FEASIBILITY OF EVALUATING THE BURDEN OF \( \beta \)-THALASSEMIA WITH GERMAN CLAIMS DATA

Kathrin Borchert\(^1\), Kim-Sarah Krinke\(^1\), Clark Paramore\(^2\), Ulrike Sager\(^2\), Michaela C Haeger\(^3\), Wolfgang Greiner\(^4\), Sebastian Braun\(^1\)

\(^1\) Xonnda GmbH, Hanover, Germany
\(^2\) bluebird bio Inc., Cambridge, USA
\(^3\) University of Bielefeld, Bielefeld, Germany

Poster number: PSY33

BACKGROUND

\( \beta \)-thalassemia is an inherited genetic disease characterized by reduced or absent production of functional \( \beta \)-globin, resulting in an impaired development and survival of red blood cells (RBCs) and leading to chronic anemia and other serious complications.\(^5\)

• Patients with severe \( \beta \)-thalassemia require regular blood transfusions and treatment for iron overload to survive while patients with minor forms may not experience any symptoms.\(^6\)

• The incidence and prevalence of \( \beta \)-thalassemia differs according to geographic location, with endemic populations primarily found in South Asia, the Middle East, North Africa, and Southern Europe.\(^6\)

• While migration is spreading the global distribution of the disease, in most European countries as well as the United States \( \beta \)-thalassemia is still a rare disease.\(^7\)

• The prevalence of \( \beta \)-thalassemia in Germany and its burden to patients and the German healthcare system has not yet been systematically assessed.

OBJECTIVE

The aim of the study was to assess the prevalence of \( \beta \)-thalassemia in Germany and to evaluate its burden to patients and the healthcare system.

METHODS

• A retrospective claims database analysis was conducted using the “Institut für angewandte Gesundheitsforschung Berlin” (IAGfB) research database.

• The database comprises anonymized healthcare claims of about 4 million covered lives insured in the Statistisches Bundesamt (10% of the German Health Insurance (SHI) in Germany).

• This sample represents about 4.8% of the German population and 5.6% of the German SHI population and is stratified to represent the population in terms of age and gender.

• The IAGfB research database was proven to have good external validity to the German population in terms of morbidity, mortality, and drug use.\(^4\)

• Prevalent \( \beta \)-thalassemia patients within the database were identified retrospectively between January 1, 2015 and December 31, 2015 using the International Statistical Classification of Diseases and Related Health Problems, 10th revision, German Modification (ICD-10-GM) code D56.1 “\( \beta \)-Thalassemia” in the outpatient sector (visited diagnosis) or in the inpatient sector (primary or secondary diagnosis).

• Individuals who died in the study timeframe were not excluded from the analysis.

• The proportion of prevalent \( \beta \)-thalassemia patients receiving blood transfusions was determined by Operation and Procedure Codes (OPC) for blood transfusions in the inpatient setting and Pharmacological Registration Numbers (PRN) for blood products in the outpatient setting, namely erythrocyte concentrate and whole blood. Categories of the number of received blood transfusions were pre-defined as “0 blood transfusion”, “1-12 transfusions”, and “≥13 blood transfusions”.

• Study outcomes of interest were the prevalence of \( \beta \)-thalassemia as well as demographic characteristics, member status and reduction in earning capacity, and mortality of identified \( \beta \)-thalassemia patients in 2015. Demographics were determined in terms of age and gender; age was calculated based on the year of birth. The member status of the healthcare insurance was stratified by family insurance, pensioner, full member, and unknown status. Pensioners were further analyzed in terms of age (≤45 and >45 years) and whether they were retired due to reduced ability to work.

• Furthermore, the most frequent comorbidities based on ICD-10-GM code groups on a 3-digit level, relevant disease-related complications, and the number of received RBC transfusions were assessed for the year 2015.

RESULTS

• A total of 623 \( \beta \)-thalassemia patients were identified in the IAGfB database in 2015.

• The mean age of the patients was 42 years, spanning from 1 to 88 years and 53.0% of the identified \( \beta \)-thalassemia patients were female.

• The two most frequently coded comorbidities of \( \beta \)-thalassemia patients in 2015 were ICD-10-GM code group B20-B29 “Factors influencing health status and leading to use of health services” including examination and clarification, followed by the group M00-M48 “Diseases of the musculoskeletal system and connective tissue”.

• Moreover, a noticeable amount of \( \beta \)-thalassemia patients (33.3%) had diagnoses of mental and behavioral disorders (F00-F99) in 2015 (see Figure 2).

• The most common disease-specific complications were observed to be diabetes mellitus and heart failure in 17.7% and 5.3% of patients, respectively.

CONCLUSIONS

• Of all \( \beta \)-thalassemia patients, about 44.5% were full members of the SHI, 32.1% were family insured, and 22.8% were pensioners. In the subgroup of \( \beta \)-thalassemia patients with transfusions, most of the patients were pensioners (48.3%) and only 28.1% were full members and family insured, respectively.

• Reduction in earning capacity was observed in 13.4% of all pensioners with \( \beta \)-thalassemia compared to 35.7% of persons who received ≥11 blood transfusion (see Figure 4).

• The mortality rate in 2015 was notably higher in the group of transfused \( \beta \)-thalassemia patients compared to all \( \beta \)-thalassemia patients (18.8% vs. 1.6%).

• A large proportion of the German population in 2015, about 13,205 patients (95% CI 12,188-14,283) suffered from \( \beta \)-thalassemia and about 678 patients received blood transfusions (95% CI 464-952). This corresponds to a ratio of 16/100,000 persons with \( \beta \)-thalassemia and 0.8/100,000 persons with \( \beta \)-thalassemia on transfusions in Germany (see Figure 5).

DISCLOSURE

• The analysis was done by Xonnda and supported by bluebird bio inc.

REFERENCES


Figure 1: Study period and study outcomes

Figure 2: Comorbidities of \( \beta \)-thalassemia patients

Figure 3: Blood transfusions in \( \beta \)-thalassemia patients in 2015

Figure 4: Members status, early retirement and reduction in earning capacity (REC) of \( \beta \)-thalassemia patients in 2015

Figure 5: Extrapolation of identified \( \beta \)-thalassemia patients to the German population in 2015

* Due to data protection regulations, the proportion of pensioners ≥65 years could not be reported for the group of \( \beta \)-thalassemia patients with ≥11 blood transfusions in 2015.