

# The validity of the schizophrenia diagnosis in the Danish Psychiatric Central Research Register is good

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## ABSTRACT

**INTRODUCTION:** The Danish Psychiatric Central Research Register (DPCRR) has been used extensively for research purposes during the past decades. The aim of this study was to investigate the validity of the International Classification of Diseases (ICD)-10 schizophrenia diagnosis in the DPCRR.

**MATERIAL AND METHODS:** A random sample of 300 patients with a first-time diagnosis of schizophrenia (ICD-10 codes F20.0-F20.3 and F20.9) in 2009 was drawn from the register to assess its validity. The case records were reviewed by a Schedules for Clinical Assessment in Neuropsychiatry-certified psychiatric resident using the ICD-10 diagnostic criteria as reference.

**RESULTS:** The sample of 300 patients with schizophrenia represented 23.3% of all incident cases ( $n = 1,288$ ) registered in 2009. We obtained 291 (97.0%) of the case records (nine were lost or inaccessible). Two case records (0.7%) were excluded because of foreign citizenship as these patients had prior episodes in other countries. Thirteen cases (4.3%) were erroneously registered as schizophrenia in the DPCRR. Of the remaining 276 patients, 269 (97.5%) fulfilled the ICD-10 diagnostic criteria for schizophrenia. In a worst case model including all 300 case records, the validity of the schizophrenia diagnosis was 89.7%.

**CONCLUSION:** According to this assessment of patient case records, the diagnosis of schizophrenia in the DPCRR has a high validity and is well-suited for research.

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**TRIAL REGISTRATION:** not relevant.

Psychiatric case registers provide a valuable tool in epidemiological psychiatric research, and the use of case register research in psychiatric epidemiology has enabled investigation of associations that would otherwise not have been possible to address [1, 2].

Denmark has been pioneering international psychiatric register-based research for decades owing to the nation-wide and longitudinal coverage of the Danish Psychiatric Central Research Register (DPCRR) [3]. The register contains information on all diagnoses assigned after admission to a psychiatric hospital in Denmark from 1969 and onwards.

Schizophrenia has been studied widely by using the DPCRR, including studies regarding the prevalence/incidence, outcome and aetiology of the disorder [4-7]. Furthermore, the DPCRR has been linked to the national prescription database, the National Patient Registry, which also makes it a valuable tool for pharmacoepidemiological research [8, 9].

In 1994 Loffler et al evaluated the validity of the ICD-8 diagnosis of schizophrenia in the DPCRR and estimated the validity to be 66% [10]. Despite the extensive use of the DPCRR for research purposes during the past two decades, the validity of the ICD-10 schizophrenia diagnosis in the DPCRR has not been evaluated since then. As the DPCRR contributes significantly to the epidemiological research in schizophrenia, we decided to investigate the validity of the ICD-10 schizophrenia diagnosis in the register.

## MATERIALS AND METHODS

### The register

The DPCRR includes admission/discharge dates and diagnoses of all psychiatric admissions and outpatient contacts in Denmark from 1969 onwards. Diagnostic information is based on the clinical diagnosis assigned by the attending physician at the end of the hospitalization or outpatient contact. The International Classification of Diseases, Tenth Revision (ICD-10) [11] has been used in clinical practice in Denmark since 1 January 1994.

The data in the register are person-identifiable as they are linked to the unique 10-digit personal identification number (Civil Person Registration (CPR) number) which enables linkage of information from a number of registers and databases for population-based research projects.

### The sample and the procedure

The eligible population for the study was defined as all inpatients and outpatients registered with a first-time diagnosis of schizophrenia (ICD-10 codes F20.0-F20.3 and F20.9) in the DPCRR in the year of 2009. These diagnostic codes were chosen because they are all schizophrenia subtypes in which the general criteria must be fulfilled at the index admission, which excludes post-schizophrenic depression, residual schizophrenia and simple schizophrenia (Table 1).

## ORIGINAL ARTICLE

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TABLE 1

Schizophrenia subtypes.	Subtype	Presence, n (%)
	F20.0 Paranoid schizophrenia	188 (68.1)
	F20.1 Hebephrenic schizophrenia	3 (1.1)
	F20.2 Catatonic schizophrenia	3 (1.1)
	F20.3 Undifferentiated schizophrenia	26 (9.4)
	F20.9 Schizophrenia, unspecified	56 (20.3)

TABLE 2

General diagnostic criteria for schizophrenia and the distribution of symptoms.

ICD-10, F20 Schizophrenia	Presence, n (%)
I Duration $\geq$ 1 month	269 (100)
II $\geq$ 1 first-rank symptoms	141 (52.4)
a. Thought echo, thought insertion or withdrawal, or thought broadcasting	81 (30.1)
b. Third person auditory hallucination, running commentary	69 (25.7)
c. Delusions of control, influence or passivity, clearly referred to body or limb movements or specific thoughts, actions, or sensations; delusional perception	50 (18.6)
III Persistent bizarre delusions (culturally inappropriate and completely impossible)	72 (26.8)
IV $\geq$ 2 of the following	164 (61.0.)
a. Persistent hallucinations in any modality when accompanied by delusions	188 (69.9)
b. Thought disorder	77 (28.6)
c. Catatonic behaviour	6 (2.2)
d. Negative symptoms	183 (68.0)

ICD-10 = International Classification of Diseases, tenth edition.

Psychiatric emergency room contacts were excluded because these contacts are of short duration and should not be used for defining patients with schizophrenia for epidemiological research without supporting evidence.

A random sample of 300 patients with a first-time diagnosis of ICD-10 schizophrenia (F20.0-F20.3 and F20.9) in 2009 was drawn from the register. The psychiatric case records were subsequently obtained from psychiatric hospitals all over Denmark.

All case records were reviewed by a Schedules for Clinical Assessment in Neuropsychiatry (SCAN)-certified psychiatric resident (the first author) using the ICD-10 diagnostic criteria for research as reference. Statistical analyses were performed with STATA 11. The Danish National Board of Health and the Danish Data Protection Agency approved this study.

*Trial registration:* not relevant.

## RESULTS

### Demographics

The sample of 300 patients with schizophrenia represented 23.3% of all incident cases (1,288) registered in the DPCRR in 2009.

The sample consisted of 166 males (60.1%) and 123

females (39.9%). The mean age at the time of first schizophrenia diagnosis was 32.5 years (standard deviation (SD) = 13.6) with no differences between the sexes (males: 32.3 years (SD = 12.6), females: 32.9 years (SD = 15.1),  $p = 0.5$ ). A total of 151 (54.7%) of the cases were from university hospitals and 135 (48.9%) were diagnosed during psychiatric admission. A psychiatric specialist approved the diagnosis in all cases.

### Data collection

We obtained 291 (97.0%) of the case records (nine were lost or inaccessible). Two case records (0.7%) were excluded because of foreign citizenship. These two patients were registered in the DPCRR due to admission during stays in Denmark, but had their first episode elsewhere and therefore did not meet eligibility criteria for the present study. Thirteen cases (4.3%) were erroneously registered as schizophrenia in the DPCRR. For these patients, the case note information revealed that a different diagnosis had been assigned by the treating psychiatrist, and this diagnosis should have been reported to the DPCRR in place of the F20. The remaining 276 patients were included in the evaluation of diagnostic validity.

### Validation

The ICD-10 diagnostic criteria for schizophrenia were fulfilled in 269 of the 276 cases (97.5%). Of the seven patients not meeting the criteria, one case did not fulfill the duration criteria, in five cases an organic cause had not been excluded and, finally, three cases did not fulfill the symptom criteria.

In a worst case model including all 300 case records, the validity of the schizophrenia diagnosis was 89.7%. There was no difference in the validity rate between non-university hospitals and university hospitals (94.7% versus 89.9%,  $p = 0.14$ ).

**Table 2** displays the general diagnostic criteria for schizophrenia in the ICD-10 and the distribution of symptoms of the 269 cases.

Among the 276 patients, physical/neurological examinations were performed in 55.8%, biochemical analysis of blood samples in 63.8%, electroencephalogram in 16.1% and brain imaging in 29.9% (computed tomography 25.4%, magnetic resonance imaging 9.1%). A semi-structured diagnostic interview was performed in 27.9% of the cases.

Present-state examination was the most widely used diagnostic instrument accounting for 21.8%. The SCAN were used in 6.2% and the operational criteria diagnostic checklist (OPCRIT) in 1.1% of the cases. The sum of these proportions exceeds the 27.9% since some patients were assessed with more than one diagnostic instrument.

## DISCUSSION

This is the first study investigating the diagnostic validity of the ICD-10 schizophrenia diagnosis in the DPCRR. According to this assessment of 300 randomly drawn patient case records in the DPCRR, 97.5% of the patients diagnosed with schizophrenia in 2009 fulfilled the diagnostic criteria of the ICD-10. Although the validity dropped to 89.7% in the worst case model, the use of the register for epidemiological schizophrenia research is supported.

The higher validity found in the present study compared with the previous study by Loffler et al may be owed to the more formalized diagnostic criteria of the ICD-10 than for the ICD-8 and to differences in the methods used to establish diagnostic validity. Unfortunately, comparison of the methodology in the two studies was not possible because the methods were not clearly described by Loffler et al [10].

Our findings are in line with those of validation studies of the schizophrenia diagnosis performed in other Nordic countries [12-17]. In 1987, the validity of the Diagnostic and Statistical Manual of Mental Disorders, third edition (DSM-III) schizophrenia diagnosis in Sweden was found to be only 76% [12]. An increase in the diagnostic validity over time from 76% to 86% like in Denmark was found in Sweden [16]. The design was similar to ours, except that only the diagnoses of inpatients were assessed and that the DSM-IV was used.

Other DPCRR diagnoses than schizophrenia have been validated. Kessing found a diagnostic validity of 95% among 100 patients registered with a first-time affective disorder in the DPCRR between 1971 and 1993 [18]. A more recent study found the validity to be only 75.4% in patients with major depressive episodes. However, the validation was performed by a SCAN interview of the patient several months after the episode and may

have been susceptible to recall bias. As could be expected, the diagnostic validity was highest for patients with a severe depressive episode (82.8%) and lower in patients with mild depressive episodes (65.2%) [19]. Schizophrenia is a severe, debilitating and stigmatizing disorder, and psychiatrists are probably more cautious, or even reluctant, to assign the diagnosis, which may explain the higher diagnostic validity found in this study.

The main source of incongruence between the patients' actual diagnosis and the schizophrenia diagnosis registered in the DPCRR was the 13 cases of registration error. In these cases, a diagnosis different from schizophrenia had been assigned by the treating psychiatrist and should therefore have been reported to the DPCRR in place of the F20. The reason underlying these false registrations should be investigated in further detail as they appear to represent a highly unnecessary source of error which could probably be avoided.

The validation was based solely on the description of psychopathology symptoms stated in the case record. Consequently, it cannot be taken into account whether psychiatrists misinterpreted the patients' description of symptoms or whether symptoms were present without being described in the case record. Another limitation of the design is that the validation was performed by one single rater who was not blind to the diagnosis being validated.

## CONCLUSION

Psychiatric case registers like the DPCRR remain important tools in psychiatric research. Studies involving these registers in linkage with biobanks may even elucidate subtle gene-environment aetiological mechanisms that are almost impossible to investigate by other means [20]. Such studies and register-based psychiatric research in general rely heavily on an assumption of high validity of the registered diagnoses. This study revealed that the diagnostic validity of ICD-10 schizophrenia in the DPCRR was very high which supports the use of the register for research purposes in the future.

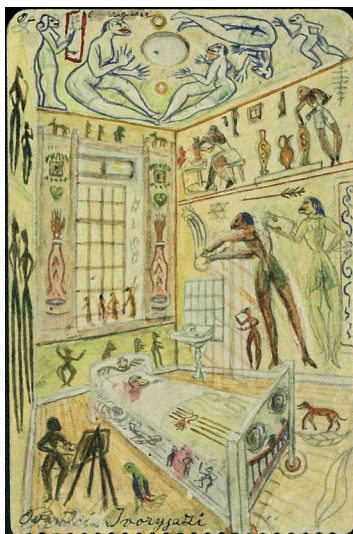
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Untitled painting by the artist Louis Marcussen, better known as Ovartaci, who was a patient and lived at the Psychiatric Hospital in Risskov for 56 years from 1929 until he died 91 years old in 1985. Courtesy of Museum Ovartaci, Risskov.

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