Substance use among individuals with intellectual disabilities living independently in Flanders

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A B S T R A C T

Background: Over the past decades, there has been increased scientific and clinical interest in substance use among individuals with intellectual disabilities (ID). Despite raised interest and awareness in the topic, lack of supportive data on prevalence and risk factors highlights the need for ongoing research. The aims of this cross-sectional multicenter study were to examine the nature and extent of substance use in individuals with ID living independently, to investigate group differences in substance use and related problems, and to explore the role of substance-related knowledge and attitudes in substance use behaviors.

Method: Participants were 123 individuals with mild to moderate ID receiving support from independent living services. Data were gathered by means of a structured interview strategy (i.e. the Substance Use and Misuse in Intellectual Disability—Questionnaire; SumID-Q).

Results: Findings revealed that rates of lifetime use of licit and illicit substances were higher than those found in earlier studies among individuals with ID and the general population. While cannabis use was the only illicit substance reported, current tobacco and alcohol use were shown to be highly prevalent (48%–45.5%). Rates for the latter were similar to earlier studies among community samples of individuals with ID. In contrast to our hypotheses, few group differences in substance use behaviors were observed. Male gender was associated with age of onset of alcohol and tobacco use and tobacco use-related problems, while younger age was found to be associated with lifetime use of cannabis. No evidence was found regarding the role of knowledge; however, smokers and alcohol users rated tobacco and alcohol use more positively.

Conclusion: This study demonstrated that individuals with ID living independently use a wide range of licit and illicit substances and present divergent levels and patterns of substance use. Notwithstanding the role of personal choice in substance use, more research is needed to better understand the nature and extent of substance use and related problems, as well as the role of substance-related knowledge and attitudes in individuals with ID.

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1. Introduction

Living in the community has proven to be beneficial for individuals with intellectual disabilities (ID) in terms of self-determination, increased autonomy and independence, and opportunities for paid employment (Cocco & Harper, 2002). The transformation from institutionalized care towards community based living has, however, not been without its challenges (Sturmye, Reyer, Lee, & Robek, 2003). Individuals with ID may be increasingly faced with stressors such as a lack of leisure and other social opportunities, as well as options for meaningful employment (Sturmye et al., 2003). According to Scott and Havercamp (2014), individuals with ID are likely to have fewer resources and adaptive skills to handle stressful events. For some individuals, increased exposure to community life has facilitated access to licit and illicit substances (Carroll Chapman & Wu, 2012; Pezzoni & Kouimtsidis, 2014; Taggart & Chaplin, 2014).

While substance use remains an under-researched topic in ID-literature (Van Duijvenbode et al., 2015), there is substantial evidence that individuals with ID use a wide variety of substances (VanDerNagel, Kiewik, Buitelaar, & De Jong, 2011). Much of this research has portrayed substance use as a health-risk behavior and commonly emphasized individuals’ vulnerabilities to and risks in engaging in these behaviors (Simpson, 2012). Although substance use behaviors in any population are often associated with significant adverse effects such as substance use-related, psychosocial and medical problems (VanDerNagel, Kemna, & Diddens, 2013), studies often fail to acknowledge that substance use is not, by definition, problematic (Slayer, 2007). It is critical to recognize that the field of ID employs an approach to disability that encourages personal choice, inclusion, independence, equity and dignity (Luckasson & Schalock, 2015; Slayer & Steenrod, 2009), which highlights the importance of considering the basic fundamental right of all people to self-determination and respecting individuals’ choices, including decisions about safe and appropriate substance use (Slayer, 2007). Nevertheless, as with any other population, researchers and daily practitioners need to be able to detect the development of substance use-related problems and to provide adequate support and treatment attuned to the individuals’ needs and choices (Slayer & Steenrod, 2009; To, Neirynck, Vanderplasschen, Vanheule, & Vandevende, 2014).

While studies suggest that the prevalence of substance use in individuals with ID is lower as compared to the general population (Chaplin, Gilvarry, & Tsakanikos, 2011; McGillicuddy, 2006; Sturmye et al., 2003), individuals with ID are considered to be at increased risk of developing substance misuse and substance-related problems (McGillicuddy, 2006; McGillicray & Moore, 2001). Several studies state that individuals with ID may be more prone to these problems because of limited knowledge about the effects and possible risks associated with substance use and an increased likelihood of deficits in social skills and increased vulnerability regarding social influences (Miller & Whicher, 2013; Whitaker & Hughes, 2003). Other studies have underscored the influence of being male and an early age of onset of initial substance use for developing substance-related problems in this population (Cocco & Harper, 2002; Taggart, McLaughlin, Quinn, & Milligan, 2006). Male gender has also been identified as a risk factor for elevated levels of licit and illicit substance use (Chaplin et al., 2011; Robertson et al., 2000; Žumić-Pavlović, Pavlović, & Glumić, 2013) and few studies have shown that poly-substance use and illicit substance use are more likely among younger individuals with ID (To et al., 2014; VanDerNagel, Kiewik, Buitelaar, et al., 2011). Furthermore, previous studies on substance-related knowledge have indicated that while, overall, individuals with ID do have deficits regarding substance-related knowledge, there also appears to be a dissociation between substance-related knowledge and substance use, meaning that levels of knowledge were higher in individuals using substances compared to those who abstain from use (McGillicray & Moore, 2001; Taylor, Standen, Cutajar, Fox, & Wilson, 2004). In addition, Taylor et al. (2004) suggested that more health education is needed for the group of substance users because, although their substance-related knowledge was higher, these individuals were less likely to express any concern about the risks. Furthermore, while only few studies have dealt with attitudes toward substance use, it is suggested that having a more negative attitude toward substance use can decrease actual use (Kiewik, VanDerNagel, Kemna, Engels, & De Jong, 2016).

There is, however, a pressing need for more extensive and detailed research to gain better insight into the extent and nature of substance use (problems) as well as to establish reliable (population-based) estimates (Carroll Chapman & Wu, 2012). Available studies are characterized by divergent methodological and practical challenges such as differences in operational definitions of substance use alongside with the scope of substance use (e.g. in- or exclusion of tobacco, (prescribed) medication and/or readily available substances such as inhalants), differences in the definition of ID (i.e. whether or not individuals with borderline intellectual functioning, IQ 70–85, are included), issues concerning the measurement of substance use (e.g. use of self- or informant-report), differences between and within countries, and variations across different subgroups (e.g. individuals supported by ID services or addiction treatment settings) (Taggart & Chaplin, 2014; Van Duijvenbode et al., 2015). These challenges have led to a wide range of estimates of licit and illicit substance use in this population. For instance, in a sample of 157 individuals with mild to profound ID living in a residential or family setting, McGuire, Daly, and Smyth (2007) identified 10.3% regular alcohol users, while VanDerNagel et al. (resubmitted) found 66.1% alcohol users in a sample of 112 individuals with mild to borderline ID who were clients of Dutch ID facilities. Studies of tobacco use in this population have found estimates ranging from 2.6% (McGuire et al., 2007) up to 36% (Steinberg, Heimlich, & Williams, 2009). Rates of illicit substance use vary between 1.5% and 13% (Carroll Chapman & Wu, 2012). In spite of a growing body of research, knowledge about the prevalence and risk factors of substance use among individuals with ID remains limited (Van Duijvenbode et al., 2015) with many assumed factors as opposed to thoroughly reported evidence (Simpson, 2012).

The primary aim of this study was to investigate the extent and nature of substance use, substance-related knowledge and attitudes toward substance use in a sample of individuals with ID living independently in Flanders. Because previous studies have suggested gender and age differences in the prevalence and patterns of substance use among individuals with
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