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Capture recapture estimation of the prevalence of mild intellectual disability and substance use disorder

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ABSTRACT

Persons with mild to borderline intellectual disability (MID) have been identified as a group at risk for substance use disorder (SUD). However, prevalence estimates of co-occurring SUD and MID rely largely on single source studies performed in selected samples. To obtain more reliable population estimates of SUD and MID, this study combines data from an Intellectual Disability Facility (IDF), and an Addiction Treatment Centre (ATC) in a semi-rural area in the Netherlands. Capture–recapture analysis was used to estimate the hidden population (i.e., the population not identified in the original samples). Further analyses were performed for age and gender stratified data. Staff members reported on 88 patients with SUD and MID in the IDF (4.0% of the IDF sample) and 114 in the ATC (5.2% of the ATC sample), with 12 patients in both groups. Only strata for males over 30 years provided reliable population estimates. Based on 97 patients in these strata, the hidden population was estimated at 215. Hence the estimated total population of males over 30 years old with MID and SUD was 312 (95% CI 143–481), approximately 0.16% (0.05–0.25%) of the total population of this age and gender group. This illustrates that while patients with co-occurring SUD and MID often receive professional help from only one service provider, single source data underestimate its prevalence, and thus underestimate treatment and service needs. Therefore, population prevalence estimations of co-occurring SUD and MID should be based on combined multiple source data.

1. Introduction

Little is known about the prevalence of substance use disorders (SUD) among persons with a mild or borderline intellectual disability (MID) (Carroll Chapman & Wu, 2012; McGillicuddy, 2006; VanDerNagel, Kiewik, Buitelaar, & DeJong, 2011). This is problematic because in this group the use of psychoactive substances – such as alcohol, cannabis and other

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illicit drugs – is associated with high levels of substance misuse and addiction. Reliable estimations of population prevalence are needed to plan treatment capacity and develop strategies for prevention (Carroll Chapman & Wu, 2012; McGillicuddy, 2006; VanDerNagel et al., 2011). Though population-based studies into SUD and co-occurring MID are lacking, several smaller-*n* studies conducted in various clinical, residential, and community settings, have provided data on prevalence rates of substance use, misuse, or abuse by persons with intellectual disabilities. For instance, among patients from addiction treatment facilities, Westermeijer, Kemp, and Nugent (1996) found that 6% of them had mild ID. In a sample of persons ($n = 122$) with mild to moderate ID from local community agencies, McGillicuddy and Blane (1999) found that 21% were misusing alcohol. Didden, Embregts, Van der Toorn, and Laarhoven (2009) found that among a sample of 39 patients with MID admitted to a specialized inpatient treatment facility, 46% were substance misusers. Chaplin, Gilvarry, and Tsakanikos (2011) reported that among referrals to a psychiatric facility for ID, 29% were substance misusers ($n = 115$). Since these studies concern highly selected samples the prevalence rates cannot be generalized. Moreover, these studies do not specify substance use rates for relevant subgroups, such as gender and age based strata, even though SUD prevalence rates differ across these groups (Laar et al., 2011). Finally, prevalence data from single sources (e.g., treatment facilities) are limited since persons with MID and SUD can be referred to several types of facilities.

Under Dutch law, persons with MID and SUD are eligible for help from both an Intellectual Disability Facility (IDF) and an Addiction Treatment Centre (ATC). Persons with an IQ between 70 and 85 are also eligible for IDF support and treatment if they have significant impairments in adaptive behaviour and if they present with a range of psychosocial problems such as unemployment, financial problems, and social isolation. Many persons with MID do not need (or want) inpatient or outpatient institutional care and are thus missed in surveys in IDF samples (Ras, Woittiez, van Kempen, & Sadiraj, 2010). Since persons with MID and SUD also seem to be less likely to receive addiction treatment or to remain in treatment (Carroll Chapman & Wu, 2012; VanDerNagel et al., 2011), data from ATCs will not cover the total population with SUD and MID either. Thus, although persons with both MID and SUD are eligible for two types of support or treatment, it has been noted that many of them receive only one type of help or no help at all (VanDerNagel, Kiewik, & Didden, 2012). Hence, prevalence rates of co-occurring SUD and MID cannot be reliably estimated from single sources, such as ATCs or IDFs. Nevertheless, single source information has been used to estimate population prevalence, and has served as a basis for policy makers. For instance, in 2007 the Dutch Health Minister estimated – based on reports from IDFs – that in the Netherlands (total population about 16.8 million) (Centraal Bureau voor de Statistiek [Statistics Netherlands], 2007) there were 'several hundreds' of youth present with MID and SUD (Parliament Proceedings, 2007). From clinical experience and data of a survey among IDFs (VanDerNagel et al., 2011) we concluded that this is an underestimation of the true population rate of SUD and MID (VanDerNagel et al., 2011, 2012).

In the present study, we used the data from an ATC and an IDF, located in a semi-rural area in the eastern region of the Netherlands with approximately 600,000 inhabitants (Centraal Bureau voor de Statistiek [Statistics Netherlands], 2010). In a capture recapture analysis we estimated the total number of individuals with both MID and SUD in this region. To obtain information on relevant subgroups, we also performed age- and gender-based stratified analysis.

2. Materials and methods

2.1. Overview

The capture recapture method estimates the number of individuals in a population using data from multiple and incomplete samples (Böhning, 2008; Brittain & Böhning, 2009; Chao, 2001). In its original biological application, a sample (n_1) from a target population (N) is captured, marked and released while the second sample (n_2) is recaptured later. An estimate of the total population size can then be obtained by dividing the number of marked individuals (n_1) by the proportion of marked individuals in the second sample (m_2/n_2).

Capture recapture analyses have also been applied in human populations and proven especially useful when the target population is elusive or when reliable screening instruments are not available (Allgar et al., 2008; Böhning, 2008; Holland et al., 2006). In these applications, two (or more) independent datasets can be used as samples. Individuals who are found in both datasets are the 'recaptured' group. Major advantages of this strategy are that neither dataset needs to be complete and that the analysis provides an estimate of the 'hidden' population (i.e., the population not present in the original samples).

The assumptions of capture recapture analyses are that (1) the population size is constant during the sampling time and (2) all subjects can be matched (for instance by their social security numbers or a combination of name, gender and date of birth) (Chao, 2001; Gill, Ismail, & Beeching, 2001). Additionally, this approach assumes that (3) each subject in the target population has an equal chance of being sampled (homogeneity assumption) and that (4) the samples are independent (Gill et al., 2001). In our study, the first assumption is met because the data were collected in a relatively short time period. The second assumption is also met because of the availability of unique patient identifiers and the possibility to match individuals in both samples.

To reduce the chance of violating the (third) assumption of homogeneity, gender- and age-based stratification is used to reduce heterogeneity (i.e., the existence of subgroups with unequal [re]catchability). Sample dependence (a violation of assumption 4) in our study is not assumed since ATC and IDF care are not mutually exclusive. Referral criteria for both types of care are independent of the involvement of other care. Also, the Chao estimator (see Eq. (1)) that we used is relatively