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Health-related quality of life in people with intellectual disability who use long-term antipsychotic drugs for challenging behaviour

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ABSTRACT

Background: Many people with intellectual disabilities use long-term antipsychotics for challenging behaviour and experience side-effects from these drugs, which may affect Health-related Quality of Life (HQoL).

Aims: This study aimed to investigate HQoL in people with intellectual disabilities who use long-term antipsychotics and to investigate its associations with challenging behaviour and physical symptoms often associated with antipsychotics.

Materials and methods: We used baseline data of two studies of long-term used antipsychotics. The RAND-36 and the emotional and physical wellbeing subscales of the Personal Outcome Scale (POS) were used to assess HQoL. Associations with challenging behaviour, measured with the Aberrant Behavior Checklist (ABC) and physical symptoms (extrapyramidal, autonomic, metabolic) with HQoL outcomes were analysed by univariate and multivariate linear regression.

Results: The mental subscales of the RAND-36 and emotional wellbeing of the POS were associated with the irritability and lethargy ABC-subcales. Physical wellbeing was negatively associated with parkinsonism urinary problems, dysphagia and temperature dysregulation possibly due to antipsychotics use.

Conclusion: Both mental and physical wellbeing are related to challenging behaviour and physical symptoms associated with antipsychotics. Therefore HQoL could be a helpful measure when balancing benefits and disadvantages of antipsychotics prescribed for challenging behaviour.

What this paper adds

Little is known about the effects of long-term antipsychotic drug use for challenging behaviours on health-related quality of life in people with intellectual disabilities. Many studies have focussed on the short term effects of antipsychotic drugs on challenging behaviours and the side effects. Furthermore, some studies have looked at the influence of side effects on quality of life. However, the impact of long-term antipsychotic drug use on the health status (physical and mental health) remains unclear. We aimed to provide a wider look at the effects of antipsychotic drugs, by looking at the associations of symptoms associated with side effects of antipsychotics and symptoms of challenging behaviour on the one hand with health-related quality of life on the other. By doing so we aimed to introduce a comprehensive outcome measure that assesses both the benefits and disadvantages of treatment of challenging behaviours with antipsychotic drugs.

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1. Introduction

Over the years Quality of Life (QoL) has become a broadly used concept in the care for people with intellectual disability (Morisse, Vandemaële, Claes, Claes, & Vandeveldde, 2013). Quality of life has been advocated to be used as a measure to evaluate care for people with intellectual disabilities, so far mainly focusing on social care outcomes, such as wellbeing and happiness (Nota, Ferrari, Soresi, & Wehmeyer, 2007; Schalock, 2004; Schalock, Bonham, & Verdugo, 2008; Verdugo & Schalock, 2009). Several studies found that QoL is associated with health status (mental- or physical- wellbeing), challenging behaviour and perceived social support (Koch et al., 2015; Rand & Malley, 2016; Schalock, 2004). The concept of health-related Quality of Life (HQoL) is meant to describe the health status of a person comprehensively. The various models of HQoL often include domains of physical functioning, social functioning, role limitations by physical functioning, mental health and general health perceptions, including aspects of vitality, pain and cognitive functioning (Hays & Morales, 2001; Wilson & Cleary, 1995).

Antipsychotic drugs may influence HQoL by its effect on symptoms of psychosis and schizophrenia, but also by its side-effects. Several studies found that patients with schizophrenia had an improved HQoL after starting treatment with antipsychotic drugs (Meltzer, Burnett, Bastani, & Ramirez, 1990; Voruganti et al., 2000). Nonetheless, side-effects, such as weight gain, were found to be related to a lower HQoL in patients with schizophrenia (Allison, Mackell, & McDonnell, 2003; Faulkner, Cohn, Remington, & Irving, 2007).

Antipsychotic drugs are not only prescribed for psychotic disorders and schizophrenia, but even more often for challenging behaviour in people with intellectual disabilities (De Kuijper et al., 2010; Ramerman, De Kuijper, & Hoekstra, 2017). These challenging behaviours may be associated with somatic disorders and mental health conditions, which are sometimes hard to diagnose in people with intellectual disabilities. Yet, the effectiveness of antipsychotic drug use on challenging behaviour has not been proven (Gagiano, Read, Thorpe, Eerdeken, & Van Hove, 2005; Tyrer et al., 2008) and side-effects of antipsychotic drugs in people with intellectual disabilities are very common (Matson & Mahan, 2010). Most common are metabolic and hormonal side-effects, such as weight gain and elevated prolactin blood plasma, which may increase the risk of cardiovascular disorders and osteoporosis. Furthermore, neurological side-effects may arise, such as extrapyramidal symptoms, autonomic symptoms and sedation, which may affect motor, behavioural and cognitive functioning (Bhuvaneswar, Baldessarini, Harsh, & Alpert, 2009; Haddad & Dursun, 2008; Matson & Mahan, 2010). A recent study in people with mild intellectual disabilities showed that those who experienced antipsychotic drug-induced side-effects had a lower quality of life, compared to those who used antipsychotic drugs in absence of side-effects (Scheifes et al., 2016).

We aimed to cross-sectionally study challenging behaviour and physical symptoms associated with antipsychotic drug use in relation to HQoL in people with intellectual disabilities who use long-term antipsychotic drugs. To our knowledge, there have been no such studies that considered the relationship of challenging behaviour and of physical symptoms associated with antipsychotic drugs with health-related quality of life.

2. Materials and methods

2.1. Study design and participants

This paper reports on the baseline data from two antipsychotic drug discontinuation studies in people with intellectual disabilities in the Netherlands, which took place between 2015 and 2017. The first study ($n = 134$) was an open label discontinuation study and the second a double-blind placebo-controlled discontinuation study ($n = 25$).

Patients for the first study were recruited between January 4th 2015 and February 1st 2016 and for the second between January 1st 2016 and February 28th 2017. All participants had an intellectual disability (intelligence quotient < 70 , as noted in the medical record), were aged six years or older and used antipsychotic medication for behaviour problems for at least one year. Participants on all types of medication registered for the treatment of symptoms of psychosis could be included. Patients were excluded from the studies if they had a diagnosis of a chronic psychosis, schizophrenia or bipolar disorder, or used antipsychotic drugs less than one year. Other psychotropic drugs or mental health conditions were not a reason for exclusion. All patients received 24-h care from either family/relatives or intellectual disability care organizations.

Participants were recruited through their physicians in medical services of care organizations and from in- and outpatient intellectual disability mental health care clinics. Written informed consent was obtained from participants and/or their legal representatives. Both studies had been approved by the Medical Ethical Committee of the University Medical Centre Groningen (METc 2014/402 and METc 2015/171).

2.2. Assessments

Quality of life was assessed by two measures of HQoL: the physical- and emotional wellbeing scales of the Personal Outcome Scale (POS) (Claes, Van Hove, van Loon, Vandeveldde, & Schalock, 2010) and the 36-item Research and Development survey (RAND-36). The RAND-36 has eight different domains: vitality, physical functioning, bodily pain, general health perceptions, physical role functioning, emotional role functioning, social role functioning and mental health. These domains can be combined into a Physical Component Score (PCS) and a Mental Component Score (MCS) (Ware et al., 1998). Both the POS and RAND-36 were either completed by a proxy (i.e., primary caregiver or parent) together with the participant, or by the participant him- or herself. The POS has a separate version for proxies and for self-completion by the participant. For the RAND-36 the same version was used for proxies as for

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