Concordance of EDI-based prevalence rates of health disorders with administrative data in two Canadian provinces

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Introduction

Population level data provide unprecedented opportunities to explore low-frequency health disorders, yet few suitable sources exist for young children. Early Development Instrument (EDI) data on child development in kindergarten in publically-funded schools in Canada include information on children’s health disorders that may be used as a source for prevalence estimates.

Objectives and Approach

We aimed to examine the concordance of EDI-based prevalence rates of health disorders with administrative data in two Canadian provinces by linking data at various levels. In Manitoba, individual EDI data were linked with health and educational data containing information on diagnosis prior to kindergarten for six health disorders: Autism Spectrum Disorder (ASD), Fetal Alcohol Spectrum Disorder (FASD), Attention Deficit and Hyperactivity Disorder (ADHD), Cerebral Palsy (CP), Anxiety, and Asthma. In Ontario, the prevalence rate of ASD based on the EDI was compared to the prevalence rate obtained from regional ASD service providers, matched on area geocodes.

Results

In Manitoba, the total number of children with one of the six diagnoses in the linked database was 10,181. EDI data from 2011 and 2013 demonstrated concordance rates ranging from 0% (Anxiety) to 37% (ASD) between EDI and pre-kindergarten individual administrative data for the prevalence of the health disorders. In Ontario, interrater reliability was established with 2010-2012 EDI data in 12 regions (total number of children with ASD based on the EDI =1,329) to examine consistency among the two data sources. Results showed a “fair” concordance rate for the two sources of ASD prevalence information (Kappa = 0.329; p < 0.001), with rates varying from 0.85% to 1.05%. Linkages with subsequent cohorts of children are ongoing and will be examined for consistency with current results.

Conclusion/Implications

While the results are somewhat lower than expected, they established feasibility of linkages in 2 provinces and will be repeated in others, potentially with a broader time-frame (up to 1-2 years post-kindergarten). This will further inform successful utilization of existing data sources to monitor the prevalence of children’s health disorders.