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Substance use in individuals with mild to borderline intellectual disability: A comparison between self-report, collateral-report and biomarker analysis

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ABSTRACT

Background and aims: Individuals with mild or borderline intellectual disability (MBID) are at risk of substance use (SU). At present, it is unclear which strategy is the best for assessing SU in individuals with MBID. This study compares three strategies, namely self-report, collateral-report, and biomarker analysis.

Methods and procedures: In a sample of 112 participants with MBID from six Dutch facilities providing care to individuals with intellectual disabilities, willingness to participate, SU rates, and agreement between the three strategies were explored. The Substance use and misuse in Intellectual Disability – Questionnaire (SumID-Q; self-report) assesses lifetime use, use in the previous month, and recent use of tobacco, alcohol, cannabis, and stimulants. The Substance use and misuse in Intellectual Disability – Collateral-report questionnaire (SumID-CR; collateral-report) assesses staff members' report of participants' SU over the same reference periods as the SumID-Q. Biomarkers for SU, such as cotinine (metabolite of nicotine), ethanol, tetrahydrocannabinol (THC), and its metabolite THCCOOH, benzoylecgonine (metabolite of cocaine), and amphetamines were assessed in urine, hair, and sweat patches.

Results: Willingness to provide biomarker samples was significantly lower compared to willingness to complete the SumID-Q ($p < 0.001$). Most participants reported smoking, drinking alcohol, and using cannabis at least once in their lives, and about a fifth had ever used stimulants. Collateralreported lifetime use was significantly lower.

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However, self-reported past month and recent SU rates did not differ significantly from the rates from collateral-reports or biomarkers, with the exception of lower alcohol use rates found in biomarker analysis. The agreement between self-report and biomarker analysis was substantial (kappas 0.60–0.89), except for alcohol use (kappa 0.06). Disagreement between SumID-Q and biomarkers concerned mainly over-reporting of the SumID-Q. The agreement between SumID-CR and biomarker analysis was moderate to substantial (kappas 0.48 – 0.88), again with the exception of alcohol (kappa 0.02). In this study, the three strategies that were used to assess SU in individuals with MBID differed significantly in participation rates, but not in SU rates. Several explanations for the better-than-expected performance of self- and collateral-reports are presented. We conclude that for individuals with MBID, self-report combined with collateral-report can be used to assess current SU, and this combination may contribute to collaborative, early intervention efforts to reduce SU and its related harms in this vulnerable group.

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What this paper adds?

This paper is the first to compare three strategies to assess substance use among individuals with mild to borderline intellectual disability: self-report with a questionnaire developed for this population (i.e., SumID-Q), collateral-report by staff members, and biomarker analysis of urine, hair and sweat patch samples. We found that biomarker analysis was of limited additional value compared to self-report or collateral-report in the assessment of substance use, especially given the additional costs of and lower willingness to participate in biomarker analysis.

1. Introduction

Individuals with mild to borderline intellectual disability (MBID) (IQ 50–85, [American Psychiatric Association \[APA\], 2013](#)) are at risk of substance use (SU) and substance use disorder (SUD; [Carroll Chapman & Wu, 2012](#); [van Duijvenbode et al., 2015](#)). For epidemiological purposes as well as case identification in clinical settings, several strategies may be used to assess SU: self-report, collateral-report (report by professionals, family members, or peers on participant's use), and biomarker analysis of urine, hair, or sweat patches. At present, it is unclear which strategy is most suitable for the assessment of SU in individuals with MBID.

In individuals without MBID, self-report, collateral-report, and biomarker analysis have been compared in a range of studies (see e.g., [Akinci, Tarter, & Kiriski, 2001](#); [Connors & Maisto, 2003](#); [de Beaurepaire et al., 2007](#); [Fendrich, Johnson, Wislar, Hubbell, & Spiehler, 2004](#)). In epidemiological studies, collateral-report has yielded similar or lower estimations of SU compared to self-report (e.g., [Connors & Maisto, 2003](#); [Stasiewicz et al., 2008](#)). However, self-report has yielded lower SU rates compared to biomarker analysis (see e.g., [Fendrich et al., 2004](#)). Specifically, high rates of under-reported illicit drug use and alcohol use (i.e., no self-reported SU while biomarker analysis was positive) have been found, combined with lower rates of over-reported SU (i.e., self-reported SU while biomarker analysis was negative) ([Akinci et al., 2001](#); [de Beaurepaire et al., 2007](#)). For instance, in patients in a psychiatric hospital, [de Beaurepaire et al. \(2007\)](#) found that 52% under-reported and 14% over-reported illicit drug use and 56% under-reported and 23% over-reported alcohol use compared to the biomarker analysis. For tobacco use, the rates of under-reporting were much lower (1–10%; [Rebagliato, 2002](#)).

In individuals with MBID, both collateral-report and self-report have been used to estimate the rates of SU (see [Carroll Chapman & Wu, 2012](#); [van Duijvenbode et al., 2015](#)). However, both strategies have shortcomings. For instance, some evidence suggests that collateral-report is more sensitive to more severe cases of SU in MBID ([VanDerNagel, Kiewik, Buitelaar, & De Jong, 2011](#)). Additionally, self-reported SU may be even more biased in individuals with MBID, especially when questionnaires not adapted to the needs of this group are used ([McGillicuddy, 2006](#); [van Duijvenbode et al., 2015](#)).

Given the potential for bias related to self-report and collateral-report, biomarker analysis seems appealing as a more objective measurement of SU in individuals with MBID. Nevertheless, its usability and validity depend on several factors. First, false positive testing can occur due to environmental contamination (e.g., second hand smoking, or accidental transfer of the substance to the sampling site), the use of prescribed medication, or the use of products such as baby wash ([Brahm, Yeager, Fox, Farmer, & Palmer, 2010](#); [Cotten, Duncan, Burch, Seashore, & Hammitt-Stabler, 2012](#)). Second, false negative testing can occur due to tampering with the sample ('cheating the drug test') or dilution of the substance in incidental use ([Fendrich et al., 2004](#); [Hoiseth et al., 2008](#)). Third, both the window of detection of SU and the threshold of detectable use vary across different types of biomarker analysis. For instance, hair analysis is suitable to detect SU over long periods, depending on hair length ([Cooper, Kronstrand, & Kintz, 2012](#); [Koster, Alffenaar, Greijdanus, VanDerNagel, & Uges, 2014a](#)). Drug patches absorb traces of substances and their metabolites through the skin during the time they are worn, which can be up to one week ([Koster, Alffenaar, Greijdanus, VanDerNagel, & Uges, 2014b](#)). Urine analysis provides information about more recent use based on the pharmacokinetic properties of the substance of interest from days or even hours (cocaine, alcohol) to weeks (cannabis, nicotine) before sampling ([Moeller, Lee, & Kissack, 2008](#); [Wojcik & Hawthorne, 2007](#)). Finally,

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