Health service registry data in psychiatric epidemiology:
Challenges for definition and interpretation

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Editorial comment

Health service registry data in psychiatric epidemiology: challenges for definition and interpretation

An editorial comment to: Okkels et al.’s ‘Changes in the diagnosed incidence of early onset schizophrenia over four decades’ (1)

In the current issue of *Acta Psychiatrica Scandinavica*, Okkels and colleagues (1) estimate the incidence of early onset schizophrenia in Denmark using a mental health research registry based on administrative data from psychiatric services. The database covers in-patient services from 1969 to 1994, and both in-patient and out-patient services from 1995 to 2010. Based on these data, the investigators conclude that the incidence of early onset schizophrenia has increased across these time periods, but that the proportion of schizophrenia cases among all diagnosed mental health cases has declined. Their findings also suggest that the sex differential has narrowed over time, and that the age at first diagnosis has decreased (1).

The use of routinely collected administrative data from health service registries raises some interesting issues regarding the definition and interpretation of epidemiological measures. To begin with, measures of disease burden are often conceptualized as either treated incidence, which refers to the number of new cases admitted to a psychiatric treatment programme, or population incidence, which refers to the number of new cases in the population or the true incidence of the disorder. However, neither of these concepts is suitable for the estimates of disease burden obtained from health service administrative data, which likely lie somewhere in between treated incidence and population incidence. In their current study, Okkels and colleagues refer to this estimate as ‘diagnosed incidence’ (1), and Goldner and colleagues have previously described it as ‘contact incidence’ (2). Contact or diagnosed incidence should be distinguished from treated incidence, as some individuals will access health services but not subsequently engage with a psychiatric treatment programme. This is especially relevant for psychotic disorders, which are characterized by high rates of treatment non-adherence and disengagement from mental health services. It should also be distinguished from population incidence, as not all individuals with psychiatric disorders may come in contact with health services. Goldner argues that estimates of the contact incidence and the population incidence of psychosis should be relatively concordant in jurisdictions which emphasize early intervention for psychotic disorders (2). Nonetheless, it is important to expand and define our epidemiological lexicon to incorporate the increased use of administrative data for mental health research.

The type of health service data available in research registries is an essential consideration when attempting to interpret estimates of disease burden obtained from administrative databases. For example, Okkels and colleagues observed an increase in incidence across the two time periods, 1969–1994 and 1995–2010 (1). However, these time periods coincided with a change in availability of data, with data from out-patient services only available in the latter time period. These additional data may have partially contributed to the observed increase in incidence, as acknowledged by the authors, and may also have led to the narrowing of the sex differential if males are more likely to be treated in an in-patient setting than females. These additional data may also be responsible for the decrease in the proportion of schizophrenia cases among all diagnosed cases, because schizophrenia is more likely to be treated in an in-patient setting relative to other childhood and adolescent diagnoses. A prior study from Sweden that also used administrative data from health services reported that approximately 25% of incident cases of psychosis are treated in an out-patient setting only (3). Furthermore, in a study using health services administrative data from Québec, Canada, Vanasse and colleagues demonstrate that estimates of the incidence and preva-
lence of schizophrenia can vary substantially depending on whether out-patient data are included in the case definition (4). This issue is especially relevant for databases covering more recent time periods, given the increased focus on deinstitutionalization and community-based treatment of psychiatric disorders. Additionally, the availability of primary care data would be useful to estimate the proportion of patients who are diagnosed with a psychotic disorder by a general practitioner but who do not subsequently follow up with psychiatric services. Estimates of disease burden obtained from administrative databases need to be interpreted in the light of the availability of data from out-patient services and primary care.

An additional challenge associated with the use of health services administrative data is the interpretation of observed estimates and trends, especially for studies that attempt to map changes in disease burden over time. The study by Okkels and colleagues (1) demonstrates that such studies are often plagued by changes to diagnostic systems, as well as changes to the organizational structures of health services and institutional policies, which emphasize the treatment of particular disorders, such as early psychosis. As the authors acknowledge, it is difficult to disentangle the effects of these factors when interpreting the meaning of changing incidence estimates over time. Other limitations to the use of routinely collected administrative data include the limited availability of sociodemographic information, the lack of diagnostic standardization across different professionals and care settings, and the paucity of studies focused on the validation of administrative data from psychiatric services (5).

In spite of these challenges to the definition and interpretation of epidemiological measures obtained from health service registries, these data are an important source of information on the burden of disease in psychiatry. The clinical samples obtained from specialized psychiatric services that are used to estimate treated incidence may not capture all individuals if patients are being treated in primary care or are lost to follow-up after referral. Additionally, the extensive case ascertainment strategies required to obtain estimates of population incidence may not be feasible in most jurisdictions. Routinely collected administrative data from health services are an alternative source of epidemiological information and have additional advantages such as the availability of a larger number of cases and reduced costs. Estimates of disease burden obtained from health services data are also useful for policy and planning purposes, as they reflect the true state of service delivery for psychiatric disorders. As we continue to use routinely collected data from health service registries, these challenges for the definition and interpretation of epidemiological measures require further discussion, and the data used to obtain these estimates need further validation, to ensure that these registries yield accurate, population-based estimates of the burden of psychiatric illness.

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References