The Swedish Retinal Detachment Register

I. A database for epidemiological and clinical studies

Abstract • Purpose: To create a computer-based national register for epidemiological and clinical studies on retinal detachment (RD) for large populations over time.

• Methods: A database system was developed for Microsoft Windows 95 and NT platforms to support a multi-user environment, comprising 117 fields (270 parameters). The system is equipped with statistical search programs for statistical differences and dependencies between fields and with graphical display.

• Results: Information is structured into six subgroups: identification of patient, history of RD, preoperative ocular status, operations, recurrence, and follow-up. Lists of diagnoses, methods and surgical procedures facilitate data input. The drop-out frequency ("null") and follow-up recording are automatically monitored. Mean visual acuity is calculated using logMAR units. Data from the first 1116 patients yield a high RD incidence of 14 per 100000 inhabitants in an urban area. Mean age at surgery for women was 62.9 years (95% confidence interval 61.54–64.35) and for men 58.3 years (95% confidence interval 57.12–59.42). Myopia was more common before the age of 50 (mean −4.16 D, 95% confidence interval −5.00 to −3.32) than at higher age (mean −0.84 D, 95% confidence interval −1.19 to −0.49). Cataract surgery had previously been performed in 30.8% of the eyes and preoperative macular detachment was present in 52.3%.

• Conclusion: This database register is a useful and powerful tool for population-based studies on epidemiological and clinical parameters of RD. Detailed analyses of retinal reattachment surgery in relation to preoperative findings can be performed in large case materials.

Introduction

Rhegmatogenous retinal detachment (RD) exhibits a large variety of pathological changes with different degrees of severity and duration in populations of increasing age. Differences in case mix between regions and institutions may be considerable. Retinal reattachment surgery can be and is being performed using several methods, such as pneumatic retinopexy, scleral buckling, and vitreous microsurgery, carried out separately or in combination with various techniques.

Quality registers as a basis for the development and improvement in health care [7] have been used in several medical specialties, such as coronary disease [5, 6], hip arthroplasty [2], cataract surgery [8], and many other areas. A national register for RD was proposed by the National Board of Health and Welfare in Sweden. The registry is based on voluntary cooperation by clinics and hospitals in the country and is aimed at epidemiological and clinical studies on RD. Data are collected prospectively, and confidentiality is assured for patients and individual surgeons; only aggregated information is provided to participating institutions.
In order to evaluate the outcome in relation to given prerequisites for population-based cohorts of patients, modern computer techniques represent the appropriate tool for collecting and processing data. However, it is a cumbersome process to develop professional software for a special medical domain such as RD. A considerable problem is that computer engineers do not have the medical knowledge. In addition, most retinal surgeons know little about software development and are not sufficiently aware that information has to be extremely well and accurately structured in computer science.

This paper describes the structure of the software upon which the Swedish national RD register is based and which is currently in use at 12 eye clinics. In addition, we present some epidemiological and clinical preoperative data for the first 1116 cases.

Methods

The creation of this computer-based register and its use for RD studies was approved by the Data Inspection Board of Sweden and was in accordance with the 1964 Declaration of Helsinki. The medical data are handled according to Swedish laws and regulations, and details that might disclose the identity of the subjects are omitted.

In 1995, our first database system for RD was developed in collaboration with vitreoretinal surgeons and computer engineers. Since then the system has been continuously refined, improved and extended (AmotioBase 4; Multisoft Consulting, Stockholm, Sweden). The functionality of the AmotioBase system is displayed on the Internet (www.MultisoftConsulting.com). The system is developed for Microsoft Windows 95 and NT platforms and supports network possibilities. This offers a multi-user environment since the system can be equipped with several work stations. The information is stored as a relational database in the industrial Borland Paradox format. The system comprises 117 fields, including 270 parameters.

Calculation of average visual acuity

For calculating average visual acuity, the program automatically converts the numerical values of visual acuity measurements to logMAR (minimum angle of resolution) units. Calculation is performed in logMAR units and the result, again, automatically converted to visual acuity values. Low visual acuites, such as hand motion, are stored in digital form and also included in the logMAR calculation.

Statistics

All parameters in the database can be used for statistical analysis. The statistical package can handle calculations in an easy-to-use way. The package contains cross questions, diagrams, significant differences, and dependencies between fields. The cross question, for instance, displays counts, averages, medians, maximums, minimums and standard deviations. In addition, the confidence interval of the average of a field is calculated. By combining two database fields, for example ‘preoperative duration of retinal detachment’ and ‘follow-up visual acuity’, all statistical information is shown in two dimensions.

To compare different statistical groups, the system is to search for significant differences between groups by comparing two statistical groups for differences in fields. The system answers ‘yes’ or ‘no’ at different degrees of confidence ($P=0.10$, $P=0.05$, $P=0.01$). The user can specify the search conditions, the search combinations comprising all parameters stored in the database. This is performed by dragging-and-drop with the mouse.

To make the system more powerful and flexible, it supports exporting functions. Raw data can be exported for calculation to other statistical programs.

Dependencies between fields

A dependency inspector is included in the system. This is a rewarding way to examine statistical material. The system will automatically search for dependencies between fields within a statistical group. Dependency tests are performed on every pair of fields. This offers the possibility of more than 5000 tests, which are calculated using the unpaired $t$-test, regression confidence interval and the binomial distribution. A description of every dependency hit is automatically and separately displayed on the monitor, provided that a confidence interval of 95% is achieved. With one mouse click a diagram of the corresponding field is created. An example of such a dependency is shown in Fig. 4.

Graphics

Results can be tabulated, transformed into several types of diagrams, and displayed as graphs in a variety of layouts. The graphical unit delivers bar diagrams with and without subpiles and point diagrams. There are manifold fonts, colors and other entities available for producing graphical layout. The cross question function also supports a dividing system, which automatically divides a certain field into subgroups, for example, age at surgery 10–20 years, 20–30 years, etc.

Data storage

Information is fed into the database by filling in ready-made fields that are shown on the monitor screen. According to the standard of Windows 95, the tabulator moves from one field to the next so that all fields are filled in consecutively and in a logical order. The user indicates ‘yes’ or ‘no’ or ‘information lacking’ by clicking the mouse or the space bar. When several possibilities exist, a table is displayed and the relevant item(s) can be selected by clicking the mouse.

There are two ways to register information. The user (the surgeon) can fill in a paper form, the data from which can later be fed into the computer, or the doctor feeds data directly into the database at the nearest workstation in the hospital department. In spite of the large amount of fields delivered, some departments may want to use hospital-specific fields. It is possible to add new fields and to attach free text in each subgroup. The database can be used as the patient’s hospital record for RD (computerized record).

Results

Structure of the database

A committee of vitreoretinal surgeons agreed to limit the clinical information to the most essential data, which nevertheless comprise more than 110 fields with a total 270 parameters. In order to facilitate the handling of clinical information, the system structures the data fields into