0.001$
Hematologic	6 (2.0)	3 (2.7)	3 (1.6)	NS
Tumours	6 (2.0)	4 (3.5)	2 (1.1)	NS
Other	16 (5.4)	8 (7.1)	8 (4.3)	NS
Comorbid mental conditions (n (%))[a, b]				
None	28 (9.4)	20 (17.7)	8 (4.3)	$p<0.001$
Autistic disorder	175 (58.5)	72 (63.7)	103 (55.4)	NS
Mood disorder	42 (14.0)	17 (15.0)	25 (13.4)	NS
Personality disorder	16 (5.4)	2 (1.8)	14 (7.5)	$p=0.032$
ADHD	57 (19.1)	10 (8.8)	47 (25.3)	$p<0.001$
Trauma/PTSS	21 (7.0)	2 (1.8)	19 (10.2)	$p=0.006$
Attachment disorder	15 (5.0)	3 (2.7)	12 (6.5)	NS
Psychosis/ schizophrenia	26 (8.7)	11 (9.7)	15 (8.1)	NS

[a] *Chi square test*
[b] *Mental conditions which were present in more than 10 cases of the sample*

Domain 2: Prescription practice

In mental health care organizations, the target symptoms for the treatment with antipsychotic drugs were more often unknown compared to specialized ID care. In both settings, the most frequently recorded target symptom was aggression and destructive behaviour. In mental health care, 53.2% received additional psychological or psychosocial treatment, compared to 29.2% in specialized ID care. Pipamperone was the most frequent prescribed antipsychotic drug in specialized ID care (31.9%), while in the mental health care settings risperidone was prescribed most frequently (48.5%). In specialized ID care the majority of clients used their antipsychotic drug more than ten years, which was significantly longer than clients in mental health care, who often used their antipsychotic drug one to five years.

Table 3. Reasons for prescribing antipsychotic drugs (AP) in two different care settings.

	Total	Service providers for people with ID (n=113)	Mental health care for people with ID (n=186)	Significance
Target symptoms (n (%))[a]				
Unknown	48 (16.1)	5 (4.4)	43 (23.1)	$p<0.001$
Self-injurious behaviour	39 (13.0)	28 (24.8)	11 (5.9)	$p<0.001$
Stereotypical behaviour	32 (10.7)	19 (16.8)	13 (7.0)	$p=0.008$
Withdrawn behaviour	89 (29.8)	40 (35.4)	49 (26.3)	NS
Aggressive/ destructive behaviour	138 (41.3)	67 (59.3)	71 (38.2)	$p<0.001$
Irritability/ restlessness	81 (27.1)	48 (42.5)	33 (17.7)	$p<0.001$
Sleeping problems	29 (9.7)	13 (11.5)	15 (8.6)	NS
Psychosis and Psychotic symptoms	37 (12.4)	15 (13.3)	22 (11.8)	NS
Mood swings	28 (9.4)	19 (16.8)	9 (4.8)	$p=0.001$
Hyperactivity	30 (10.0)	7 (6.2)	23 (12.4)	NS
Inappropriate sexual behaviour	8 (2.7)	5 (4.4)	3 (1.6)	NS
Other non-psychotic mental health condition[b]	9 (3.0)	5 (4.4)	4 (2.2)	NS
On- or off label prescription (n (%))[a]				
Unknown	34 (11.4)	3 (2.7)	31 (16.7)	$p<0.001$
Diagnosis of psychosis/ schizophrenia	16 (5.4)	8 (7.1)	8 (4.3)	NS
Problem behaviour diagnosis of mental disorder	227 (75.9)	85 (75.2)	142 (76.3)	NS
Problem behaviour without diagnosis of mental disorder	22 (7.4)	17 (15.0)	5 (2.7)	$p<0.001$
Number of APs[c] used simultaneously (n (%))				
1	273 (91.3)	103 (91.2)	170 (91.4)	NS
2	25 (8.4)	9 (8)	16 (8.6)	NS
3	1 (0.3)	1 (0.9)	0 (0)	NS

Table 3. continued

	Total	Service providers for people with ID (n=113)	Mental health care for people with ID (n=186)	Significance
Type of AP[d] (n (%))				
Risperidone	112 (37.5)	21 (18.6)	91 (48.9)	$p<0.001$
Pipamperone	82 (27.4)	36 (31.9)	46 (24.7)	NS
Olanzapine	29 (9.7)	22 (19.5)	7 (3.8)	$p<0.001$
Quetiapine	25 (8.4)	3 (2.7)	22 (11.8)	$p=0.005$
Aripiprazole	23 (7.7)	3 (2.7)	20 (10.8)	$p=0.011$
Haloperidol	17 (5.7)	6 (5.3)	11 (5.9)	NS
Clozapine	12 (4.0)	11 (9.7)	1 (0.5)	$p<0.001$
DDD (mean (SD))[c,e]	0.46 (0.47)	0.63 (0.55)	0.43 (0.42)	$p<0.001$
Duration of use (n (%))[a]				
0-6 months	8 (2.7)	1 (0.9)	7 (3.8)	NS
6-12 months	9 (3.0)	3 (2.7)	6 (3.2)	NS
1-5 years	103 (34.4)	23 (20.4)	80 (43.0)	$p<0.001$
5-10 years	69 (23.1)	14 (12.4)	55 (29.6)	$p=0.001$
> 10 years	81 (27.1)	69 (61.1)	12 (6.5)	$p<0.001$
Unknown	29 (9.7)	3 (2.7)	26 (14.1)	$p=0.001$
Use of other psychotropic drugs (n (%))[a]				
None	96 (32.1)	47 (41.6)	49 (26.3)	$p=0.006$
Anti-convulsants	43 (14.4)	26 (23.0)	17 (9.1)	$p=0.001$
SSRIs [c]	81 (27.1)	25 (22.1)	56 (30.1)	NS
TCAs[c]	6 (2.0)	5 (4.4)	1 (0.5)	$p=0.020$
Benzodiazepines	81 (27.1)	36 (31.9)	45 (24.2)	NS
Methylphenidate/ dexamphetamine	64 (21.4)	1 (0.9)	63 (33.9)	$p<0.001$
Lithium	4 (1.3)	2 (1.8)	2 (1.1)	NS

[a] *Chi-square test*
[b] *Autism Spectrum Disorder or depressive disorder*
[c] *Antipsychotic drugs (AP), Defined Daily Dose (DDD), Serotonin reuptake inhibitors (SSRI), tricyclic antidepressants (TCA)*
[d] *Antipsychotic drugs (AP) which were present in more than 10 cases of the sample are presented in the table*
[e] *Mann-Whitney U test*

Domain 3a. Treatment evaluation

Table 4 shows the adherence to guidelines regarding treatment evaluation. Treatment effects were seldom evaluated with help of validated scales. Change in dosage and type of antipsychotic drug during the treatment, was most often because of adverse effects.

Table 4. Evaluation of antipsychotic drug treatment.

	Total	Service providers for people with ID (n=113)	Mental health care for people with ID (n=186)	Significance[a]
Evaluation of treatment effect with validated instrument (n (%))	8 (2.7)	3 (2.7)	5 (2.7)	NS
Change in dose[b] (n (%))				
Dose increase and reduction	80 (26.8)	34 (30.1)	46 (24.7)	NS
Dose increase	75 (25.1)	28 (24.8)	47 (25.3)	NS
Dose reduction	55 (18.4)	26 (23.0)	29 (15.6)	NS
Reason for dose reduction/ attempt of discontinuation (n (%))				
Part of treatment plan	10 (3.3)	7 (6.2)	3 (1.6)	$p=0.033$
Due to adverse effects	54 (18.1)	24 (22.1)	9 (15.6)	NS
No more reason for prescription	14 (4.7)	6 (5.3)	8 (4.3)	NS
Treatment >1 year	13 (4.3)	8 (7.1)	5 (2.7)	NS
No effect	16 (5.4)	4 (3.5)	12 (6.5)	$p=0.09$
Other	16 (12.1)	7 (12.1)	3 (10.7)	NS
Unknown	22 (7.4)	10 (8.8)	12 (6.5)	NS
Change in AP (n (%))	136 (45.5)	59 (52.2)	38 (40.9)	$p=0.013$
Reason for AP change (n (%))				
Unknown	47 (37.0)	22 (37.3)	25 (13.4)	NS
Adverse effects	37 (29.1)	7 (11.9)	30 (16.1)	$p=0.011$
Treatment effects	28 (20.6)	12 (20.3)	16 (8.6)	NS
Effects and adverse effects	5 (3.7)	5 (8.5)	0 (0)	$p=0.02$
Other	9 (6.6)	6 (10.2)	3 (1.6)	NS

[a] *In last 5 years*
[b] *Chi-square test*

Domain 3b. Monitoring of adverse effects

Table 5 shows the number of medical records, which showed evidence of systematic monitoring of adverse effects. In 22.4% of all medical records, it was mentioned that there were "no adverse effects".

Table 5. Numbers and percentages of symptoms of adverse effects related to antipsychotic drug use that was monitored at least once during 1 year of treatment.

	Total	Service providers for people with ID (n=113)	Mental health care for people with ID (n=186)	Significance[a]
Adverse effects overall (n (%))[b]	208 (69.6)	97 (85.8)	111 (59.7)	$p<0.001$
Metabolic (n (%))				
Weight	163 (54.5)	72 (63.7)	91 (48.9)	$p=0.013$
Waist	6 (2.0)	6 (5.3)	0 (0)	$p=0.002$
Fasting Glucose	51 (17.1)	43 (38.1)	8 (4.3)	$p<0.001$
Fasting cholesterol	39 (13.0)	33 (29.2)	6 (3.2)	$p<0.001$
Fasting Triglycerides	38 (12.7)	32 (28.3)	6 (3.2)	$p<0.001$
Neurologic (n (%))				
Extrapyramidal symptoms[b]	63 (21.1)	49 (43.4)	14 (7.5)	$p<0.001$
Autonomic symptoms[b]	71 (23.7)	49 (43.4)	22 (11.8)	$p<0.001$
Central Nervous system symptoms[c]	44 (14.7)	19 (16.8)	25 (13.4)	NS
Hormonal (n (%))				
Prolactin	6 (2.0)	2 (1.8)	4 (2.2)	NS
Cardiovascular (n (%))				
Pulse rate	107 (35.8)	39 (34.5)	68 (36.6)	NS
Blood pressure	131 (43.8)	56 (49.6)	75 (40.3)	NS
ECG	11 (3.7)	8 (7.1)	3 (1.6)	$p=0.015$
Laboratory (n (%))				
Liver function	37 (12.4)	34 (30.1)	3 (1.6)	$p<0.001$
Renal function	44 (14.7)	42 (37.2)	2 (1.1)	$p<0.001$

[a] *Chi-square test*
[b] *At least one symptom of an adverse effect monitored in the last year*
[c] *Includes sedation, tiredness and Emotional and motivational blunting*

Discussion

In this analysis of medical records of clients with intellectual disabilities in specialized ID care and mental health care, we found that adherence to antipsychotic drugs' prescription guidelines was generally poor. Similar to previous studies (de Kuijper et al., 2010; Holden & Gitlesen, 2004; Stolker, Heerdink, Leufkens, Clerkx, & Nolen, 2001; Young & Hawkins, 2002), results of this study revealed that antipsychotic drug prescriptions were often not for treatment of a psychotic disorder or psychotic symptoms, but most frequently for problem behaviour with or without the presence of a comorbid non-psychotic mental condition. Furthermore, in this study reasons for prescription were rarely evaluated by a validated scale and adverse effects were not monitored as frequently as guidelines recommend. These results were also found in previous studies (Cleary et al., 2012; Griffiths et al., 2012; Marshall, 2004; Paton et al., 2016; Paton et al., 2011; Teeluckdharry et al., 2013; Thalitaya et al., 2011).

Results of this study showed that a majority of clients had a change in dose or type of antipsychotic drug at least once during their treatment, even though proof of systematic treatment evaluations was lacking. Adverse effects were the main reason to lower the dosage or change of the type of antipsychotic drugs. Besides the use of a validated scale and adverse effects, it was difficult to identify from the medical records what evaluations took place and why changes in antipsychotic drugs occurred. The only signs of treatment evaluation that were found in some of the medical records, were the monitoring of adverse effects, the use of a validated scale and annual care plan evaluation reports. Two other studies showed a reverse situation from this study; evaluation of the ongoing need for treatment with antipsychotic drugs did occur annually for most users, but hardly ever resulted in a lower dosage (Paton et al., 2011; Thalitaya et al., 2011). In contrast, Marshall (2004) only found evidence of evaluations of ongoing need of treatment with antipsychotic drugs in 26% of users (Marshall, 2004).

Mean dosage and duration of use were the highest in the specialized ID care organizations of this study. Moreover, in the same specialized ID care organizations there were significantly more clients who used antipsychotic drugs for behavioural symptoms in absence of a comorbid non-psychotic mental condition. The clients in specialized ID care were often more severely intellectually disabled than the clients of the mental health care settings of this study. Furthermore, the absence of a diagnosis of a mental condition was associated with more severe intellectual disability. An explanation may be found in the current diagnostics used in mental health care for people with intellectual disabilities, which are not always equipped to make proper diagnosis in people with severe intellectual disability. Furthermore, specialized ID care organizations seem to provide fewer additional psychological and psychosocial treatments. Therefore, mental conditions often remain poorly diagnosed and treated in specialized ID care, such as those included in this study. When proper diagnosis and alternative treatments are more difficult, medication often seems the only treatment option, making dose reductions less likely.

Besides the shortcomings in the monitoring of treatments effects, the monitoring of adverse effects was also found to be insufficient. Laboratory testing was seldom done in the mental health care organizations. However, laboratory testing was carried out on a more regular base in specialized ID care, because this was part of the policy of their medical practises. In this study weight was monitored most frequently. This is in line with the high frequency of prescriptions of risperidone in the current sample, especially in mental health care, which is well known to be associated with weight gain. In addition, previous studies also found that weight was monitored most frequently (Griffiths et al., 2012; Marshall, 2004; Paton et al., 2011; Teeluckdharry et al., 2013; Thalitaya et al., 2011). Other adverse effects related to risperidone use,

such as increased abdominal fat mass (increase in waist circumference) and plasma prolactin levels, were monitored less frequently. Insufficient monitoring of metabolic adverse effects was also found in several other studies (Cleary et al., 2012; Griffiths et al., 2012; Paton et al., 2016; Paton et al., 2011; Teeluckdharry et al., 2013).

The majority of clients in the mental health care organizations received psychological or psychosocial treatment prior or in addition to treatment with antipsychotic drugs, which is recommended by guidelines especially when used for problem behaviour. This was often lacking or at least not noted in the medical records of clients from specialized ID care organizations. This may be explained by how the care is organised in specialized ID care, with a focus on primary health care, yet in a special population. While this kind of care includes intellectual disability mental health care, there are mostly no facilities for psychotherapeutic treatments. This means that in general, no specialized mental health care and psychotherapeutic treatments will be offered.

The present study has limitations that need to be considered. First, it was not possible to differentiate between items "not done" and "not registered" in the records, making it more difficult to draw conclusions on the status of current practice. Second, we failed to properly determine the initial reason for antipsychotic drug prescription and the early evaluation of treatment effects in many cases, due to medical records on paper, which were hard to read or did not address the reason of prescription. However, we assume this evaluation took place, as changes in dose and type of antipsychotic drugs was recorded, sometimes including their reasons for these changes.

To conclude, both specialized ID care organizations and mental health care organizations did not adhere sufficiently to guidelines on prescribing antipsychotic drugs. Treatment effects and adverse effects were monitored infrequently. Furthermore, only half of the medical records showed evidence of dose reductions or attempts at discontinuation. Last, despite long-term use for symptoms of problem behaviour, less than half of the antipsychotic drug users received additional psychological or psychosocial treatment for these symptoms. While this study gives insight to what extent clinicians adhered to guidelines we were not able to find out why they did or did not adhere to the various recommendations. Further research is needed to investigate facilitators and barriers, which may influence adherence and implementation of guidelines.

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