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Research paper

Needles in the haystack: Using open-text fields to identify persons with intellectual and developmental disabilities in administrative home care data

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ABSTRACT

Background: Use of administrative health data to study populations of interest is becoming more common. Identifying individuals with intellectual and developmental disabilities (IDD) in existing databases can be challenging due to inconsistent definitions and terminologies of IDD over time and across sectors, and the inability to rely on etiologies of IDD as they are frequently unknown.

Aims: To identify diagnoses related to IDD in an administrative database and create a cohort of persons with IDD.

Methods: Open-text diagnostic entries related to IDD were identified in an Ontario home care database (2003–2015) and coded as being either **acceptable** (e.g. Down syndrome) or **ambiguous** (e.g. intellectually challenged). The cognitive and functional skills of the resulting groups were compared using logistic regressions and standardized differences, and their age distributions were compared to that of the general home care population.

Results: Just under 1% of the home care population had a diagnostic entry related to IDD. **Ambiguous terms** were most commonly used (61%), and this group tended to be older and less impaired than the group with more **acceptable terms** used to describe their IDD.

Conclusions: Open-text diagnostic variables in administrative health records can be used to identify and study individuals with IDD. **Implications:** Future work is needed to educate assessors on the importance of using standard, accepted terminology when recording diagnoses related to IDD.

What this paper adds?

With growing interest in and use of administrative data to study populations of interest, there is a need to ensure that those populations are easily identified in such data. As persons with intellectual and developmental disabilities (IDD) are known to experience more health complexities and higher use of healthcare services throughout their lives, the ability to identify persons with IDD in administrative data is important. This paper provides the methods to identify individuals with IDD in an administrative health database that relies on open-text entries for diagnoses. More specifically, this study is based on data collected with the Resident Assessment Instrument – Home Care (RAI-HC) assessment, which is used not only in Ontario, but in other jurisdictions within Canada and internationally (see www.interrai.org/worldwide). As such, the ability to conduct international comparison studies of home care

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users with IDD is facilitated.

In addition, this paper reveals that modern terminology is not consistently used in health records to identify presence of an IDD. As such, there is a need to educate assessors on the importance not only of using accepted terms, but on the need for standardization of terms used to describe IDD, in order to ensure that this population is easily identifiable in administrative databases. As interest in and use of administrative health data in decision-making grows, this becomes all the more important.

1. Introduction

The growing availability of administrative data has provided new opportunities for health services research (Benchimol et al., 2011; Langan et al., 2013). Some administrative health data (also called “claims data”, “health care utilization data”) are produced and passively collected at every encounter with the health care system, including visits to a physician’s office, a hospital admission, a diagnostic procedure, an assessment for services, or a prescription (Cadarette & Wong, 2014; Benchimol et al., 2011). Other data is captured in databases built from health assessments completed as part of regular clinical practice to assist with identifying service needs and care planning. The advantages of accessing such data for research purposes are numerous. There are fewer costs, greater population coverage, minimal reliance on recall and self-report, large sample sizes, and less bias due to missing information assuming that records are complete and accurate (Benchimol et al., 2011; Dodds et al., 2009; Roos et al., 1987). As such, findings can be more confidently generalized to populations of interest (Benchimol et al., 2011). Further, with data linkage, long-term follow-ups are possible (Jutte, Roos, & Brownell, 2011).

In the field of intellectual and developmental disabilities (IDD), perhaps one of the greatest potential benefits of administrative data is the ability to study individuals who would ordinarily be underrepresented using traditional study designs (Jutte et al., 2011). Persons with IDD, however, can be “invisible” in health surveillance systems (Haider, Ansari, Vaughan, Matters, & Emerson, 2013; Krahn, Fox, Campbell, Ramon, & Jesien, 2010). As they rarely access health care services because of their disabilities per se, care providers do not always record the presence of an IDD (Iezzoni, 2002). Additionally, administrative datasets rarely provide all of the necessary information on cognition, functioning, and clinical evaluations to determine the true presence of disability (Iezzoni, 2002). Krahn et al. (2010) found that determining an operational case definition (i.e. who is included), finding cases, and obtaining accurate information are the three main challenges to population-level study of persons with IDD.

Determining a case definition of IDD is complicated by dynamic and ever-changing terminology (Foreman, 2005). In the early to mid-1900s, terms such as “idiot”, “feeble-minded”, “mentally deficient”, and “mental retardation” were commonly used to refer to individuals with a low IQ (Foreman, 2005; Simpson, 2015). As these terms gained strong negative connotations and self-advocacy groups argued for language changes, many medical, educational, and governmental bodies around the world ceased using the term “mental retardation” (Ford, Acosta, & Sutcliffe, 2013; Foreman, 2005; Schalock et al., 2007). That said, the term was not replaced in U.S. federal policy documents until as recently as 2010, when Rosa’s Law forced the removal of the term “mental retardation” (Pub. L. 111–256).

The term “mental handicap” was commonly used in the 1990’s, but became less popular with increased recognition that handicap is a social and environmental construct, rather than an objective condition (Eayrs, Ellis, and Jones 1993; Simpson, 2015). For a period, “intellectually challenged” was used, although it came to be considered overly euphemistic (Foreman, 2005). Today, some terms used to refer to those with IDD are also those used to refer to other conditions. Perhaps the most salient example is use of the term “learning disability” in the United Kingdom (to replace “mental sub-normality” and “mental handicap”; Warren, 2000), which is used in North American education systems to denote specific learning difficulties, such as dyslexia, that do not impede general intellectual functioning (Simpson, 2015). Another example is use of the term “mental disability”, which is also used in reference to mental health disorders (Manitoba, 2016).

“Developmental delay” is a broader term that includes IDD, as well as other conditions without intellectual impairment (Simpson, 2015). “Developmental disability” (DD) often means IDD, especially in Canada (Simpson, 2015). In the United States, DD is an umbrella term used to describe both intellectual and physical impairments, including spina bifida, cerebral palsy, Down syndrome and autism, and indicating substantial functional limitations (National Association of Councils on Developmental Disabilities, 2014). However, DD is also used in some areas of Canada, for example, in Ontario (Developmental Services Ontario, 2016). Perhaps the most recent and least ambiguous term is “intellectual and developmental disability”, which is acceptable to different stakeholders and appropriate for various purposes (e.g. diagnosing, support planning) (Schalock et al., 2007). In 2006, the American Association on Mental Retardation announced plans to become the American Association on Intellectual and Developmental Disabilities (AAIDD, 2006). The International Association for the Scientific Study of Intellectual and Developmental Disabilities used the term Mental Deficiency when it was first created in 1964, replaced it with Intellectual Disabilities in 1995 (Parmenter, 2004) and adopted its current name in 2012 (International Association for the Scientific Study of Intellectual and Developmental Disabilities, 2012).

Currently, three definitions and related terms are in use across the AAIDD, the World Health Organization (WHO) and the American Psychiatric Association (APA). The AAIDD defines intellectual disability as “significant limitations both in intellectual functioning and adaptive behaviour” (p. 118) (Schalock et al., 2007), which considers conceptual skills, social skills and practical skills. In 2011, the WHO International Classification of Diseases (ICD) Working Group defined intellectual and developmental disorders as: “a group of developmental conditions characterized by significant impairment of cognitive functions, which are associated with limitations of learning, adaptive behaviour and skills” (p.177) (Salvador-Carulla et al., 2011). The APA uses three criteria to diagnose an intellectual developmental disorder: deficits in intellectual functions (e.g. reasoning, problem solving, planning), deficits in adaptive functioning, and onset during the developmental period (APA, 2013).

While the definitions themselves are clear, unless administrative registration is based on the diagnostic criteria for IDD, the

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