

Dual Diagnosis or Dual Confusion: Limitations When Utilizing Non-specialist Clinical Data

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Abstract

In this paper, we review challenges encountered when utilizing clinical data collected from non-specialists about persons with intellectual disabilities and psychiatric disorders. We draw on our experience with a dataset of adult inpatients and outpatients drawn from the nine psychiatric hospitals in Ontario (see Lunsky et al., 2003). First we discuss the problem of identifying patients with intellectual disabilities based on standard information collected in hospitals. Many hospitals categorize their patients by primary or secondary diagnosis only, so that a co-existing intellectual disability may or may not be recorded. Then we discuss problems related to the accuracy of psychiatric diagnoses made by individuals with limited training with the population. We found major differences in diagnostic patterns between specialized dual diagnosis programs and more generic programs. We conclude the paper with the argument that it is important to study dual diagnosis not just within the population of persons with intellectual disabilities but also within the broader mental health system. Doing so, however, can lead to problems as such data has its limitations.

Dual diagnosis generally refers to persons with intellectual disabilities and mental health disorders. The majority of dual diagnosis research is published in intellectual disability journals and is either descriptive in nature or is a comparison of intellectually disabled people with and without mental health problems. There are significantly fewer studies that compare individuals with dual diagnosis to individuals who have psychiatric disorders but no intellectual disabilities. Such research is essential because it allows us to directly compare symptoms, patient characteristics and treatment outcomes of those with dual diagnosis to the general population with mental health

problems. Knowing how individuals with a dual diagnosis compare to other patients in the mental health system has implications for how we modify mental health services to better meet their needs (Chaplin, 2004).

In this paper, we review challenges encountered when utilizing clinical data collected by general (non-specialist) psychiatrists in the mental health system about persons with intellectual disabilities and psychiatric disorders. We draw on our experience with a dataset of adult inpatients and outpatients served by nine psychiatric hospitals in Ontario (see Lunskey, Bradley, Durbin, Koegl, Canrinus, & Goering, 2003; Lunskey, Bradley, Durbin, Koegl, & Goering, in press). Seven of these nine hospitals had specialized dual diagnosis programs, including five inpatient and six outpatient programs. First we discuss the problem of identifying those with "dual diagnosis" using only primary or secondary diagnostic information. Next we discuss problems related to diagnostic accuracy. We conclude the paper with some recommendations on how to study dual diagnosis using psychiatric archival datasets.

Method

Sample and Data Collection

A unique opportunity to examine the clinical profile and service needs of individuals with dual diagnosis receiving tertiary level mental health care emerged with the development of a province-wide client database (known as the Comprehensive Assessment Project, or CAPS database) to support service and system planning under mental health reform (see Lunskey et al., 2003 for details on methodology). Patients were drawn from all of the nine psychiatric hospitals (serving a total population base of 11 million) responsible for providing tertiary mental health services to urban, semi-urban and rural communities in Ontario between 1999 and 2003. At each hospital facility, all individuals receiving inpatient services were assessed along with a random sample of individuals receiving outpatient services, stratified by clinical program. The final CAPS study database (weighted data) consisted of 2218 inpatients and 10323 outpatients. Patients were assessed with the Colorado Client Assessment Record (CCAR; see Lunskey et al., 2003) by clinicians familiar with the client. On the first page of the CCAR, staff note whether the individual has any disabilities (deaf, blind, speech, non-ambulatory, intellectual). Later in the questionnaire, staff list the primary and secondary psychiatric diagnoses (of which intellectual disability could also be included).

Results and Discussion

Problems with patient identification: We hypothesized that patients with dual diagnosis would be under-identified by the first six hospitals because they only recorded primary and secondary diagnoses (common clinical practice) rather than recording an unlimited number of diagnoses. From a sample of 8545 individuals receiving inpatient or outpatient services in those six hospitals, 13% were reported as having intellectual disability in the disability section of the CCAR. However, only 8.2% of the sample were listed as having intellectual disability as a primary or secondary diagnosis. Put another way, 37.2% of patients with intellectual disability from the first six hospitals did not have intellectual disability identified as one of their psychiatric diagnoses.

We hypothesized that allowing for unlimited diagnoses would reduce the percentage of individuals not identified as having intellectual disability. We were able to test this hypothesis with patients from the last three hospitals, where an unlimited number of diagnoses could be provided. For these hospitals, 468 out of 3991 patients (11.7%) had a diagnosis of intellectual disability as one of their psychiatric diagnoses. Only 2.5% (in contrast to 37.2%) of patients with intellectual disability (as rated on the CCAR) did not have intellectual disability listed as a psychiatric diagnosis. Therefore, allowing for unlimited diagnoses led to more accurate detection of intellectual disability in the last three hospitals compared to the first six hospitals.

Problems concerning accuracy of diagnoses: We had some concerns regarding the accuracy of psychiatric diagnoses, when made by psychiatrists with limited training in intellectual disabilities (e.g., non-specialists). Such concerns were echoed by community and hospital stakeholders in each region of the province, who participated in focus groups conducted in 2004-2005 regarding this project (Lunsky, et al., in preparation; Puddicombe & Lunsky, 2005). In Canada, psychiatry residency programs offer minimal, if any, training on diagnosing psychiatric disorders in persons with intellectual disabilities (Lunsky & Bradley, 2001) and we hypothesized that this lack of expertise would lead to diagnostic errors in psychiatric diagnoses.

We could not investigate these concerns directly because of the secondary nature of the data. We could, however, compare diagnostic patterns for patients in generic versus specialized dual diagnosis programs with the hypothesis that the diagnostic profiles would differ between the two groups because psychiatrists in dual diagnosis programs would have greater expertise. In order to make this comparison, odds ratios were calculated.

We found that patients in specialized dual diagnosis programs, when compared to patients in generic programs, had higher rates of mood disorders (34% versus 16%, Odds Ratio of 2.7), higher rates of anxiety disorders (15% versus 5%, Odds Ratio of 3.4), and much lower rates of psychotic disorders (26% versus 62%, Odds Ratio of 0.2).

Some differences in diagnostic profiles that were found may reflect true differences in patient populations. However, we propose that clinician biases also played a role: Clinicians with specialized training are more likely to recognize mood and anxiety disorders in those with intellectual disabilities than clinicians without such training (see also Hurley, Folstein & Lam, 2003), and are less likely to classify any bizarre or psychotic-like behaviour as psychotic disorder (see also Bresch, 2004). Also, clinicians with specialized training are less likely to diagnose lower-functioning (IQ above 70-75) individuals who have schizophrenia as having intellectual disabilities unless these individuals met all three DSM-IV criteria (IQ below 70-75, adaptive behaviour deficits, and onset before age 18).

Conclusion

Studies on dual diagnosis in generic mental health services are an important contribution to the literature on dual diagnosis. We need to understand patients with dual diagnosis in the context of other patients in the mental health system in order to tailor services to best meet their needs. However, this kind of research has its limitations, which must be understood in order to make sense of the findings. One limitation is that studies which use mental health databases based on primary and secondary diagnosis alone (such as those in Ontario), likely under-identify the dual diagnosis group and perhaps also miss the opportunity to examine the most complex cases (e.g. those with three or more diagnoses).

A second limitation is that not everyone identified in generic services as having dual diagnosis has been accurately diagnosed. "Dual diagnosis" in these studies, then, may actually refer to a heterogeneous group made up of several subpopulations, including: 1) Persons with "true" intellectual disability (who meet all three DSM-IV criteria) who also have an accurately diagnosed psychiatric disorder; 2) Persons who are now functioning in the intellectual disability range associated with psychiatric illness, (particularly schizophrenia) but whose onset of intellectual disability was after age 18; and, 3) Persons with "true" intellectual disability but with an inaccurate psychiatric diagnosis (some of whom may not even have a definitive psychiatric diagnosis but are in hospital because their severe behaviour

disturbances, sometimes referred to as "challenging behaviours", have been too difficult to manage in the community).

In our review of the literature on "dual diagnosis" in tertiary mental health services, this heterogeneity in the population defined as having dual diagnosis has not received much attention. Future research on individuals identified as "dually diagnosed" should differentiate between the above-mentioned subgroups and compare individuals in these subgroups to determine whether they differ in terms of their clinical needs or treatment outcome. More rigorous study of these separate subgroups would lead to a better understanding both of the aetiology of mental health disturbances in persons with intellectual disabilities and of the unique assessment and treatment needs of the individuals in these different subgroups.

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