

# Validation of the cholesteatoma diagnosis in the Danish National Hospital Register

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## ABSTRACT

**INTRODUCTION:** The aim was to evaluate the validity and the degree of completeness of the cholesteatoma diagnosis in the Danish National Hospital Register (DNHR).

**MATERIAL AND METHODS:** Validity: A random sample of 286 patients with a cholesteatoma diagnosis who had been admitted to an ear-nose-throat department on Funen between 1977 and 2007 was selected from the DNHR for validation. The diagnosis was verified on the basis of surgical chart review. Completeness: The DNHR was compared with the local Ear-database at Odense University Hospital (EDOUH) covering the 1996-2007 period.

**RESULTS:** Validity: A total of 273 patients had 422 registrations of a cholesteatoma diagnosis combined with relevant surgery (CWRS). The remaining 13 of the initially 286 selected patients had a cholesteatoma diagnosis, but without relevant surgery. Surgical charts could be retrieved for 262 patients with 401 registrations. The positive predictive value (PPV) of the CWRS in the DNHR was 85.8%. When only the first-time patients with CWRS were recorded, the PPV was 89.3%. Completeness: A total of 329 cases of surgery were recorded in the DNHR, the EDOUH or both. Surgical charts could be retrieved for 322. The diagnosis was confirmed for 277. Based on the confirmed cases, the degree of completeness of the CWRS in the DNHR was estimated to 91.0%. When only the first-time patients were included, the degree of completeness was estimated to 89.3%.

**CONCLUSION:** Misclassification of the first CWRS in the NHR was close to 10%, and the DNHR may be considered a useful tool for epidemiological research on cholesteatoma.

Cholesteatoma (**Figure 1**) can cause serious complications such as hearing loss, facial palsy, dizziness and intracranial infections. A cholesteatoma usually appears as a defect in the eardrum through which squamous epithelium grows into the middle ear or mastoid. Here, the cholesteatoma can destroy important structures such as the ossicles, the facial nerve, the vestibular organ and the cochlea, thus requiring meticulous surgical removal [1].

Previous studies, which were primarily based on local hospital districts, have demonstrated annual incidence rates of cholesteatoma ranging from three to 17 per 100,000 person-years [2-7]. To our knowledge, no

study has elucidated the epidemiology of cholesteatoma using data from a nationwide register.

Population-based health registries can provide valuable information on disease epidemiology. However, a prerequisite for the use of these registries is that they are valid, i.e. the registered diagnoses are correct, and that the degree of completeness is high. The purpose of this study was to validate the cholesteatoma diagnosis in the Danish National Hospital Register (DNHR) and to estimate the degree of completeness, hereby answering the question whether the DNHR may be used for epidemiological research on cholesteatoma.

## MATERIAL AND METHODS

In this study, we used two registries, the DNHR and the local Ear Database (EDOUH) of the Ear-Nose-Throat (ENT) Department at Odense University Hospital (OUH).

The DNHR contains data on all admissions to Danish hospitals since 1977. In practice, the registration is done at discharge. From 1977 to 1993 the diagnostic information was based on the Danish version of the International Classification of Diseases, 8th revision (ICD-8) [8], and from 1994 and onwards the International Classification of Diseases, 10th revision (ICD-10) [9] was used. From 1977 to 1995, surgical information was based on the "Surgery- and Treatment Classification" from the Danish Board of Health [10], and from 1996 and onwards, the Danish editions of the "Classification of Surgical Procedures" from the Nordic Medico-Statistical Committee [11] were used.

The EDOUH is a locally developed database in which all ear operations performed at the ENT Department since 1996 have been registered

For the assessment of the cholesteatoma diagnosis, we followed the definition of cholesteatoma described in Scott-Brown's "Otolaryngology", i.e. a squamous epithelially lined pocket full of squamous epithelial and inflammatory debris which mostly arises in the pars flaccida but can also occur from a pars tensa retraction pocket [12]. We thus only included diagnostic codes for cholesteatoma of the middle ear and mastoid (ICD-8: 387.09; ICD-10: H71 including subgroups, H95.0 and Q16.4A) and omitted cholesteatoma of the external ear (ICD-10: H60.4).

## ORIGINAL ARTICLE

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As it can be difficult to determine whether or not cholesteatoma is present in the middle ear or mastoid by otomicroscopy alone, and as the vast majority of cholesteatoma patients are surgically treated relatively soon after being diagnosed, we chose to consider the cholesteatoma diagnosis in combination with surgical procedures and to validate the cholesteatoma diagnosis by reviewing medical charts from hospitalisations in which surgery had been performed. Hence, we additionally defined which surgical codes should be considered relevant for cholesteatoma surgery. These included codes concerning mastoidectomy, mastoid obliteration, tympanoplasty, myringoplasty and exploration of the middle ear (Surgical- and Treatment Classification: 20380–20700 and 20990; Nordic Classification of Surgical Procedures: all surgical codes starting with KDC, KDD, KDE and KDFD30 except KDCA10, KDCA20, KDCW00, KDEE and KDEE00).

For the validation procedure, we selected all registrations in the DNHR with a cholesteatoma diagnosis in combination with relevant surgery for a random sample of patients admitted to an ENT department on Funen in the period from 1 January 1977 to 31 December 2007. Sample selection was based on the individual's civil registration number and included were all patients with a number ending on three or four. Outpatients were not included in the sample, as they were only recorded in the DNHR after 1995 and as most cholesteatoma surgery is performed after admission to hospital. On Funen, patients with cholesteatoma are surgically treated either

at the ENT department at OUH or at the ENT department at Svendborg Hospital. The medical charts were retrieved either in electronic form or in paper form from local archives. The complete medical charts were read. As the cholesteatomas were only histologically examined in rare cases, we relied on the surgeons' descriptions. If a patient had received cholesteatoma surgery elsewhere in the country prior to the current operation, the medical charts were retrieved from the relevant hospitals. As the site of disease (right/left) was not recorded in the DNHR throughout the whole period, we did not take the site or the presence of bilateral cholesteatoma into consideration in the present paper.

For the estimation of completeness, we chose to review all registrations of cholesteatoma combined with relevant surgery in either the DNHR, the EDOUH or both in the period from 1 January 1996 to 31 December 2007 after admission to the OUH and applied the capture-recapture method [13] to the confirmed cases.

The study was approved by the Danish Data Protection Agency.

### Analysis

The positive predictive value (PPV) of the cholesteatoma diagnosis in the DNHR in combination with a relevant surgical code was calculated as a proportion by dividing the number of registered cases with a confirmed diagnosis after surgical chart review by the total number of retrievable surgical charts.

The degree of completeness of the cholesteatoma diagnosis in combination with a relevant surgical code was estimated applying the capture-recapture method [13]. The number of registrations missing in both the DNHR and the EDOUH was calculated as the product of the registrations only recorded in one of the registries divided by the number of registrations recorded in both. Next, the degree of completeness was calculated as the proportion of cases registered in the DNHR divided by the estimated true number of cholesteatomas.

## RESULTS

### Positive predictive value

For validation of the cholesteatoma diagnosis, a total of 273 patients were included in the sample. The included patients had a total of 422 registrations with a cholesteatoma diagnosis in combination with relevant surgery as illustrated in **Table 1**. Another 13 patients were registered with a cholesteatoma diagnosis, but without relevant surgical codes.

Among the 422 registrations with a cholesteatoma diagnosis combined with relevant surgery sampled for validation, surgical charts could be retrieved from 401 (262 patients). The diagnosis was confirmed in 344 operations, which yielded a PPV of 85.8% (95% confidence

 FIGURE 1

The right eardrum of a 27 year-old male with a cholesteatoma in the posterior half of the middle ear. As a child, the patient had numerous middle ear infections and had ventilation tubes inserted several times.

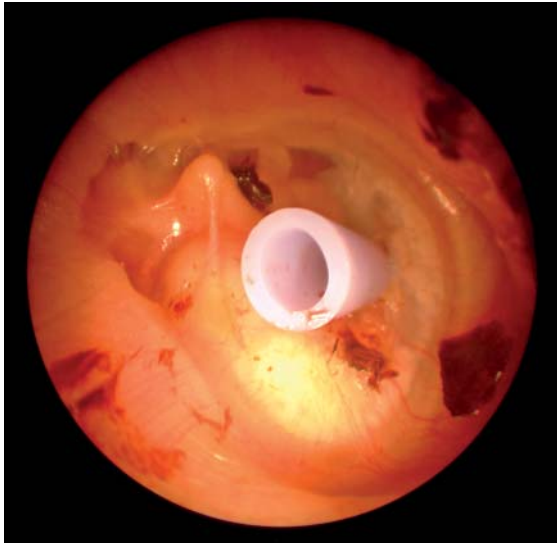




TABLE 1

Distribution of the 422 registrations with a cholesteatoma diagnosis combined with relevant surgery selected for validation.

	Total	First-time registration
Admissions with surgery	422	273
Surgical chart not found	21	11
Surgical chart reviewed	401	262
Cholesteatoma dismissed	57	28
Cholesteatoma verified	344	234
Positive predictive value	85.8% (95% CI 82.4-89.2)	89.3% (95% CI 85.5-93.1)

CI = confidence interval

interval (CI) 82.4-89.2). When reviewing the charts, it became apparent that in 43 of the incorrect registrations (75%), the patient had previously undergone cholesteatoma surgery. This yielded a PPV of present or previous cholesteatoma of 96.5% (95% CI 94.7-98.3).

By only including the first time the patient had a cholesteatoma diagnosis combined with relevant surgery, the surgical charts could be retrieved in 262 of 273 cases. The diagnosis was confirmed in 234 cases, which yielded a PPV of 89.3% (95% CI 85.5-93.1). In 15 of the incorrect registrations, the patient had been operated at an earlier time for cholesteatoma, which resulted in a PPV of present or previous cholesteatoma of 95.0% (95% CI 92.4-97.7).

Among the 13 patients who fulfilled the criteria for sample selection, but who were not operated, the medical charts could be retrieved for 11. In five patients (46%), the cholesteatoma diagnosis was dismissed.

The registrations in the DNHR may contain several surgical codes. For a separate validation of the surgical codes in the DNHR, we selected a random sample of 28 patients whose surgical charts could be retrieved; this provided us with a total of 107 surgical codes. Among the 107 surgical codes, 105 were confirmed by surgical chart review, which gave a PPV for a single surgical code of 98.1% (95% CI 95.5-100.0).

#### Degree of completeness

A total of 291 registrations of cholesteatoma combined with relevant surgery (245 patients) were registered in the DNHR after hospitalisation at the OUH. A total of 298 operations for cholesteatoma (254 patients) were registered in the EDOUH after hospitalisation at the OUH. Adding data from the EDOUH and the DNHR, we identified a total of 329 surgery registrations for cholesteatoma after admission to the OUH (264 patients).

Among the 329 operations recorded in the EDOUH, the DNHR or both, the surgical charts could be retrieved

for 322 (264 patients). The diagnosis was verified in 277 operations of which 242 were registered in both the DNHR and the EDOUH, 11 only in the DNHR and 24 only in the EDOUH. Using the capture-recapture method, we calculated an estimated number of missing registrations in both registries of 1.1 (rounded to 1). This gave an estimated true number of cholesteatoma operations of 278. As the number of confirmed registrations of cholesteatoma combined with relevant surgery registered in DNHR was 253, the estimated degree of completeness of the DNHR was 91.0% (95% CI 87.0-94.1).

By only including the first time patients had a cholesteatoma diagnosis combined with relevant surgery, the surgical charts could be retrieved for 275 operations recorded in the DNHR, the EDOUH or both. The diagnosis was verified in 240 operations of which 203 were registered in both the DNHR and the EDOUH, while 13 were found in the DNHR only and 24 were only found in the EDOUH. Using the capture-recapture method, we found an estimated number of missing registrations in both registries of 1.5 (rounded to 2). This gave an estimated true number of cholesteatoma operations of 242. As the number of confirmed registrations of cholesteatoma combined with relevant surgery registered in the DNHR was 216, the estimated degree of completeness of the DNHR was 89.3% (95% CI 84.7-92.9).

#### DISCUSSION

The PPV of the cholesteatoma diagnosis in the DNHR combined with relevant surgery was 85.8% and the degree of completeness was 91.0%. When only the first time patients were recorded with a cholesteatoma combined with surgery was included, the PPV was 89.3% and the degree of completeness 89.3%. The majority of false positive cases had previously been surgically treated for cholesteatoma. The PPV for the surgical codes was 98.1%.

To our knowledge, no studies have previously been performed to validate otological diagnoses or surgical procedures in national registers. The PPV of the epilepsy diagnosis in the DNHR was estimated to 81% [14]. The validity and degree of completeness of the stroke diagnosis in the Finnish Hospital Discharge Register have been estimated to 86% and 85%, respectively [15]. As regards the PPV of surgical codes, hysterectomy had a PPV of 99.8% in the DNHR [16].

A possible limitation of this study is that validation was only performed for surgery performed on Funen. However, the population of Funen represents almost ten percent of the Danish population [17] and is generally considered demographically representative of the entire country. Furthermore, we have no reason to believe that diagnostic or surgical coding was performed differently on Funen than in the rest of the country. We

therefore consider the applied sample to be representative. For the estimation of the completeness by the capture-recapture method, only data from the OUH during the period 1996-2007 were applied. However, we consider the sample to be representative.

The Danish population has equal access to health-care. Healthcare costs are covered by the National Health Service, which is financed through taxation; hence, nearly complete registration of somatic hospital events is achieved [18].

As the vast majority of patients with cholesteatoma undergo surgery and most often do so relatively soon after having been diagnosed, we believe that an acceptable estimation of the incidence of cholesteatoma can be obtained by combining the diagnosis with a relevant surgical procedure. About half of the cases admitted to an ENT department but never registered with relevant surgery did not have cholesteatoma according to a review of their medical charts. Kemppainen et al found that among 500 cholesteatoma patients, 478 received surgery [7], equalling 95.6%. The mean waiting period before operation was six months [7]. We thus conclude that the first occurrence of the cholesteatoma diagnosis combined with relevant surgery in the DNHR may be used as an estimated surrogate for the diagnosis of cholesteatoma.

We carefully validated the cholesteatoma diagnosis in the DNHR by reviewing the surgical charts. We found the PPV and the degree of completeness of the DNHR to be within an acceptable range. The misclassification of the first cholesteatoma diagnosis in the DNHR combined with relevant surgery was close to 10%. Hence, we conclude that the DNHR can be used as a valuable tool for epidemiological research on cholesteatoma.

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**CONFLICTS OF INTEREST:** None

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