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Prevalence and characteristics of psychotropic drug use in institutionalized children and adolescents with mild intellectual disability



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ABSTRACT

Psychotropic drugs are a cornerstone in the treatment of psychopathology and/or behavioral problems in children with intellectual disability (ID), despite concerns about efficacy and safety. Studies on the prevalence of psychotropic drug use have mainly been focused on adults with ID or children without ID. Therefore the aim of this cross sectional study was to assess the prevalence and characteristics of psychotropic drug use in children with mild ID who were institutionalized in specialized inpatient treatment facilities in The Netherlands. Demographic data, psychiatric diagnoses, the nature of the behavioral problems, level of intellectual functioning, and medication data were extracted from medical records using a standardized data collection form. Adjusted relative risks (ARR) for the association between patient characteristics and psychotropic drug use were estimated with Cox regression analysis. Of the 472 included children, 29.4% ($n = 139$) used any psychotropic drug, of which 15.3% ($n = 72$) used antipsychotics (mainly risperidone), and 14.8% ($n = 70$) used psychostimulants (mainly methylphenidate). Age, sex, and behavioral problems were associated with psychotropic drug use. Boys had a 1.7 (95%CI 1.1–2.4) higher probability of using psychotropic drugs, compared to girls adjusted for age and behavioral problems. Having any behavioral problem was associated with psychotropic drug use with an ARR of 2.1 (95%CI 1.3–3.3), adjusted for sex and age. The high prevalence of psychotropic drug use in children with ID is worrisome because of the lack of evidence of effectiveness (especially for behavioral problems) at this young age, and the potential of adverse drug reactions.

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1. Introduction

Children and adolescents with Intellectual Disability (ID) have a 3–4 times higher probability of developing psychopathology and/or behavioral problems compared to children and adolescents with normal intelligence (Dekker & Koot, 2003; Wallander, Dekker, & Koot, 2003). Previous research has shown that around 50% of children with ID show any form of behavioral and/or emotional problems compared to 18% of children without ID (Dekker, Koot, Van Der Ende, & Verhulst, 2002). Although there is limited evidence of the effectiveness of psychotropic drugs for these problems in children and adolescents with ID, and there are concerns about their safety (Posey, Stigler, Erickson, & McDougle, 2008; Scheifes, Stolker, Egberts, Nijman, & Heerdink, 2011; Van Daalen & Buitelaar, 1999; Vitiello et al., 2009), psychotropic drugs remain a cornerstone in the treatment of psychopathology and behavioral problems, and are widely prescribed to children for unlicensed or off-label uses (Haw & Stubbs, 2005; Lakhan & Hagger-Johnson, 2007).

The majority of published studies on the medicines given to children with ID are open trials, case reports, or controlled studies with small samples (Handen & Gilchrist, 2006). These studies generally focused on a limited number of medications. There is evidence that methylphenidate has produced desirable results for ID children suffering from Attention-Deficit/Hyperactivity Disorder (ADHD) (Simonoff et al., 2013), however, this medication appears to be less effective in children with ID compared to children with normal intelligence (Aman, Buican, & Arnold, 2003). Among the antipsychotics, the majority of studies were on risperidone managing behavioral problems (Matson & Neal, 2009). Though there is some evidence in favor of risperidone, caution is necessary because of possible adverse drug reactions from consumption, such as weight gain and somnolence (Unwin & Deb, 2011). Randomized controlled trials (RCTs) on children and adults with ID investigating the effects of antipsychotics for the treatment of behavioral problems rely on small samples, heterogenic populations, a wide variation of follow-up time, and measurement scales that assess different outcomes (Scheifes et al., 2011).

Although long-term data about the safety and efficacy of psychotropic drug use in children is nearly absent, the amount of psychotropic drug use in children increased over the past decades (Kalverdijk et al., 2008; Olfson, Marcus, Weissman, & Jensen, 2002; Zito et al., 2003). Studies investigating the prevalence of psychotropic drug use in ID populations have mainly been performed in adults with ID – drug use has been found to be present in 25–60% of that population, depending on the setting (Aman, Sarphare, & Burrow, 1995; Holden & Gitlesen, 2004; Stolker, Heerdink, Leufkens, Clerkx, & Nolen, 2001; Tsiouris, Kim, Brown, Pettinger, & Cohen, 2013). Only a handful of studies have been performed on children and adolescents with ID regarding the prevalence of psychotropic drugs within those groups, most of which were conducted with large differences in settings and with a lack of information on the characteristics of the children (Bramble, 2007; De Bildt, Mulder, Scheers, Minderaa, & Tobi, 2006; Kiernan, Reeves, & Alborz, 1995; Shireman, Reichard, & Rigler, 2005; Tobi et al., 2005). It is unclear what the current prevalence of psychotropic drug use is in children with ID, and the characteristics of those children remain for the most part unknown.

Therefore, we aimed to study the prevalence of psychotropic drug use in a large sample of institutionalized children and adolescents with mild ID and characteristics thereof, using extensive data on medication use and medical records with information on diagnoses, intellectual functioning, and behavioral problems.

2. Methods

2.1. Setting, design, and study population

A cross sectional study was performed from May to August 2011 on specialized inpatient treatment facilities for children and adolescents with mild ID. The reason for admission to these facilities was the presence of severe behavioral problems in combination with mild ID. In The Netherlands there are 18 specialized inpatient treatment facilities with a total residential capacity of approximately 3700 beds. These are long-time care facilities with over 50% of the children and adolescents staying more than one year, and even up to ten years. Facilities can have multiple centers/locations. Eight of the treatment facilities, located across The Netherlands, volunteered to participate. In the participating facilities the children and/or their parents were informed about the study and its goals, and gave permission through an informed consent procedure. Children under 16 years were required to have their parents or guardians give permission for participation. A sample of children and adolescents, with ages ranging from 6 to 23 years, who were admitted to one of those eight participating facilities, were included. In the three larger facilities, with more than 80 patients who gave permission, a random sample of 80 children was selected. In the five smaller facilities, all children who did not object were included. A standardized data collection form was used to extract patient data: data on the use of medication from medical files, and medication records of the participating children. The study protocol was approved by the Institutional Review Board of Utrecht University.

2.2. Outcomes

Medication data were collected by using current (in the week of the data collection) medication distribution lists generated by the pharmacy, of the children and adolescents. Psychotropic drugs were coded according to the World Health Organization Anatomic Therapeutic Chemical (ATC) classification system (WHOCC – ATC/DDD index, 2013). The following

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