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ORIGINAL ARTICLE

Is it feasible to merge data from national shoulder registries? A new collaboration within the Nordic Arthroplasty Register Association

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Background: The Nordic Arthroplasty Register Association was initiated in 2007, and several papers about hip and knee arthroplasty have been published. Inspired by this, we aimed to examine the feasibility of merging data from the Nordic national shoulder arthroplasty registries by defining a common minimal data set.

Methods: A group of surgeons met in 2014 to discuss the feasibility of merging data from the national shoulder registries in Denmark, Norway, and Sweden. Differences in organization, definitions, variables, and outcome measures were discussed. A common minimal data set was defined as a set of variables containing only data that all registries could deliver and where consensus according to definition of the variables could be made.

Results: We agreed on a data set containing patient-related data (age, gender, and diagnosis), operative data (date, arthroplasty type and brand), and data in case of revision (date, reason for revision, and new arthroplasty brand). From 2004 to 2013, there were 19,857 primary arthroplasties reported. The most common indications were osteoarthritis (35%) and acute fracture (34%). The number of arthroplasties and especially the number of arthroplasties for osteoarthritis have increased in the study period. The most common arthroplasty type was total shoulder arthroplasty (34%) for osteoarthritis and stemmed hemiarthroplasty (90%) for acute fractures.

Conclusion: We were able to merge data from the Nordic national registries into 1 common data set; however, the set of details was reduced. We found considerable differences between the 3 countries regarding incidence of shoulder arthroplasty, age, diagnoses, and choice of arthroplasty type and brand.

Level of evidence: Epidemiology Study; Large Database Analysis

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Keywords: Registry; shoulder; arthroplasty; collaboration; epidemiology; incidence

Ethical Committee approval: not required.

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New arthroplasty types can be released onto the market without any evidence of clinical efficacy and safety. The main advantage of arthroplasty registries is postmarketing surveillance as demonstrated by national hip and knee arthroplasty registries in Norway and Sweden.^{3,6,7,15} From an international perspective, however, the number of inhabitants in the Nordic countries is small, with <10 million people in each country (Denmark, Finland, Norway, and Sweden). Recognizing this limitation, the Nordic Arthroplasty Register Association was initiated in 2007, and several papers about hip and knee arthroplasty have been published since then.^{8,9,14,19,24}

National shoulder arthroplasty registries were established in Finland,¹⁸ Norway,⁵ Sweden,²¹ and Denmark²² between 1980 and 2004. So far, a few publications regarding revision rates have been published by the registries. However, because of the relatively small number of cases, statistically significant differences between arthroplasty types could not be detected.^{4,23} To report revision rates and especially to examine differences between arthroplasty types, collaboration between the national shoulder arthroplasty registries is needed. There is today no international standard available for terminology and definition of diagnosis, arthroplasty type, or reasons for revision. This may limit the possibility not only of merging data but also of comparing results.

The aim was to examine the feasibility of merging data from the Nordic national shoulder registries by defining a common minimal data set, to report demographic data, and with the reverse shoulder arthroplasty as an example, to demonstrate the advantage of merging data.

Materials and methods

A group of orthopedic surgeons with a special interest in shoulder surgery met in March 2014 to discuss the feasibility of merging data from the Nordic national shoulder arthroplasty registries. Differences in organization, definitions, variables, and outcome measures were discussed. A common minimal data set was defined as a set of variables containing only data that all participating registries could deliver and where consensus regarding definition of the variables and related values could be made. Because the Danish register was established with the Swedish register as a model, the data sets in Denmark and Sweden were compatible. The Norwegian data set, however, is based on a common joint replacement form and is somewhat different from the Danish and the Swedish registries and not as rich in details. So, to establish the common data set, some variables and related values were transformed to fit the common data set.

In all the Nordic countries and consequently in the national registries, each patient is identified by a unique civil registration number given at birth. Transformation of national data, including deletion of the civil registration number and the day of birth, was performed within the national regis-

tries. Instead, a serial number and a code for nationality were given to each patient. Anonymous data were then merged into one common data set without the possibility of identifying patients at an individual level. Thus, data were treated with full confidentiality according to the standards of the data protection agencies in the individual countries.

The Finnish register was unable to deliver data for the present study because of incomplete format and inadequate maintenance of the registry. The national registries in Denmark, Norway, and Sweden were able to deliver data on primary shoulder arthroplasty from 2004 to 2013. Revision procedures, defined as removal or exchange of any component or the addition of a glenoid component, were linked to the primary operation using the civil registration number.

Two annual meetings with a minimum of 2 participants from each registry were planned. Authorship is first and foremost based on the recommendation developed by the International Committee of Medical Journal Editors. We anticipate that at least 1 participant from each country will qualify by acquisition of data. An additional participant from each country will often qualify by contribution to the conception of study and by interpretation of data, leaving each country with 2 authorships.

Descriptive statistics were used to report demographic data for the individual registries and for the common data set. Differences in demographic data between countries were compared using χ^2 test for categorical variables and analysis of variance for continuous variables. The Kaplan-Meier method was used to illustrate the unadjusted cumulative revision rate. A Cox regression model was used to calculate hazard ratios as a measure of the relative risk of revision. The statistical analyses were performed using SPSS version 19.0 (IBM Corp, Armonk, NY, USA). The level of statistical significance was set at $P < .05$, and all P values were 2 tailed.

Results

We agreed on a data set containing patient-related data (age, gender, and diagnosis), operative data (date, arthroplasty type and brand), and data in case of revision (date, reason for revision, and new arthroplasty brand) (Table I). The variables gender, age, date of surgery, side, and arthroplasty brand were easily defined. Other variables, especially diagnosis, arthroplasty type, and reason for revision, were inconsistently defined and not fully compatible. In these cases, we redefined and transformed data from the individual registries (Tables II to IV). For instance, the variable “fracture sequelae” exists only in the Norwegian register; but by defining “fracture sequelae” as fractures reported as nonunion, malunion, with previous osteosynthesis, or together with osteoarthritis or humeral head necrosis, we were able to extract data from the registries in Denmark and Sweden. If more than 1 diagnosis or reason for revision had been reported to the individual registries, we used a hierarchy of diagnosis and a hierarchy of reason for revision, respectively, so that only 1 diagnosis

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