European Psychiatry 35 (2016) 16–24

Contents lists available at ScienceDirect

European Psychiatry

journal homepage: http://www.europsy-journal.com

Original article

The validity and reliability of the diagnosis of hyperkinetic disorders in the Danish Psychiatric Central Research Registry

C. Mohr-Jensen [a,*], S. Vinkel Koch [b], M. Briciet Lauritsen [a], H.-C. Steinhausen [a,c,d]

[a] Research Unit of Child and Adolescent Psychiatry, Aalborg Psychiatric Hospital, Aalborg University Hospital, Aalborg, Denmark
[b] Child and Adolescent Mental Health Centre, Mental Health Services, Capital Region of Denmark and Institute of Clinical Medicine, Faculty of Health Sciences, University of Copenhagen, Copenhagen, Denmark
[c] Clinical Psychology and Epidemiology, Department of Psychology, University of Basel, Basel, Switzerland
[d] Department of Child and Adolescent Psychiatry, University of Zurich, Zurich, Switzerland

ARTICLE INFO

Article history:
Received 3 December 2015
Received in revised form 29 January 2016
Accepted 30 January 2016
Available online 7 April 2016

Keywords:
ADHD
Hyperkinetic disorders
Diagnostic validity
Research registry

ABSTRACT

Objective: To validate the diagnosis of hyperkinetic disorders (HD) in the Danish Psychiatric Central Research Registry (DPCRR) for children and adolescents aged 4 to 15 given in the years 1995 to 2005.
Method: From a total of 4568 participants, a representative random subsample of $n = 387$ patients were used to validate the diagnosis. Patient files were systematically scored for the presence of ICD-10 criteria for HD and oppositional defiant disorder/conduct disorder (ODD/CD; F91). Further to this, an inter-rater reliability study was also conducted, whereby two experienced child and adolescent psychiatrists who were blind to patients discharge diagnoses, rated a random subsample of $n = 101$ participants.
Results: Information was available for 372 out of 387 patients. Out of $n = 372$ available files, $n = 324$ (86.8%) were evaluated to fulfil diagnostic criteria for HD. Due to missing information it was not possible to reach a conclusion for 5.1% of the cases, 3.8% of the diagnoses were registration errors, and in 4.3% of the files the diagnosis had to be rejected. Inter-rater agreement was high ($\kappa = 0.83$, $z = 10.9$, $P < .001$). The validity of hyperkinetic disorders, unspecified (F90.9) was lower and comorbid CD/ODD were under-diagnosed in the sample. All participants fulfilling HD criteria also fulfilled DSM-5-criteria for ADHD.
Conclusion: The risk of misclassification of patients with HD in the DPCRR is relatively low, with the exception of the diagnosis of hyperkinetic disorders, unspecified (F90.9).

1. Introduction

With the emergence of modern classification systems in the last century, nosological concepts have been increasingly homogenized by introducing a clear definition of the various mental disorders and sets of operationalized criteria for the diagnosis of disorders. Both clinicians and researchers are more or less obliged to use the criteria of major classification systems, namely, the International Classification of Disorders (ICD-10) [1] and the American Diagnostic and Statistical Manual (DSM-5) [2]. Both of these classifications describe a disorder with the core symptoms of attention-deficits, hyperactivity, and impulsivity, namely hyperkinetic disorder (HD) in the ICD-10 and attention-deficit/hyperactivity disorder (ADHD) in the DSM-5.

Despite great overlap in the criteria between HD and ADHD, the definition of HD is narrower. Studies based on samples with ADHD have found that 25 to 26% of DSM-IV defined ADHD cases fulfil the criteria for HD [3,4]. A diagnosis of HD requires six or more symptoms of inattention, three symptoms or more of hyperactivity, and one or more symptom of impulsivity. For ADHD, the DSM-5 requires the same number of symptoms of inattention, but six or more symptoms of hyperactivity/impulsivity based on a two rather than a three-factor symptom model.

Beyond the defining criteria of a disorder, a strict adherence to the diagnostic rules as set up in the nosography is important for both the reliability and validity of diagnostic assessment. However, a recent experimental study demonstrated that clinicians may not always sufficiently follow these criteria [5].

This therefore raises the question of the reliability and validity of such diagnoses in clinical studies. In particular, the validity of diagnostic criteria is crucial in studies using diagnoses obtained from numerous clinicians. This is the case when comprehensive data on patient information is collected from large registries, for example, the large Scandinavian registries that contain health and social data. One such frequently used source is the Danish Psychiatric Central Research Registry (DPCRR), which has collected

* Corresponding author.
E-mail address: christina.j@rn.dk (C. Mohr-Jensen).

http://dx.doi.org/10.1016/j.eurpsy.2016.01.2427
0924-9338/

data since 1969. The DPCRR is based on clinical diagnoses classified according to ICD-8 criteria up until 1994 and ICD-10 criteria since 1994, due to the ICD-9 never being in use in Denmark [6]. Public healthcare is free of charge in Denmark and available regardless of income and socioeconomic status. Furthermore, mental health care is assessable for all citizens, and records containing information on all patient contacts to psychiatric hospitals are stored in the DPCRR [6].

Due to the national coverage of the registry, the DPCRR has been the origin of a sizeable number of studies of various mental health disorders including HD. Based on DPCRR data, researchers have studied the risk of developing HD as a function of various conditions ranging from exposure from injuries [7], environmental toxins [8–14] to a lack of nutrients during the perinatal period [15] to name but a few. HD based on the DPCRR has also been studied for time-trends including age, cohort and time-effects [16,17], the protective and risk effects of medication use [18,19] and as a predictor of early mortality [20], somatic diseases and psychiatric disorder [21–23].

Although these studies have provided important contributions to research, a potential weakness of these studies is that the data on which they were based on had not been validated for HD diagnoses, and it was therefore assumed that clinicians had adhered to the diagnostic criteria. If a substantial number of individuals with HD in the DPCRR had been misclassified, this bias could deflate or inflate the risk of certain outcomes or exposures, and therefore lead to inaccurate conclusions. Thus, it is of great importance to gain insight into the validity of the HD diagnosis in the DPCRR.

From 1990 onwards, an increasing number of children and adolescents were diagnosed with HD in Denmark, and the incidence and cumulative prevalence of diagnosed children and adolescents has risen for every consecutive birth cohort and calendar year [16,17]. During the years 1995–2010, the number of children and adolescents diagnosed with HD increased with an average annual percent increase of 16.1% in preschoolers (age 4–5) and school-aged children (age 6–12) and of 29.3% in adolescents (age 13–17) [17]. Thus, we have not only seen a shift in the use of nosological criteria since the first cohort of ICD-8 to ICD-10, but we are now potentially observing a different group of children to what had been studied previously. The changes in nosology might also have had an impact on the clinical understanding and the awareness of HD. These time-trends also add to the relevance of the study of the validity of diagnoses, as the diagnostic validity may have changed over the years.

A previous study addressed the issue of diagnostic validity of HD by assessing a historical cohort of 208 children treated with stimulants in a single Danish clinic during the years 1969 to 1989. During these years, ICD-8 was the official classification used in Danish psychiatry, but did not include formal diagnostic criteria for HD. This study found that even when using ICD-10/DSM-IV criteria for this historical cohort, 81% of children treated with stimulant medication fulfilled criteria for full or subthreshold ADHD [24]. ICD-10 defined HD as diagnosed in children and adolescents of the Aarhus Birth Cohort and registered in the DPCRR was also validated using DSM-IV criteria. In this study, 84% of the HD diagnoses also fulfilled criteria for ADHD and 10% were considered subthreshold cases [25].

While HD has not been validated in the DPCRR in a nationwide sample, validation of other diagnoses resulted in rather positive findings. In a study of adult schizophrenia based on a random sample of $n = 300$ incident cases in 2009, a total of 89.7 to 97.5% of the sample fulfilled diagnostic criteria for schizophrenia [26]. Among all $n = 499$ childhood autism cases born in 1990–1999, a total of 94% of the participants fulfilled diagnostic criteria [27]. Finally, the diagnosis of dementia was analysed in a random sample of $n = 197$ individuals registered in the first six months of 2003 in the DPCRR and in the National Patient Registry (NPR) with the finding that 85.8% of dementia diagnoses were correct [28].

2. Aims

The primary aim of this study was to identify how many cases diagnosed with HD for the first time in their life in Danish child and adolescent psychiatric hospitals and registered in the DPCRR, fulfilled the diagnostic criteria according to ICD-10 for the disorder after careful review of the patient records. In addition, the reliability of the ratings were also studied by assessing inter-rater agreement.

3. Methods

3.1. Case definition

The DPCRR was used for the identification of a cohort of children and adolescents (age 4–15 years) diagnosed with HD (ICD-10 codes F90.x) for the first time in their lives in psychiatric services during the years 1995–2005. First time diagnosis was defined as a first time registration of F90.0 (hyperkinetic disorder), F90.1 (hyperkinetic conduct disorder), F90.8 (other hyperkinetic disorders) or F90.9 (hyperkinetic disorder unspecified). The following exclusion criteria were used: Individuals with a diagnosis of HD in 1994, or an ICD-8 diagnosis of 308.3 (hyperkinetic syndrome of childhood) in the period prior to 1994, or with incomplete data on sex, year of birth, or region of the psychiatric hospital where the diagnosis was made.

3.2. Validation sample

A total of $n = 4568$ individuals fulfilled the case definition (sample A, see Fig. 1). The total sample had a mean age at diagnosis of 8.7 (SD = 2.8) years and 85.1% were males. Due to a lack of resources for a validation of all cases fulfilling the inclusion criteria, a random sample of patients was drawn for the validation study (sample B, see Fig. 1). Using the formula for sample size determination to estimate a population proportion with specified absolute precision [29], we calculated the size of the subsample that formed the basis of the validation study. It was the intention to detect a 60–90% prevalence of HD in our sample with 95% confidence intervals and an absolute precision of 5%. To fulfil these criteria, a random subsample of $n = 138$ to $n = 369$ was needed. To ensure a large enough sample, and in the eventuality that some patient records could not be identified, a random sample of $n = 387$ individuals (sample B) was drawn from the total sample using a computerized random sample generator from SPSS [30].

Out of the 387 patients selected for the validation study, we were successful in retrieving full or partial patient records on $n = 372$ patients (96.1%) forming the definite validation sample (Sample B1). Analysis of the data on the 15 (3.9%) missing patient records revealed that the numbers of files were relatively evenly distributed among the various hospitals and with respect to sex and age at diagnosis. The only clear pattern was that patient records from the earliest years of the inclusion period were more likely to be missing. For example, five (29.4%) of the missing files represented cases diagnosed in 1995, i.e. the earliest year of inclusion. The absence of these files was most likely the result of Danish laws requiring hospitals to save patient records for no more than 10 years. The validation sample had a mean age of 8.8 (SD = 2.0) years and 83.2% were males.

3.3. Validation procedure

For investigating the validity of the diagnoses in the DPCRR, historical information on all cases from sample B was retrieved