

The Danish Amputation Register 1972-1984

B. EBSKOV

Department of Orthopaedic Surgery T, University Hospital, Herlev, Denmark

Abstract

The DAR was established in 1972 for the purpose of collecting data on major upper and lower extremity amputations as well as details on corresponding prosthetic fitting in Denmark. During phase 1 (1972-1980) voluntary reports were submitted by surgical departments and prosthetic manufacturers, totalling about 5000. During phase 2 (1978-1984) data on all amputations in Denmark were supplied on a yearly basis by the National Patient Register, a division of the National Health Board. The information collected during phase 1 is rather detailed, but does not represent the entire national output. The phase 2 data are less detailed, but yield full national coverage. The information is compatible as to distribution of age, sex and etiology. The methods and present status of dataprocessing are described and the planning for the foreseeable future is outlined.

Introduction

Despite the centralized character of Danish government and a long tradition of medical statistics, no details were available in the early seventies on the number and types of amputations performed, nor on the size and composition of the amputee population. For many years the delivery of prostheses for amputees was recorded centrally, but unfortunately this work was abolished in 1970, and for reasons unknown the accumulated records were maculated. The situation was no better in other countries, in fact one of the best documented studies at that time was that of Hansson (1964) on the amputee population of Gothenburg City, Sweden. This work, like all other available studies built on small or modestly sized groups is more often than not unrepresentative and biased. Small wonder then, that information on standard parameters

like types of amputation, etiology, complications, reamputation and contralateral amputation as well as mortality varied to a degree that rendered it impossible to obtain a valid picture of the quantitatively and qualitatively serious problems of amputation.

Consequently the Danish Amputation Register (DAR) was founded in 1972 in order to

1. Permit analysis of etiological factors, operative details, incidence and type of complications and reamputation, per- and postoperative death, duration of hospitalization, degree of mobility on discharge and certain basic social information.
2. Facilitate the selection of well-defined groups of amputees for the purpose of in-depth analysis.
3. Generate statistics on the number and type of prostheses delivered (initially and later) and to analyse technical aspects relative to the prostheses.
4. Permit trend analysis for prognostication of future needs in personnel, facilities and economy.

The present work is a report on the activities of the DAR from 1972 through 1984.

The administrative infrastructure

By 1972 the Danish population numbered about 5 million. Since the mid-sixties all Danes were given a 10-digit "person number", composed of birth data plus four check-digits, the last representing sex. The system was monitored by the Central Person Register (CPR), which also recorded all births and deaths continuously. The entire hospital system was publicly owned and run and every hospital and department had a numeric code. In the individual hospitals diagnoses were recorded according to the International Classification of Diseases (ICD- nr.).

Since 1972 operations were coded locally according to a nationally adopted classification system. There was *no* central recording. All counties and townships were systematically

All correspondence to be addressed to Dr. B. Ebskov, Danish Amputation Register, Department of Orthopaedic Surgery T, University Hospital Herlev DK 2730, Herlev, Denmark

numbered. The CPR was accessible to professionals with a legitimate (e.g. scientific) interest in the information contained. The other code systems mentioned were publicly available upon request.

Method — phase 1

Because no centralized patient recording existed in 1972, a set of standard reports was designed, i.e. 1 - Hospital Report, 2 and 3 - Prosthetist's Reports on respectively, upper and lower extremity prostheses delivered. Each report was one sheet (quarto) which could be folded to constitute a letter, postage prepaid.

Hospital Reports

By early 1973 an appeal detailing the purpose and set-up of the DAR was issued to all Danish surgical and orthopaedic departments, as well as to all prosthesis establishments. Also all departments received sets of reporting forms with accompanying step-by-step instructions for filling in the forms.

The hospital reports (type 1) contain information on the individual patient's personal data; the hospital and department where the amputation was performed; the dates of admission, discharge and disposal (home, nursing home etc); further information on previous amputation(s), including when and where; as well as details on the actual amputation such as etiology, method of operation, the limbs involved, complications, eventual revisions or reamputation during the same admission; plus details on the state of mobilization on discharge. In-patient death and its cause was also recorded. The reporting being voluntary, nationwide coverage was not possible during the period from 1973 to 1980 when the collection of this type of data was terminated. However, approximately 70 per cent of all operating hospital departments were involved in reporting for shorter or longer periods. In most departments the recording was handled by senior residents, who received a small remuneration for the services rendered. Upon receipt in the DAR the reports were validated for completeness and, as far as possible, for coherence. Immediately upon the foundation of the DAR, concomitantly with the design and printing of the reporting forms, work was initiated on a data-processing system, based upon the OSIRIS data-base management system

for mainframes. The data were transferred to magnetic tape via punch cards. The tape was then encoded in compliance with the exigencies of law. The data processing was carried out on the Northern Europe University Computing Centre (NEUCC) in Copenhagen.

During the project period a total of more than 5000 reports were processed in this way. A number of preliminary computations were carried out for ad hoc reporting and presentations. Moreover the long term mortality was established in comparison with the general population in the CPR. A preliminary report on the occurrence of ipsilateral reamputation, contralateral amputation and death was published earlier (Ebskov & Josephsen, 1980).

Prosthetist's reports

Until 1972 almost all upper and lower extremity prostheses in Denmark were manufactured in the workshops of "The Home and Society for Crippled Children" (SAHVA). Due to certain political complications the reporting did not get well under way until 1974, but thereafter functioned very satisfactorily for all but one establishment.

The prosthetists' reports (types 2 and 3) contain information on the individual patient's personal data, previous amputation(s) and general hospital information identical with the hospital reports, and, in addition, the prosthetist's code + number, details on time of stump measurements, delivery of the prosthesis at the fitting stage, the outcome of the ensuing training, adjustments and the final result. Finally the technical details regarding type of prosthesis and the components used in the production were recorded. Besides information on the lower extremity prosthesis supplied (type 2), information on the eventual postoperative immediate fitting, and other aids to mobilization employed prior to the delivery of the definitive prosthesis was recorded.

During the period up to 1980 a total of more than 5000 reports were received and processed.

Method — phase 2

As already mentioned, the DAR never succeeded in obtaining national coverage on a voluntary basis. In 1976 the Danish National Health Board established the National Patient Register (LPR), and decreed a duty for all hospitals, other than mental hospitals, to submit

certain standardized information on all patients admitted. After a slow start the LPR was productive by 1978. As is the case with the CPR, persons and organizations with a documented legitimate scientific interest may obtain access to the information contained in the LPR. The DAR has had such access since 1978 and has subsequently received an annual report on all patients amputated during the preceding year. Whereas the individual patient records correspond to those of the DAR system in a number of respects, they lack information with regard to the side involved as well as finer details of the operative procedures and any complications.

By 1980 it was evident that the mainframe-based data analysis was too rigidly schematic to profitably utilize the increasing wealth of information contained in the DAR. Further, because of the complexity of the OSIRIS software we were depending upon expensive programmer's assistance.

Consequently a study was undertaken of the feasibility of using microcomputers for future analysis. By December 1981 the DAR acquired the first Apple microcomputer with the presently best available analytical tools. It soon became evident that whereas the principle was right, the realization was far too cumbersome to be realistic in the long run. Consequently by 1983 the Apple was replaced by an IBM PC/XT. This tool has proved fully satisfactory for handling the LPR data with a combination of compatible software packages (Infostar, Lotus 123 and Wordstar). In fact it has been possible upon short notice to process random segments of the data base for the purpose of specific presentations with a minimal consumption of time. Because of the very large amount of data now present, it has been necessary to establish connection to the hospital mainframe which is used for storage.

Until now it has not been possible to co-analyse corresponding pairs of hospital and prosthetist's records on the same individual. Very recently the advent of a sophisticated data base management tool (R-base 4000) has eliminated this obstacle to utilizing the hitherto inaccessible information contained in the phase 1 records.

Discussion

The data collected during the two phases

complement each other. The sets are compatible inasmuch as a comparison demonstrates equal distribution as to age, sex and etiology.

The phase 1 data permit a detailed analysis of reamputation and mortality. One such study, based on part of the entire material, was previously published (Ebskov, 1980). Further, these data are accessible to very detailed analysis of the relationships between age, sex, etiology, surgical procedure, complications, mortality and type of department where the amputation was performed. The relationships between these parameters and the types of prostheses fitted, the duration of training with the prosthesis and the incidence of failure is also accessible.

The phase 2 data permit an analysis of the nationwide picture. A preliminary study has been published (Ebskov, 1983). At present inexplicable geographical differences have been isolated, and are now being subjected to further study. Because of the yearly reporting from the LPR, trend analyses as well as a reasonable approximation of the total amputee population is possible, and at the planning stage.

Conclusion

It may be argued that the information contained in the DAR should have been continuously published. However the author feels that the proper basis for valid reporting has not been established until now.

At present recruiting of interested colleagues is under way for a coordinated utilization of the DAR for the purpose of establishing "the natural history of amputation in Denmark".

Acknowledgements

The activities of the Danish Amputation Register were continuously supported by the Krista og Viggo Petersen Foundation. The author is deeply indebted to the curators for constant understanding, patience and faith.

REFERENCES

- EBSKOV, B. (1977). Fruhergebnisse des Danischen Amputationregisters. *Orthopad. Prak.* **13**,430-433.
- EBSKOV, B. (1983). Choice of level in lower extremity amputation — nationwide survey. *Prosthet. Orthot. Int.* **7**, 58-60.
- EBSKOV, B. JOSEPHSEN, P. (1980). Incidence of reamputation and death after gangrene of the lower extremity. *Prosthet. Orthot. Int.* **4**, 77-80.
- HANSSON, J. (1964). The leg amputee: a clinical follow-up study *Acta. Orthop. Scand (suppl. 69)*, 1-104.