

The future of psychiatric case register studies

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Psychiatric case registers have been acknowledged as a valuable source of data especially within the field of psychiatric epidemiology (Dupont *et al.*, 1986; Munk-Jørgensen *et al.*, 1993; Häfner and an der Heiden, 1986). It seems natural that psychiatric research based on case registers has mainly been within the field of psychiatric epidemiology, because this field of research depends upon access to large study populations where selection mechanisms can be described explicitly. Applications have included descriptive epidemiological studies of the incidence and prevalence of treated mental disorders (e.g. Der *et al.*, 1990; Gater *et al.*, 1995; Munk-Jørgensen & Mortensen, 1992). Studies of risk factors for mental illness where both the exposure and the outcome data come from the same case register include Wesley & Castle (1991) who studied schizophrenia risk in Afro-Caribbeans. Follow-up studies of the readmission course include Eaton *et al.* (1991) and Tansella *et al.* (1995). Case registers have also been used as a sampling frame when selecting groups of patients for further clinical and epidemiological studies (e.g. Vaughn & Leff, 1976; Munk-Jørgensen *et al.*, 1991). The combination of data from psychiatric case registers and other population-based data collections, i.e. record linkage studies (Baldwin *et al.*, 1987) have been applied in different areas of psychiatric epidemiology. Mortality studies include Allebeck & Wistedt (1986) and Mortensen & Juel (1993) as well as many others. Perhaps it is less well known that several classical genetic epidemiological studies in psychiatry as adoption studies, twin studies, and high-risk studies, (Wender *et al.*, 1986; Gottesman & Bertelsen, 1989; Fischer, 1973; Parnas *et al.*, 1993) in part have been based on record linkage.

However, in order to further develop the utility of case register data in psychiatric research it is necessary to understand the problems and limitations inherent in this type of studies. Some of these problems have recently been described in more detail elsewhere (Mortensen, 1995), and will only briefly be reviewed here.

Firstly, case register-based datasets as any other dataset should have a sufficient size to ensure the necessary statistical power. In this connection it should be noted that many mental disorders may occur with a low incidence, even though the chronicity of the conditions may result in a relatively high population prevalence. This makes it difficult to get sufficiently large patient samples for studies of risk factors for mental disorders as this type of study will ideally be based on incident cases. As an example it could be mentioned that in Denmark with a total population of 5 million inhabitants only approximately 200-250 first admissions with a diagnosis of schizophrenia occur every year. Also in follow-up studies many relevant outcomes may occur with a relatively low frequency, necessitating long-term follow-up of large patient groups. For example suicide risk is very much increased in most patients with psychoses, but even in the groups with the highest risk it will be less than 1-3% per year who actually commit suicide. Therefore many topics will require sample sizes and durations of follow-up which are practically impossible to obtain, unless one has access to routinely collected data covering a large background population. Thus, case register-based datasets may represent the only feasible alternative for this type of research.

Another important issue to consider, when deciding which data sources to use, is selection. When register data is used, the selection mechanisms operating when individuals are entered into the register should be made explicit. This means that the case register should cover a delineated population, that reporting ideally should be complete from the relevant reporting agencies, and that e.g. private treat-

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ment facilities not reporting to the case register should be described. Possible problems regarding selective immigration and emigration into the catchment area of the register should also be documented in as much detail as possible. Obviously, the same considerations would be equally relevant for studies based on data collected for a specific project, as it is for case register-based research.

Both in studies based on data from a single case register and in record linkage studies, a key issue to consider is the person identifier used at every entry into the register, e.g. in connection with a treatment episode of the patient. If for example the case register is used for a study of psychiatric readmissions, problems with the identification of the patient as e.g. misspelling of the name, errors in the registration of birth dates, etc., may lead to the erroneous conclusion that a patient has not been readmitted even if the opposite is the case. The same would happen in a record linkage study of for example mortality, if those patients who are not reidentified in a register of death certificates are assumed to be alive. These problems would introduce information bias in the studies. Therefore, it is important to describe and document these problems and their possible solutions. Some of these considerations are described in detail in Baldwin *et al.* (1987), and a possible solution is exemplified by the Danish CPR-number. This number is a unique person identifier which is given to all inhabitants at birth or immigration. It is used across all public registration systems, and it can be logically checked for typing errors. This minimizes the risk of failure to reidentify patients correctly, e.g. at a readmission.

Again, these problems of incomplete follow-up due to errors in the re-identification of registered persons are not only relevant for register-based research, since any follow-up study will have less than complete follow-up and thus can be subject to the same type of bias.

Finally, obviously case register-based studies can only address research problems regarding the patient groups which are entered into the case register. This means that the interpretation of e.g. studies of affective disorders should take into account the fact that only a minority of the patients experiencing an episode of affective disorder in the community during a delineated period will be referred to inpatient treatment for this disorder, meaning that conclusions may only be valid for a minority of these patients.

However, bearing these limitations in mind, case

register-based datasets may provide the foundation for addressing scientific issues, which otherwise could not be studied.

One important perspective for register-based research would be the continuing integration of epidemiological thinking into other disciplines in psychiatric research. For example case registers may provide the opportunity to select epidemiologically defined patient cohorts for studies in neuroimaging and other biological psychiatric research, thus adding to the generalizability of this type of research. It will probably also be of great value to supplement the traditional randomized clinical trials in evaluation of psychopharmacological treatment with population-based studies. For example, the combination of information of hospitalization patterns and mortality in psychiatric patients, with routinely collected data on prescribed drugs, may provide valuable insight into the practical applications and limitations of psychopharmacological treatment, and also give the possibility to study the impact of this treatment on relatively uncommon outcomes such as suicide.

We are also currently trying to develop the integration of genetic and epidemiological research in psychiatry by establishing large population-based datasets where individuals can be linked together in pedigrees or nuclear families, permitting population-based estimates of familial risk of psychiatric morbidity as well as many other studies. Within the field of social psychiatric research linkage between psychiatric data and the large number of public information systems regarding income, unemployment benefits, disability pension, etc., may permit more comprehensive studies and monitoring of the impact of unemployment and other social changes on psychiatric morbidity at the individual level as well as the impact on social and occupational prognosis, in individuals experiencing an episode of mental disorder.

These possible developments will obviously vary from country to country depending on which information systems are available, and also on the political climate in which this research will take place. The public attitude towards case registers and the use of case registers in research may vary considerably from time to time, a fact sometimes leading to rapidly changing political attitudes and legislation. Therefore, it is very important both to be open and active in the information towards the public about how these case register data are used, how privacy is protected, and how the use of these data can lead to improvements in treatment and prevention of mental

disorders. This may seem as laborious and unusual tasks for psychiatric researchers, but if a reasonable balance between the legitimate guaranties of the privacy of the registered individuals and the researcher's need for accessible data can be reached through these efforts, case register-based studies may also in the future provide valuable insight into the causes and outcome of mental disorders.

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