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Adverse events and the relation with quality of life in adults with intellectual disability and challenging behaviour using psychotropic drugs



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ABSTRACT

Background: Psychotropic drugs are prescribed to approximately 30–40% of adults with intellectual disability (ID) and challenging behaviour, despite the limited evidence of effectiveness and the potential of adverse events.

Aims: To assess the prevalence of adverse events in association with psychotropic drug use in adults with ID and challenging behaviour and to examine the relation of these adverse events with the person's quality of life.

Method: The presence of adverse events was measured with a questionnaire that had to be filled in by the physicians of the participants. Movement disorders were measured separately with a standardised protocol. The strength of the association between adverse events and Intellectual Disability Quality of Life-16 (IDQOL-16), and daily functioning was investigated using linear regression analyses, taking into account the severity of disease (CGI-S) as potential confounder.

Results: Virtually all of 103 adults with ID and challenging behaviour had at least one adverse event (84.4%) and almost half had ≥ 3 adverse events (45.6%) across different subclasses. Using psychotropic drugs increased the prevalence of adverse events significantly. Respectively 13% of the patients without psychotropic drugs and 61% of the patients with ≥ 2 psychotropic drugs had ≥ 3 adverse events. Having adverse events had a significantly negative influence on the quality of life.

Conclusions: A large majority of all patients had at least one adverse event associated with psychotropic drug use. More attention is needed for these adverse events and their negative influence on the quality of life of these patients, taking into account the lack of evidence of effectiveness of psychotropic drugs for challenging behaviour.

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1. Introduction

The prevalence of challenging behaviour in adults with intellectual disability (ID) is high: estimates vary from 20% to over 50%, depending on the setting, definition and measurement method (Cooper, Smiley, Morrison, Williamson, & Allan, 2007; Cooper et al., 2009; Crocker et al., 2006; Deb, Thomas, & Bright, 2001; Singh, Ellis, & Wechsler, 1997). In these people psychotropic drugs, especially antipsychotics, are frequently (30–40%) used to treat the challenging behaviour even though there is a lack of evidence of effectiveness and a considerable risk of adverse drug reactions (Brylewski & Duggan, 1999; de Kuijper et al., 2010; Deb & Unwin, 2007; Holden & Gitlesen, 2004; Matson & Mahan, 2010; Matson & Neal, 2009; Scheifes, Stolker, Egberts, Nijman, & Heerdink, 2011; Tsiouris, 2010; Tsiouris, Kim, Brown, Pettinger, & Cohen, 2013). Most adults with ID treated with antipsychotics use them for many years, sometimes even decades (de Kuijper et al., 2013).

Frequently occurring adverse events of psychotropic drug use are, amongst others, psychological symptoms (e.g., sedation, inner unrest), neurological symptoms (e.g., epileptic seizures, dyskinesia), weight changes, sexual symptoms (e.g., diminished sexual desire, erectile dysfunction) and psychological or physical dependence (Advokat, Mayville, & Matson, 2000; Deb & Unwin, 2007; Friedlander, Lazar, & Klancnik, 2001; Frighi et al., 2011; Mahan et al., 2010; McKee, Bodfish, Mahorney, Heeth, & Ball, 2005; Roke, Buitelaar, Boot, Tenback, & Van Harten, 2012). These adverse events can be more difficult to detect in adults with ID than those without ID, because impaired communication of the adult with ID hampers the recognition and interpretation of signs and symptoms (Dosen & Day, 2001). Furthermore the adverse event may overlap with the appearance of the psychopathology; for example irritability and agitation may seem a psychiatric or behavioural symptom instead of an adverse event (Charlot et al., 2011; Valdovinos, Caruso, Roberts, Kim, & Kennedy, 2005).

Although quality of life is an important aspect of treatment outcome, measurements of quality of life are rarely included in pharmacological intervention studies in adults with ID (Bertelli et al., 2013; Hemmings, Deb, Chaplin, Hardy, & Mukherjee, 2013; Zarcone, Napolitano, & Valdovinos, 2008). Studies on the effect of psychotropic drugs report adverse events as secondary outcomes (Aman et al., 2002; Gagiano, Read, Thorpe, Eerdeken, & Van Hove, 2005; Snyder et al., 2002; Tyrer et al., 2008). A small percentage of published studies systematically address adverse events and risk factors thereof (de Kuijper et al., 2013; Fodstad et al., 2010; Frighi et al., 2011; Mahan et al., 2010). There are no studies on the consequences of adverse events on the quality of life.

The aim of this study was to assess the prevalence of adverse events in association with psychotropic drug use in adults with ID and challenging behaviour and to examine the relation of these adverse events with the person's quality of life.

2. Methods

2.1. Setting and study design

A cross sectional study was conducted in three Dutch inpatient treatment facilities (Wier-Altrecht Aventurijn, Ipse de Bruggen, Hoeve Boschoord–Trajectum) for adults with mild to borderline ID and severe challenging behaviour. Adults with ID are referred to these institutions if treatment in general mental health institutions and/or specialised units of residential settings leads to unsatisfactory results regarding their challenging behaviour. The medical ethical committee of the University Medical Centre Utrecht approved the study. The research period was from August 2009 until October 2011.

2.2. Participants

All admitted persons to the participating centres were eligible if they were able to give informed consent to participate in this study. Persons admitted to the centres before the start of the study period as well as persons newly admitted during the study period were included in the current study (and followed up during their admission, or the end of data collection). Participants were informed about the study and its goals, and gave permission through an informed consent procedure. Because of the nature of the treatment facility, all participants exhibited severe challenging behaviour before admission. To be able to compare groups, both people with and without psychotropic medication were included.

Baseline characteristics data were collected from the standardised basic registration lists from the three participating centres. These lists were filled in by the professional staff and contained demographic information (e.g., age, gender and ethnicity) and information on hospitalisation (e.g., duration of stay at the day of measurement and codes of DSM-IV disorders or descriptive diagnoses). Diagnoses were coded according to DSM-IV; if these were not available the descriptive diagnosis was used. These diagnoses were grouped into the following main disorders: psychotic disorders, pervasive developmental disorders, Attention-Deficit/Hyperactive Disorder (ADHD) and conduct disorders, mood disorders, anxiety disorders, alcohol/drug dependence or abuse, personality disorders, sexual disorders and other diagnoses. The categorisation was performed by the authors S.W. and A.S.

Level of intellectual functioning was measured through different standard intelligence scales (e.g., WAIS-III, GIT-2 and WISC-R) and if the IQ was not available, the DSM-IV diagnosis was used (American Psychiatric Association, 2000). The level of intellectual functioning was categorised in the following levels: mild ID (IQ 50–70), borderline intellectual functioning (IQ 71–84) and unspecified.

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