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A comparison of clinical and research DSM-III-R diagnoses of schizophrenia in a Finnish national birth cohort

Clinical and research diagnoses of schizophrenia

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Abstract As a prerequisite to the use of the Finnish National Hospital Discharge Register in psychiatric epidemiological research, we studied the diagnostic reliability of the register in terms of the psychiatric morbidity experienced by a national birth cohort. We investigated all entries to the register for a sample based upon the Northern Finland 1966 birth cohort at the age of 16 years ($n = 11\,017$). Until the end of 1993 (age 27 years), a total of 563 subjects had a register diagnosis indicating a psychiatric illness, 37 of them being schizophrenia. When operational criteria (DSM-III-R) were applied to clinical information in the available original hospital records for cases of psychosis, personality disorder and substance abuse ($n = 249$), 71 fulfilled criteria for schizophrenia, including all of the 37 cases in the register and an additional 34 (48% false-negatives), most frequently diagnosed in the register as schizophreniform or other psychosis. Despite the official use of DSM-III-R nomenclature, it appears that the clinical concept of schizophrenia in Finland, manifest within the register, remains very restrictive. The application of operational criteria is a necessary prerequisite for scientific research on schizophrenia.

Introduction

The Finnish Hospital Discharge Register (FHDR) was established in 1967 and covers all mental and general hospitals, as well as bed wards of local health centres nationwide. The FHDR contains the personal and hospital identification code, and data on age, gender, length of stay and primary diagnosis at discharge, together with three subsidiary diagnoses. Diagnostic information is based on clinical diagnoses made by the attending physician. Diagnoses are written by clerks in the case summary prepared routinely at the end of an episode of hospital treatment and also transferred to the FHDR.

The FHDR has been found to be a valid and reliable tool for epidemiological research on ischaemic heart disease [1]; in the studies of Koskenvuo [2] and Poikolainen [3], the agreement between hospital case records and the FHDR is good. Keskimäki and Aro [4] have found that the accuracy of the principal diagnosis of 339 cases of mental disorder was good: in 98% the medical record and the FHDR had the same diagnosis. Although the FHDR is applied in some Finnish studies [5], the reliability of the psychiatric diagnoses has not been studied in terms of operational criteria: diagnoses are transferred faithfully between case records and the FHDR, but do these diagnoses agree, for example, with DSM-III-R diagnostic criteria?

Since 1 January 1987 routine psychiatric diagnosis in Finland has been coded according to the Finnish version of ICD-9 [6] using [7] DSM-III-R diagnostic criteria [8]. In 1989, the National Board of Health published an official book entitled *The Finnish classification of diseases* 1987, as well as a booklet on diagnostic criteria, and imposed the classification for clinical use. Prior to that time, ICD-8 with minimal operational criteria were used.

As a prerequisite to the use of the FHDR in psychiatric epidemiological research, we studied the diagnostic validity of the register in terms of the psychiatric morbidity experienced by a national birth cohort. Our future aim is to study predictors (e.g. pregnancy and obstetric complications, CNS viral infections, major neurological abnormalities) of psychiatric morbidity

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arising in adult life, especially schizophrenia. The present study had three aims. Firstly, we wished to establish the reliability between diagnoses of schizophrenia contained within the FHDR and DSM-III-R diagnoses made for research purposes using case notes. Secondly, we wished to investigate the proportion of people with schizophrenia who are never admitted to hospital. Finally, we wished to establish the accuracy of the FHDR as a source for psychiatric cases. To achieve these aims, we used the psychiatric illness experienced by members of the Northern Finland 1966 birth cohort.

Material and methods

Study population

The Northern Finland 1966 Birth Cohort Study comprised an unselected, general population birth cohort ascertained during mid-pregnancy and based upon 12068 pregnant women in the provinces of Lapland and Oulu with an expected delivery date during 1966. Their 12058 live-born children represented 96% of all births in the region. The detailed description of the study population and general design are presented elsewhere [9–11]. Data concerning biological, socio-economic and health conditions, living habits, and family characteristics of cohort members have been collected prospectively from pregnancy up to the age of 27 years. The current investigation of psychiatric morbidity arising in adult life concerned only the 11017 individuals alive and living in Finland at the age of 16 years. From 1041 lost cases, 273 had died and 768 had emigrated, mainly to Sweden.

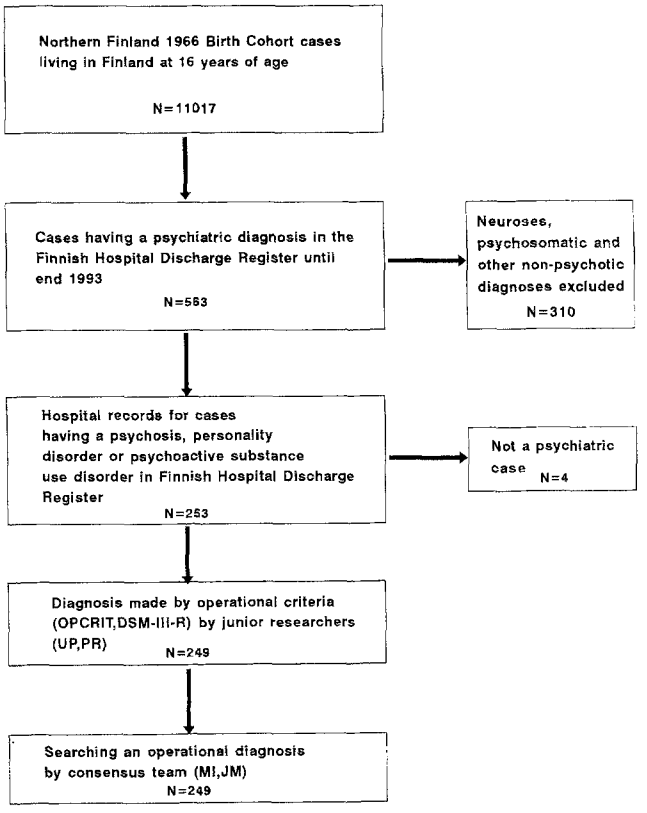

Fig. 1 The presentation of the case ascertainment and diagnostic validation process used in the study

Case ascertainment

The case ascertainment and diagnostic validation process is presented in Fig. 1. All study members appearing on the FHDR until end 1993 for any mental disorder (i.e. DSM-III-R diagnoses 290–319) were identified (n = 563). Diagnosis, dates of hospital stay and name of the hospital concerned were extracted. Some ICD-8 codes used before 1987 were transcribed into comparable DSM-III-R codes which are used in this paper. To investigate the proportion of people with schizophrenia never admitted to hospital, we analysed the outpatient register of Oulu District where about 40% of the cohort lived. In addition, we asked all of the 20 Finnish psychiatrists with district management responsibilities to inform us of all outpatients born in Northern Finland during 1966.

Diagnostic validation

The validation of the use of DSM-III operational criteria is described in Fig. 1. All hospital case notes of the identified individuals with psychosis (290–299; major depressions only with psychotic features), personality disorder (301) and psychoactive substance use disorders (303–305) were scrutinised. Individual hospitals were requested to send original hospital records or copies to the study centre in Oulu.

Clinical information was extracted from the case records and processed in two ways. Firstly, the Operational Criteria Checklist for Psychotic Illness [12] was completed and the associated OPCRIT program was used to yield diagnoses according to DSM-III-R criteria. In addition, clinical data were transferred to a separate proforma for DSM-III-R criteria for schizophrenia, which had been used in the Finnish Adoptive Family Study [13]. This was performed by the junior researchers (U.P. for psychoses P.R. for personality disorders and psychoactive substance use disorders, not using OPCRIT). For all individuals, both the OPCRIT and the DSM-III-R proforma diagnoses were then each rechecked against clinical records by two senior researchers (M.I., J.M.), making a consensus DSM-III-R diagnosis based on all information. Every case was checked by both senior researchers.

Reliability was ensured in the following way. One senior researcher (J.M.) has participated in a cross-national reliability exercise for the Finnish Adoptive Family Study of Schizophrenia [13] where 40 case summaries were reviewed, and two others (U.P., M.I.) also diagnosed these 40 cases. In the Finnish Adoptive Family Study, eight hierarchical diagnostic categories were used: (1) schizophrenia and schizoaffective disorder, (2) schizotypal, paranoid and schizoid personality disorders, (3) schizophreniform and delusional disorders, psychotic disorders NOS, (4) affective psychoses and brief reactive psychosis, (6) antisocial, borderline, histrionic and narcissistic personality disorders, (6) non-psychotic affective disorders, (7) other diagnoses (e.g. personality disorders cluster c, substance use disorders, anxiety disorders and (8) no diagnosis. In this reliability exercise, 40 cases were diagnosed by the cross-national expert team, consisting of two Americans and eight Finns. The opinion of the majority was a reference diagnosis against which the diagnoses of our study group (U.P., M.I., J.M.) were compared. The kappa for this approach was good (U.P. 0.84, M.I. 0.78, J.M. 0.87, M.I. vs. J.M. 0.77).

When the junior researcher's (U.P.) DSM-III-R (OPCRIT in parenthesis) diagnoses were compared with the consensus DSM-III-R diagnoses, the agreement was good, especially between DSM-III-R diagnoses. Kappa/sensitivity/specificity values for two-class categorisation schizophrenia vs. non-schizophrenia were 0.84/0.93/0.92 (0.64/0.76/0.96), and for four-class diagnostic categorisation as described in Fig. 2, the kappa was 0.75 (0.55). In diagnoses of

personality disorder and psychoactive substance use disorder ($n = 109$), there was disagreement only in three cases between junior (P.R.) and senior researchers (M.I., J.M.).

If a case had many hospitalisations, we adopted a hierarchical approach, taking the most severe diagnosis over the subject's lifetime, e.g. classifying cases as DSM-III-R schizophrenia if any episode met the criteria; if many, the first one was selected. This was the case for both hospital and operational diagnoses. Age at onset was defined as the age when psychotic symptoms first became evident, as assessed from clinical observations described in the records.

Statistical methods

The sensitivity and specificity of hospital discharge diagnoses of schizophrenia were used as a diagnostic test, as well as kappa values between the hospital and operational diagnoses and between junior and senior researchers.

Results

When the hospital and operational diagnoses (4-digit DSM-III-R code) of all cases were tabulated in a two-way table, 112 out of 249 diagnoses (45%) were situated on the diagonal, i.e. both diagnoses were identical. The results of the validation process with respect to cases of DSM-III-R schizophrenia are condensed in Table 1. By the end of 1993 (up to age 27 years), a total of 37 cohort members had a clinical diagnosis of schizophrenia on the FHDR. Following the consensus process, 71 cases were classified as DSM-III-R schizophrenia. There were 34 (48%) false-negative diagnoses of schizophrenia and no false-positive. The kappa for a hospital diagnosis of schizophrenia was 0.60, sensitivity 0.52 and specificity 1. The major finding was that in the FHDR we found 34 false-negative diagnoses of schizophrenia; a total of 7 patients diagnosed in hospital as schizophreniform psychosis, 4 as delusional disorder, 1 as paranoid personality disorder, 2 as brief reactive psychosis, 19 as psychotic disorder NOS (atypical psychosis) and 1 as personality disorder had an operational diagnosis of DSM-III-R schizophrenia.

To demonstrate and summarise differences between clinical FHDR diagnoses and the operational classifications, diagnoses were grouped into four categories (see Fig. 2): (1) DSM-III-R schizophrenia: 295.10, 295.30, 295.60, 295.90; (2) schizophrenia spectrum: schizophreniform (295.40) and schizo-affective schizophrenia (295.70), delusional disorder (297.00), schizoid (301.20) and schizotypal (301.22) personality disorder; 3) other psychoses (291–299 except 295, 297); (4) Non-psychotic disorders (301–319 except 301.20 and 301.22). Seven cases with no diagnosis or condition on Axis I as an operational diagnosis were also placed in the non-psychotic category. Their mild psychiatric symptoms did not meet any diagnostic criteria although the psychiatric diagnosis was settled in the hospital. The numbers in the circles of the arrows in Fig. 2 describe the number of diagnostic validations or changes during the validation process.

Table 1 Comparison of hospital and operational DSM-III-R diagnosis in the cases of schizophrenia in the Northern Finland 1966 birth cohort (kappa 0.60, sensitivity 0.52, specificity 1)

Hospital diagnosis	Operational diagnosis		
	Schizophrenia	Non-schizophrenia	All
Schizophrenia	37	0	37
Non-schizophrenia	34	178	212
All	71	178	249

We found only two additional cases of schizophrenia treated as outpatients up to the end of 1993 (age 27 years) who also passed the diagnostic validation process. Out of 20 psychiatrists in district management, half replied, all except 1 reporting negative findings. One informed us of a single patient with schizophrenia treated solely as an outpatient. Another case was found from the Oulu outpatient register.

The cumulative risk of hospital-treated schizophrenia up to age 27 years – based on hospital discharge diagnoses – was 0.34% (37/11017): 0.48% (24/5036) among men and 0.24% (13/5381) among women. Including both the 71 DSM-III-R inpatient cases and the two outpatient cases, the cumulative risk increased to 0.66% (73/11 017; 95% confidence interval 0.54–0.85%), 0.99% among men (50/5036) and 0.43% among women (23/5381). Deaths between 1982 and 1993 ($n = 88$) were not censored but their effect was minimal. The diagnostic codes appeared to have been transferred reliably into the FHDR. In validation we found 4 out of 253 (1.6%) erroneously coded as psychiatric cases.

Discussion

Our main finding concerned the restrictive way in which a clinical diagnosis of schizophrenia appears to be used in Finland, despite the fact that use of DSM-III-R operational criteria has been demanded by state authorities since 1987. Only a small proportion (2/73 or 3%) of schizophrenics were treated solely as outpatients, thereby escaping the FHDR. Diagnoses of schizophrenia were transferred reliably to the FHDR. The standard of hospital case notes varied, but was generally good from the diagnostic point of view; 17% of case records had inadequate clinical details for our purposes. In these cases we avoided a diagnosis of schizophrenia if the criteria were not explicitly met, thereby biasing the study against making operational diagnoses of this disorder and tending to underestimate the discrepancy between clinical and research diagnoses.

The cumulative risk (0.66%) until age 27 years for operationally defined schizophrenia was in accordance

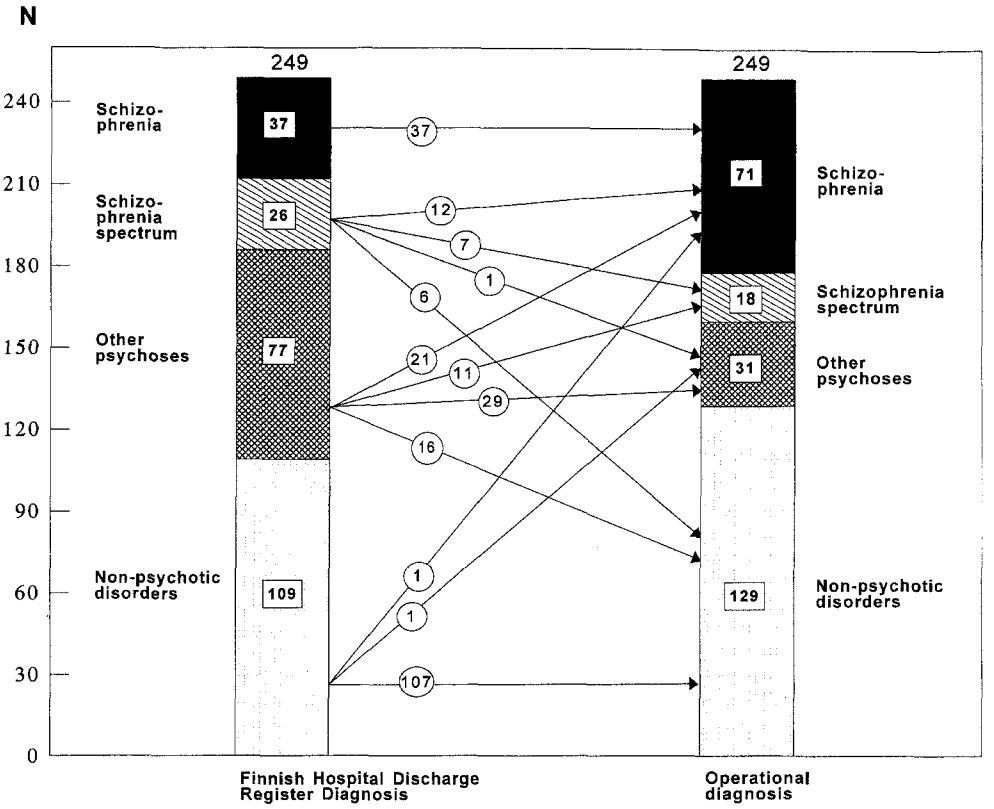

Fig. 2 The frequency distribution of Finnish Hospital Discharge Register (FHDR) diagnoses and operational diagnoses, using DSM-III-R codes. Diagnoses are condensed into four diagnostic entities. The *numbers in the circles of the arrows* describe the number of diagnostic changes during the validation process

with comparable epidemiological studies. By this age the population has lived through slightly over half of the period of risk for schizophrenia [14, 15]. In a case series in Germany, Häfner et al. [16] have demonstrated that 62% of men and 47% of women with lifetime schizophrenia had developed the disorder before age 25 years. In Finland, the incidence of schizophrenia may be higher than in some other countries, with lifetime risks of 1.3% [17, 18] and 1.5% [19] being quoted. The incidence of psychoses may be higher in Northern Finland than in other parts of the country, even as high as 2.4% [17]. A figure of 1.3% lifetime risk of schizophrenia has also been demonstrated in an American sample [20]. Samples defined by operational and relatively narrow diagnostic criteria, such as DSM-III-R, may still contain substantial clinical heterogeneity and result in lower (0.5–1.0%) lifetime risks [21]. Jones [22], using DSM-III-R criteria in the British 1946 birth cohort, has reported a cumulative risk of 0.63% (95% CI 0.41–0.86%) between ages 16 and 43 years, a little lower than in the Northern Finland sample aged between 16 and 27 years. However, the cumulative incidence calculated from the FHDR diagnoses of 0.34% was, therefore, not in accordance with either Finnish or British epidemiological data and represented an under-diagnosis of schizophrenia in the Finnish clinical setting.

Schizophrenia-like psychoses related to alcohol and drugs were rare in the study sample. In Northern Finland – contrary to some other Western countries [23] – a history of substance abuse is still uncommon among the psychotic patients. This comorbidity or causal relation did not influence our incidence rates.

We found a high number (34 cases; 48%) of false-negative cases. Although the kappa value of 0.60 might show good agreement, in this case it did not because the disagreement was all in one direction. Our result is in contrast to the International Pilot Study of Schizophrenia [24], where the main finding concerned false-positive cases, mostly around 5–10% in different centres; the false-negative rate was much lower than in the present study. Our situation was different from the WHO study in the early 1970s where systems for hospital diagnoses were not structured in any way and the broad diagnostic tradition of schizophrenia was dominant. Also, previous studies have demonstrated poor agreement between chart and research diagnoses for schizophrenia even in the 1980s. Robins et al. [25] have obtained a kappa value of 0.27 for schizophrenia, and Erdman et al. [26], 0.31. In a study from New York by Fenning et al. in 1994 [27] on first-admission subjects with a psychotic disorder, the overall kappa between clinical and research diagnosis was 0.38.

Our finding is very similar to that of Pakaslahti's [28] Finnish study in the early 1980s. In analysing 297 first-admission patients aged 15–44 years in Helsinki, he realised that hospital diagnoses of schizophrenia were specific but not very sensitive: the CATEGO

program classified as schizophrenia almost twice as many cases as did the clinicians. Pakaslahti's conclusions seem to be applicable to our study: "...clinicians may use these "milder" diagnoses (reactive paranoid and unspecified psychoses) to categorise a substantial proportion of patients with a clear-cut schizophrenic symptomatology". Also, Kuusi in 1986 [29] has found only moderate agreement between a researcher using DSM-III and "a psychiatrist using common Finnish diagnostic criteria" (94 cases of schizophrenia and schizophreniform psychosis: 18% false-negative and 17% false-positive) or a psychiatrist "well informed about DSM-III" (52 cases of DSM-III schizophrenia: 35% false-negatives and 7% false-positives).

One possible reason for underdiagnosis may be a deficient diagnostic system, or the limitations of DSM-III-R. The 6-month duration criterion seemed to be one reason for underdiagnosis, because many patients stay only short periods in hospital. There is an increasing tendency for this in Finland [30]. Scrutiny of case records, as performed in this study, allows a more longitudinal view of symptomatology.

Another reason for underdiagnosis may be the deficient diagnostic skills of the clinicians. In principle, the diagnosis included in the case summary and transferred to the FHDR should be made by the psychiatrist responsible for care. In practice, there was shortage of psychiatrists in the 1990s, especially in the more remote, northern areas of Finland, and some final diagnoses were made by non-specialist physicians. The majority (77.4%) of the study sample were treated in psychiatric hospitals after 1987, and 72.6% after 1988 (the corresponding figures for cases of schizophrenia being 90% and 89%), and the possibilities to apply official, mandatory (since 1 January 1987) DSM-III-R criteria existed.

The study aims, design, population and resources determined the need and content of diagnostic reassessment and reliability checks. For instance, in this material, agreement between a register and research diagnosis of psychosis was good. Only 22 cases out of 140 with a clinical diagnosis of psychosis (all schizophrenia spectrum cases are included here in the psychosis category) had a research diagnosis of non-psychosis, and only 2 out of 109 cases with a clinical diagnosis of non-psychosis had a research diagnosis of psychosis (kappa 0.81). However, when DSM-III-R diagnoses of schizophrenia are required – as is the case in our future research – there may be a need to reassess the diagnoses in the FHDR.

In conclusion, schizophrenia is a clinical syndrome lacking a single defining feature. International agreement on its definitions and diagnostic criteria is substantial, and modern theoretically neutral diagnostic classifications (e.g. DSM-III-R) are robustly valid for research purposes. However, DSM-III-R may be too complex for clinical use. The use of its operational criteria demands training. Investigators and clinicians only partly shared a clear concept of schizophrenia when diagnosing hospitalised patients in Northern Finland in the late 1980s and 1990s. Reliability problems, narrow diagnostic tradition and underdiagnosis of schizophrenia in hospitals in Finland necessitates diagnostic validation for scientific work. These issues also have implications for the dissemination and implementation of research findings amongst practising clinicians, who seem to be reluctant to diagnose schizophrenia, as well as the use of the more or less artificial 6-month (DSM-III-R, DSM-IV) or other duration criterion.

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