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Substance Use Among Persons with Mild Intellectual Disability: Approaches to Screening and Interviewing

Joanneke VanDerNagel, Louise E.M. Kemna, and Robert Didden

Abstract

Abuse of substances by persons with a mild or borderline intellectual disability (IQ 50-85) (ID) is frequently missed, as our cases illustrate. The first client, a 19-year-old man, denied illicit drug use on admittance to a facility for persons with ID. His mood swings, irritability, and fatigue could eventually be attributed to cannabis and cocaine use. The second client, a 35-year-old woman with a history of cocaine dependency developed social, financial, and emotional problems. These were first attributed to her ID in combination with borderline personality traits and ADHD. It took a year and a half before these symptoms were recognized as signs of a relapse in the use of cocaine. The third client, a 38-year-old woman, referred for recurrent alcohol intoxications, appeared to use other substances as well. Systematic and comprehensive screening for signs of substance use and discussing this issue in an empathetic, non-judgmental manner can contribute to earlier identification and referral to substance use treatment.

Introduction

Though substance (ab)use and addiction sometimes are seen as a condition afflicting only a small subgroup of socially marginalized persons, these stereotypes are far from reality. The use and misuse[1] of psychoactive substances such as alcohol, cannabis, and other illicit drugs is widespread across society, and addiction (or substance abuse) also affects a wide variety of people. Over the past decades, more attention has been drawn to other groups of substance (ab)users, including persons with a mild or borderline Intellectual Disability (Carroll Chapman & Wu, 2012; McGillicuddy, 2006; VanDerNagel, Kiewik, & Didden, 2012).

Persons with a mild or borderline Intellectual Disability are considered a risk group for substance use because of the accumulation of substance (ab)use risk factors, such as low social economical status (SES), impaired inhibition, the desire to 'fit in' (Taggart, McLaughlin, Quinn, & Milligan, 2006; VanDerNagel et al., 2012), a higher burden of stress and traumatic experiences (Taggart et al., 2006) as well as lack of adequate coping skills (Didden, Embregts, Van der Toorn, & Laarhoven, 2009), and lack of inability to understand the (adverse) consequences of substance use (Cocco & Harper, 2002; Didden et al., 2009; Slayter & Steenrod, 2009; VanDerNagel et al., 2012). Several authors suggest that though prevalence of substance use may be relatively low among persons with an Intellectual Disability, the relative risk of abuse and addiction is high (Chaplin, Gilvarry, & Tsakanikos, 2011; Didden et al., 2009; McGillicuddy, 2006; McGillicuddy & Blane, 1999; VanDerNagel et al., 2012).

Substance use in any population is associated with severe biological, psychological and social problems. However, the consequences of substance use among persons with intellectual disability may be even more problematic because of higher levels of somatic and psychiatric comorbidity (McGillicuddy, 2006; Slayter & Steenrod, 2009; VanDerNagel et al., 2012), prescribed medication (Carroll Chapman & Wu, 2012; McGillicuddy, 2006; Slayter & Steenrod, 2009) and social factors including difficulty in accessing appropriate treatment (Cocco & Harper, 2002; McLaughlin, Taggart, Quinn, & Milligan, 2007; Slayter, 2010), work related problems and social interaction problems (Didden et al., 2009; Slayter & Steenrod, 2009).

At present, the scope and magnitude of substance use and misuse among persons with intellectual disability (SUMID) is understudied. Little is known about prevalence of substance (mis)use, risk factors and consequences. Further, there is a lack of valid instruments for screening and diagnosis of SUMID.

In this article, we discuss how SUMID can be detected, and how this topic can be discussed with the client with ID and his or her caregivers. The following case examples illustrate how substance use and misuse often remain undetected.

Client A is a 19-year-old male with a borderline intellectual disability (IQ=74). At admittance at a facility for persons with mild or borderline intellectual disability, he and his parents were interviewed. During this interview, he conceded to being addicted to tobacco and to drinking a beer or two occasionally. He denied the use of illicit

[1]Substance Misuse – the use of a substance for unintended purposes or for intended purposes but in improper amounts or doses, Substance Abuse – the deliberate, persistent, excessive use of a substance without regard to health concerns or accepted medical practices.

drugs, and his parents explain they would not tolerate such behavior. After placement the client appeared passive and lethargic. At other times he was irritable and uncooperative. His personal hygiene was poor, and the client looked increasingly unhealthy and tired. At first, it was hypothesized that the burden of living semi-independently and working irregular shifts was too difficult for this client. Only when a staff member smelled cannabis in the client's apartment was substance use suspected. Cannabis use was discussed with the client in a nonconfrontational style, and agreements were made on tapering substance use. Several months later, an acquaintance mentioned that the client also used cocaine. Again, the client admited to this when asked by a staff member. Shortly afterwards, the client moved in with his girlfriend and refused further help.

Client B is a 35-year-old woman with a borderline ID (IQ=76), ADHD, borderline personality traits and past (a history of) cocaine dependency. She lives independently with support from a local ID organization. In the course of time her emotional, social, emotional, and financial problems got worse. Her mood became increasingly instable, interaction with caregivers/social workers was hindered by her irritability, and the client seemed to spend more money. These symptoms first were attributed to the borderline personality traits and/or ADHD. Many months later, a concerned neighbor called the police because she heard the client crying incessantly. The client was found collapsed in the hallway of her apartment. The last couple of days she had used several grams of cocaine daily and had not slept or eaten. Later she admited she has been using drugs on and off for more than a year.

Client C, a 38-year-old woman with Down syndrome (estimated IQ: 50), was referred for a psychiatric consultation after several alcohol intoxications that required a visit to the Emergency Department of the local hospital. Several friends seem to have encouraged her into drinking. After the ER staff explained to her that drinking more than two units of alcohol is unhealthy, the drinking incidents stopped. The client explained that she only accepted cigarettes from her friends. When questioned further, the client explained that the cigarettes offered to her are 'special cigarettes, which make you feel drowsy.' Allegedly, the client has been allured to perform sexual acts with these friends while under the influence of alcohol or cannabis.

Detection and recognition of substance use are the first steps to adequate help for those who misuse substances. Unfortunately, in many cases, substance use remains undetected for a long period of time, even when signs and symptoms are present. Clients with an intellectual disability often are – just like client A – not inclined to discuss their substance use, either because they fear consequences of admitting taking substances, or because they do not relate their daily problems to the use of psychoactive substances. Family, friends, or staff members working with persons with an ID often do not recognize substance use problems. In some cases, they hold the preconception that persons with intellectual disabilities refrain from experimenting with substances. Often, substance use signs and symptoms are misattributed to other factors such as physical or psychiatric conditions (clients A & B) (VanDerNagel et al., 2012). In other cases, substance use is detected, but its scope, magnitude, or adverse consequences are not (yet) seen. Client C, for instance, seems unaware about the fact that she is drugged with 'cigarettes.'

Signs and symptoms of substance use

Signs and signals of substance use can be divided into the following categories: direct effects (intoxication and withdrawal), long term effects (physical damage), and social problems related to substance use (table 1). It is important to note that no single symptom can be 'proof' of substance use, and the signs and symptoms should be interpreted in the light of the general behavioral pattern of the person of interest.

Often, however, symptoms caused by substance use are misattributed to a psychiatric disorder (client B) or to distress due to excessive demands (client A) or life experiences. Even when the client has been diagnosed before with a substance use disorder (client B and client C), often no relation is made between behavioral challenges or physical symptoms and substance use. Client B, for instance, had been using stimulants for a year and a half but not until after a severe physical and emotional breakdown did she bring herself to tell about her relapse into substance (ab)use. With the benefit of hindsight, many of her symptoms can be attributed to intoxication, withdrawal, or general signs of substance ab/misuse.

Both client A and client C illustrate that once one type of substance use is recognized, one should not refrain from screening for other types of substance use. Substance use often is not limited to the use of one type of substance.

Screening for and Discussing Substance Use

Screening and assessment of substance use in persons with intellectual disabilities is complicated because of their limited cognitive capacities and knowledge of substances and tendency to biased responses (McGillicuddy, 2006; Sturmey, Reyer, Lee, & Robek, 2003; VanDerNagel, Kiewik, Van Dijk, De Jong, & Didden, 2011). Widely used screening instruments (such as the CAGE, MAST, AUDIT/DUDIT) have two main shortcomings when used with clients with ID. First, they require basic substance knowledge and a conceptual understanding that persons with intellectual disabilities may lack (Finlay & Lyons, 2001; Heal, 1995; McGillicuddy, 2006; Wallace, Keenum, & Roskos, 2007). For instance, many clients do not understand that the term 'alcohol' is not solely reserved for strong liquor. Thus, those who drink beer or alcohol pops may be inclined to say 'no' to questions on alcohol use. Other clients – for instance client C – are unaware that they are consuming psychoactive substances. In the Netherlands, use of cannabis – though illegal – is not prosecuted, and this drug is widely available in so called 'coffee shops.' Some clients with ID confuse this policy with legalization, and several even concluded that cannabis use is harmless. Second, many persons with intellectual disability have a high tendency to acquiescence (i.e. "to agree with whatever statement") as well as to "Say Nay" regarding to questions relating to social taboos such as substance use (Finlay & Lyons, 2001; Heal, 1995; McGillicuddy, 2006; Sturmey et al., 2003). These tendencies are especially strong when clients are questioned directly, which is the case in screening instruments, or when the client is interviewed in the presence of persons who are unaware of the substance use (client A). Interestingly, we have also seen cases in which direct questioning may lead to positively biased answers. That is, some clients have assented to use substances, while in fact they did not. These factors may lead to biased responses when persons with ID are questioned directly about substance use.

To evoke more truthful answers on substance use, several adaptations need to be made to the screening process (table 2). First, discussing substance use in an empathetic, open, and nonconfrontational interview elicits more information on substance use, and provides a basis for further counselling. The first step in an interview, then, should be to talk about substances in general. The interviewer should take into consideration that commonly used words can be unknown to the client. Confusion on terminology can be limited by presenting pictures of substances and asking the client what the pictures stand for. This will clarify which words the client uses for various substances. The interviewer can adopt this terminology in the remainder of the interview to prevent misunderstandings and to make the client feel more at ease. Also, this approach will elicit comments that often render a lot of information ('Oh, a bottle of beer, yeah I used to do a lot of those'). Last but not least, this approach helps the client to become more talkative and share information also on more sensitive topics such as substance use. After establishing which substances are known to the client and which terms he uses for them, further questions can be asked about these substances before probing for substance use. Invitations such as 'Can you tell me more about ...' are informative and reinforce the working relationship with the client. The second step consists of talking about use of a specific type of substance by persons known to the client. Here, we recommend starting with a commonly used substance (alcohol or tobacco). Asking whether family, friends, or staff members use substances often evokes giggling remarks on how clients have caught staff members smoking secretively. Again, this question on substance use by others helps the client to understand that substance use – even in role models – is a reality and that it can be discussed without negative moral judgement. All these introductory (though still relevant) questions, in our opinion, invite the client to speak freely and truthfully when – in the third step – asked about his or her own substance use ('Did you ever use ...'). When the client admits to using a type of substance, it is important to maintain a nonconfrontational (nonjudgemental), interested attitude by the interviewer. The next step will be to explore substance use patterns (frequencies, quantities, circumstances), and the use of other substances.

All of these steps have been outlined in the SumID-Q, a Dutch-language instrument developed to assess substance use, its risk factors and consequences among persons with a mild and borderline Intellectual Disability (VanDerNagel et al., 2011). The SumID-Q has been implemented in several (Dutch) Intellectual Disability facilities, with enthusiastic responses from both clients and staff. Studies into its validity are ongoing.

Conclusion & Recommendations

Substance use among persons with intellectual disabilities often remain undetected, even when

symptoms are present. These symptoms are often misattributed to other factors such as physical or psychiatric conditions. Systematic screening for substance use as well as discussing it in an empathetic, open, and non-confrontational interview elicits information on past and actual substance use from the client. Doing so, the interviewer should be aware that common substance-related terminology may not be understood and may not be familiar to the client. Sometimes the use of slang words for or pictures of substances may be helpful to assess the client's substance use status. Systematic and comprehensive screening for signs of substance use and discussing this in an empathetic, non-judgmental style can contribute to early identification and adequate referral for treatment.

Take home messages:

- Substance use is prevalent among persons with intellectual disabilities, even in the institutionalized population. However, it often remains undetected, and its signs and symptoms are frequently missed.
- Persons with intellectual disability do not only use legal substances such as alcohol and tobacco, but also illegal substances such as cannabis, cocaine, GHB, ecstacy, et cetera.
- Substance use among persons with an intellectual disability is associated with high levels of substance misuse, dependence, and psychosocial and medical problems.
- Routinely screening for substance use in an empathetic and non-confrontational style facilitates early recognition of substance use related problems
- The SumID-Q is a Dutch instrument that has been developed and implemented to screen for substance use among persons with a mild and borderline Intellectual Disability.

Table 1. Signs & Symptoms of substance (mis)use

- Signs & Symptoms related to intoxication, withdrawal or due to longterm excessive use (dissimilar for different types of substances):
  - Information from the client, caregivers or others about substance use, changes in mental or physical health, accident proneness
  - Mental Health issues, altered psychological functioning or changes in behavioral patterns (e.g. impaired attention, unstable emotional functioning, aggression, disinhibition, impaired judgement)
  - Physical symptoms (e.g. tremor, cardiovascular symptoms such as change of heart rate or blood pressure, gastrointestinal symptoms, weight loss, unstable gait)
- Social problems (similar for different types of substances)
  - Work- or school-related problems such as:
    - Absenteism, especially after the weekend
    - Decreasing performance at school or at work
    - Negligence with fulfillment of obligations
  - Relational problems, problematic interaction with caregivers, loss of friends, social isolation, new 'friends' who use substances
  - Drug-related petty crime, prostitution, physical abuse
  - Financial problems
  - Lack of self-care and interest in domestic activities
  - Lack of interest in previously enjoyed activities

Table 2. Steps in screening process (SUMID-Q)

- Before step 1: Establish a good working relationship, and be willing to discuss substance use in an open, empathetic way
- STEP 1: Talk about substances
  - Assess client's familiarity with substances and his terminology (use pictures)
  - Assess client's substance knowledge
  - Assess client's attitude toward substance use
- STEP 2: Talk about other substance use in general
  - For instance, discuss other person's substance use (substance use among peers, staff, family members)
- STEP 3: Talk about client's own substance use step by step
  - Ask about life time use ('Did you ever use ... yourself?')
- STEP 4: Further inquire about the use of this type of substance to assess
  - Patterns of use (frequency, quantity)
  - Circumstances (alone/with others, at home or somewhere else)
  - Effects (positive and negative)
  - Repeat this process for other types of substances

Table 3. Interviewing persons with ID about substance (mis)use

General remarks

- Screening for substance use should be a routine part of medical and/or psychological evaluation, interview at intake, screenings, et cetera
- Consider whether the presence of relatives, trusted staff members, or other persons close to the client will be an aid or a hindrance during the screening process
- Make sure the client feels at ease and can be open about substance use without fear of punishment. This is important to ensure client openness
- Inquire about substance use in an empathetic non-confrontational style

- Use pictures to clarify which substances are known to the client and which words he uses for them. Use the client's terminology in the remainder of the interview
- Encourage 'small talk' about substance use. This will provide those who will listen to it with a lot of information
- Begin substance use screening with commonly used substances such as tobacco and alcohol. Complete the screening asking about use of other types of substances
- Ask open ended questions. Encourage the client to talk about substances and (methods of) substance use, substance use effects, the circumstances of substance use et cetera.
- Remain calm, supportive, and inquisitive (without being judgemental) when the client admits to using substances.
- Be as precise as possible when trying to establish substance use frequencies and quantities. Again, use pictures to clarify, or ask how much money is spend on substance use.

Specific (When substance (mis)use is suspected)

- Explain which signs and symptoms are seen, without commenting further on this. "I have noticed that .... (name some examples)." Then invite the client to respond to this "I wonder where this comes from. Do you know?"
- When substance use is not mentioned by the client, raise this topic in the form of a question or hypothesis: "I wonder if ....". When the client denies substance use, refrain from arguing. Propose to discuss this topic at a later time.

References

Carroll Chapman, S. L., & Wu, L.-T. (2012). Substance abuse among individuals with intellectual disabilities. *Research in Developmental Disabilities, 33*(4), 1147-1156. doi: 10.1016/j.ridd.2012.02.009

Chaplin, E., Gilvarry, C., & Tsakanikos, E. (2011). Recreational substance use patterns and co-morbid psychopathology in adults with intellectual disability. *Research in Developmental Disabilities, 32*(6), 2981-2986.

Cocco, K. M., & Harper, D. C. (2002). Substance use in people with mental retardation: Assesing potential problem areas. *Mental Health Aspects of Developmental Disabilities, 5*(4), 101-108.

Didden, R., Embregts, P., Van der Toorn, M., & Laarhoven, N. (2009). Substance abuse, coping strategies, adaptive skills and behavioral and emotional problems in clients with mild to borderline intellectual disability admitted to a treatment facility: A pilot study. *Research in Developmental Disabilities, 30*(5), 927-932. doi: 10.1016/j.ridd.2009.01.002

Finlay, W. M. L., & Lyons, E. (2001). Methodological issues in interviewing and using self-report questionnaires with people with intellectual disability. *Psychological Assessment, 13*(3), 319-335.

Heal, L. W., & Sigelman, C.K. (1995). Response biases in interviews of individuals with limited mental ability. *Journal of Intellectual Disability Research, 39*, 331-340.

McGillicuddy, N. B. (2006). A review of substance use research among those with mental retardation. *Mental Retardation and Developmental Disabilities Research Reviews, 12*(1), 41-47. doi: 10.1002/mrdd.20092

McGillicuddy, N. B., & Blane, H. (1999). Substance use in individuals with mental retardation. *Addictive Behaviors, 24* (6), 869-878. doi: 10.1016/S0306-4603(99)00055-6

McLaughlin, D. F., Taggart, L., Quinn, B., & Milligan, V. (2007). The experiences of professionals who care for people with intellectual diability who have substance-related problems *Journal of Substance Use, 12*(2), 133-143.

Slayter, E. M. (2010). Disparities in access to substance abuse treatment among people with intellectual disabilities and serious mental illness. *Health & Social Work, 35*(1), 49-59.

Slayter, E., & Steenrod, S. (2009). Addressing alcohol and drug addiction among people with mental retardation: A need for cross-system collaboration. *Journal of Social Work Practice in the Addictions, 9*(1), 71-90.

Sturmey, P., Reyer, H., Lee, R., & Robek, A. (2003). *Substance-related disorders in persons with mental retardation*. Kingston: NADD Press.

Taggart, L., McLaughlin, D., Quinn, B., & Milligan, V. (2006). An Exploration of substance misuse in people with intellectual disabilities. *Journal of Intellectual Disability Research, 50* (8), 588-597. doi: 10.1111/j.1365-2788.2006.00820.x

VanDerNagel, J., Kiewik, M., Van Dijk, M., De Jong, C., & Didden, R. (2011). *Handleiding SumID-Q, Meetinstrument voor het in kaart brengen van Middelengebruik bij mensen met een lichte verstandelijke beperking.* Deventer: Tactus.

VanDerNagel, J. E. L., Kiewik, M., & Didden, R. (2012). *Iedereen gebruikt toch? Verslaving bij mensen met een lichte verstandelijke beperking [Doesn't everybody use? Addiction*

in persons with mild intellectual disability]. Amsterdam: Boom.

Wallace, L. S., Keenum, A. J., & Roskos, S. E. (2007). Comprehensibility and readability of patient self-administered opioid assessment screening tools. *Journal of Opioid Management, 3*(6), 338-344.

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