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Development of the National Registration RIKSHÖFT

In Sweden there has been developed registers for conditions which have large socio-economic importance both concerning high number of patients as well as a great need for use of resources. The first national registers were created within the area of orthopaedics initiated by Professor Göran Bauer in Lund. He started the Swedish Knee Arthroplasty Register 1975 and then the Swedish Hip Arthroplasty Register was started 1979. In the beginning it registered only reoperations and from 1992 onwards also person linked information about primary hip arthroplasties was collected. The Swedish National Hip Fracture Registry called RIKSHÖFT [1] was started by the author in 1988. The arthroplasty registers deal with information concerning a procedure whereas the hip fracture register in addition to the fracture type and type of operation also deals with information about the patient, function and social conditions, making it a disease register. Based on the experience of the orthopaedic registers successively more registers have been introduced within other medical fields. Swedvasc, the registry for peripheral vascular surgery, was started 1987 as the first non-orthopaedic register. During the 1990s several registers have been started such as Riks-Stroke, the national quality register for stroke, which was started in 1994. Other examples of registers are the Swedish coronary angiography and angioplasty register as well as the registry on cardiac intensive care, RIKS-HIA.

During the last decade the national quality registers have after application received grants yearly from the Swedish National Board of Health and Welfare together with the Swedish Association of Local Authorities and Regions. The latter has taken over the central administration of the quality registers since 1 January 2007. All applications are evaluated by a Scientific Advisory Committee to guide the decisions of the Executive Committee composed by representatives from the Swedish Association of Local Authorities and Regions, the National Board of Health and Welfare, the Swedish Society of Medicine and the Swedish Society of Nursing. In 2008 in total 64 national quality registers received economic support in this way. There are also 18 different national cancer registers usually supported by grants from the Swedish cancer foundation. Areas with more rare diseases and smaller volumes to register are usually covered by research registers supported by specific research grants. These often have higher level of details in the registration with many parameters. To continuously register disease groups on a national level or to register procedures with large patient volumes, demands a small amount of well chosen parameters, so the registration can be complete.

One particular factor that facilitates registration in Sweden is the system with national personal identification numbers, which makes it possible to trace patients through the medical system from birth to death. Supported by law the Epidemiological Centre at the National Board of Health and Welfare has registers for statistical use such as the patient register for all in hospital care with diagnoses and operative procedures according to ICD 10, the medical birth register, the cancer register and the pharmaceutical register. They are also responsible for the register concerning dates and causes of death. Since 2006 the Swedish Association of Local Authorities and Regions is publishing a yearly report with open comparisons at regional or hospital level of some key factors from the National Quality Registers.

The National Quality Registers have been created by the medical profession which continues to handle the development and analyses of the registers. Within the sector of health care administration there has been a development of systems to follow the activity from economical and personnel administrative aspects. They have not developed registration systems concerning the work with the patients. The traditional patient filing systems have not made it possible

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Hip Fracture Demographics

The treatment of elderly patients with orthopaedic problems is dominated by the demand both from the elderly and from the society that they should be able to live an independent, mobile and pain free life [2–5]. In Sweden at the age of 50 years the risk to sustain a hip fracture is 23% for women and 11% for men during the remaining life time. Hip fracture belongs to the most resource consuming groups within health care. All these patients need operation and hospital treatment. They consume 25% of all bed days in hospital for orthopaedic diseases. Due to the increasing amount of elderly in the population the amount of hip fractures is increasing. At present the hip fracture care in Sweden costs 1.5 billions Swedish Crowns yearly. The RIKSHÖFT aims at optimising all aspects of patient treatment. The aim is to create a high and evenly distributed quality of care all over the country. RIKSHÖFT is also a basis for local development projects. Also the reorganisations after administrative decisions with changed patient flow between hospitals and cities find through RIKSHÖFT a form to be evaluated. The awareness of results leads to improved treatment and more effective cost utilisation.

During 1995–1998 RIKSHÖFT was spread in Europe with a project supported by grants from the European Commission. This registration was called SAHFE (standardised audit of hip fractures in Europe) [6]. Also other international registration has started [7–9].

National Data 2007

Hip fractures are predominant in elderly persons due to increasing osteoporosis and falling tendency by age. A hip fracture below 50 years of age is unusual (less than 3% of the total in RIKSHÖFT) and usually caused by severe trauma, like traffic accidents or fall from heights. The elderly person is usually falling on the floor when walking or raising from a chair. In the figures below therefore only patients of age 50 years and above are included. Osteoporosis is very common among the elderly patients. The small number of patients with other pathological change of the skeleton, e.g. metastatic fractures, have been excluded in the analysis. In 2007 in Sweden the patients consisted of 70% women and 30% men. Mean age which in the middle of 1990s was 81 years has now risen to 83 years. Half (48%) of the patients are living alone. There is a slight tendency to diminished living alone since 1999 (Fig. 1).

Continuing during the 1980s and the beginning of 1990s the mean hospital treatment time in the operating departments has successively decreased. In 1988 the mean hospitalisation time was 19 days for hip fractures in Sweden. Since 1996 it has been around 11 days with only small changes over the years for the mean hospitalisation time whereas the median hospitalisation time has been constant. In 2007 the mean hospitalisation time was 10.7 days and the median hospitalisation time 9 days. The waiting time from admittance to the hospital until performance of the operation was in 2007 mean 1.2 days and median 1 day (Fig. 2).

The lowered mean hospitalisation time during the last years has been possible without lowering the percentage of patients admitted from the acute hospital to their original form of living as they had before the fracture. It has been fairly constant around 50% during the last 10 years. Shortened time in the hospital has previously been related to a greater amount of patients being sent to secondary rehabilitation in some institution instead of primary rehabilitation in the form of living they had before the fracture. Thus, during the last 15 years the hip fracture care in Sweden has been optimised through diminished mean hospitalisation times in the acute hospital combined with a high number of patients possible to return to original place of living (Fig. 3).

This evolution is obvious when separate departments in Sweden are compared. In the diagrams below each dot

![Fig. 1 Mean age, percentage of women and living alone before the hip fracture](image-url)
Fig. 2 Mean and median time in the acute hospital and waiting time (time from admittance to operation)

Fig. 3 Mean time in acute hospital (orthopaedic department) and percentage of patients discharged from there directly to original place of living

represents a hospital. During the years 1988–1990 no hospital had mean hospitalisation time below 10 days and there was a broad range of values up to 27 days (Fig. 4).

In 2007 no department has a mean hospitalisation time over 20 days and the majority had a mean hospitalisation time between 6 and 12 days. One department with an extremely short mean hospitalisation time of 1.2 days combine this by sending 100% of the patients to rehabilitation or other type of institutional care. The policy in Sweden for the departments is to send as many patients as possible to their original place of living with as short hospitalisation time in acute care as possible. Some few hospitals are primarily treating the hip fracture patients directly in a geriatric ward with the orthopaedic surgeon more as a consultant. They have a mean hospitalisation time and percent of patients directly returning home to original living equal to the majority of the orthopaedic departments. In total the comparison of the two periods shows a considerable reduction of the amount of bed days needed to treat the hip fracture patients.

Fig. 4 Relation between mean hospital time (days) and percentage of patients discharged directly to origin

The fracture types have shown a stable pattern during the last years. From the medical point of view this is natural as no sudden changes in the falling tendency or grade of osteoporosis is to be expected among the patients. It also shows that the classification system is reproducible on a large scale with
well defined groups. In 2007 there were registered in Sweden 15% undisplaced cervical hip fractures, 36% displaced cervical, 3% baso-cervical, 24% trochanteric two-fragment fractures, 14% trochanteric multi-fragment fractures and 8% subtrochanteric hip fractures (Fig. 5). The type undisplaced cervical (femoral neck) fractures comprises Garden types I + II. The type displaced cervical hip fractures comprises Garden types III + IV.

Two types of primary operations for cervical (femoral neck) fractures are predominating. One is osteosynthesis with two hook pins or screws. The other is to substitute the proximal end of the femur with an arthroplasty. In Sweden beginning 1999 there has been performed a successively increasing amount of primary hemi/bipolar hip arthroplasties for the displaced cervical fractures. The number of total hip arthroplasties is comparatively constant. For per-trochanteric fractures screw plate is still the most common operation method. A small fraction of intramedullary nails is increasing since the millennium change (Fig. 6).

For all hip fractures comparing 1996–2007 the primary hemi-arthroplasties have increased from 2.1 to 25%. If also the total hip arthroplasties are included the increase of arthroplasties from 1996 to 2007 is from 5.4 to 30%. At the same time the use of two hook pins/screws have diminished from 45.2% in 1996 to 20% in 2007. The use of three screws has ceased. There is a small increase in the number of total hip arthroplasties from 3.3% 1996 to 5% 2007. During the last 4 years the change seems to have levelled off. There is an optimal balance between primary osteosynthesis and primary arthroplasty if consideration is taken to the stress by the operation on the patient and the resource utility at the different types of primary operations as well as the amount of complications and reoperations needed. The future will show when this level has been achieved.

For the undisplaced cervical hip fractures (Garden I–II) osteosynthesis is the predominant primary method in accordance with the good healing prognosis for these fractures. They have no or very little displacement which has given little damage to the blood circulation to the femoral head. The use of arthroplasty 1998 was for these fractures 0.4% hemi-prostheses and this had increased to 8% in 2007. The summarized use of arthroplasty including hemi-prostheses and total hip prostheses was 1.5% in 1998 and had increased to 11% in 2007.

For the displaced cervical hip fractures (Garden III–IV) the use of hemi-prostheses was 3% in 1998 and in 2007 it had increased to 63%. The use of total hip arthroplasty for
the displaced cervical fractures has been fairly constant around 10%. In 2007 it amounted to 13%. The summarized use of hip arthroplasty including hemi- and total was 12% in 1998 and had increased to 76% in 2007 (Fig. 7).

For the trochanteric hip fractures a screw plate is the dominating operation method. In 1998 the trochanteric two-fragment fractures were in 91% operated with a sliding screw and plate and this has slowly diminished to 84% in 2007. The trochanteric multi-fragment fractures were operated with screw plate in 86% of the cases in 1998 and this had diminished to 57% in 2007. Arthroplasty is not the first hand choice for the trochanteric hip fractures unless in some extreme exceptional case. Intramedullarly nails have increased successively since the millennium change. In 2002 for the trochanteric two-fragment fractures they amounted to 3% and for the multi-fragment fractures 15%. In 2007 12% of the two-fragment fractures and 39% of the multi-fragment fractures were operated with a proximal femoral nail.

The baso-cervical fractures constitute a transition form between cervical and trochanteric hip fractures. From the stabilisation aspect they are usually operated with a screw plate. Some times the vascular damage to the femoral head leads to pseudarthrosis or femoral head necrosis which makes them more similar to cervical hip fractures. In 2007 11% of the baso-cervical hip fracture patients were operated with two pins/screws, 68% with a screw plate, 3% with other type of osteosynthesis, 12% with hemi-arthroplasty and 4% with total hip arthroplasty.

Subtrochanteric hip fractures go by definition as far as 5 cm below the minor trochanter. If they go further they are considered a femoral shaft fracture. The sub-trochanteric fractures are often more multi-fragmented and unstable. In 2007 they were operated with a screw plate in 27%, with an intramedullarly nail in 67%, with other osteosynthesis in 2%, hemi-arthroplasty in 1% and with total hip arthroplasty in 1%.

The walking ability for the hip fracture patients shows mainly the same pattern during the last couple of years. More than half of the patients (58%) could before the fracture walk alone outdoors with a slight tendency of increase during recent years. A further 7% could walk outdoors if somebody accompanied them. The rest of the patients could walk indoors except 3% who could not walk at all before the fracture (Fig. 8).

The patient’s general walking ability gives a picture of the stability of the hip and the lack of pain as well as the general condition of the patient. The change in choice of
operations has consequently not in any major way influenced this functional level. There is however a tendency that somewhat more patients can walk alone outdoors at 4 months after the hip fracture with a slight increase from 31% in 1996 to 39% in 2007 (Fig. 9).

To evaluate walking ability the walking aids are commonly used as indicator. Before the fracture there is a trend from 1996 until 2000 that an increasing amount of elderly are using rollator whereas the fraction who did not use any walking aids or only one stick have diminished. To use two sticks or walkers before the hip fracture is unusual. The percentage of patients using a wheelchair or not walking at all before the fracture was unchanged around 5% during this period (Fig. 10).

At 4 months after the operation the use of walking aids for the hip fracture patients when they walk indoors has shown mainly the same pattern during the last years. There is a tendency to increased use of rollators from 2000 which has then levelled off mirroring the prefracture increased use of rollators. At the same time the group with good walking capacity i.e. walking without aids or with only one stick as well as the group who cannot walk at all have diminished somewhat (Fig. 11).
Motivation

It is necessary to build up registers that can be prospectively used over many years and that will facilitate the daily work. Motivating the different departments to participate is of vital importance [10–12]. Motives differ in different places and times. The first major motive is the facilitation of everyday routine medical work. The audit form can be used as a standardised party of the patient’s file, thereby simplifying routines. Less unstructured type-written text and thereby less secretarial work is needed. It is also easier to find the information in the file at a later date, e.g. at outpatient follow up visits. It can also be retrieved by computers.

The second main motive is its usefulness for administrative purposes, e.g. yearly activity reports, to support resource claims in discussions with administrative authorities and to receive funding.

The third motive is scientific. Centrally, the large amount of prospective standardised material provides possibilities for the analysis of the overall panorama of hospitals, diagnoses and modes of treatment. It also provides unique possibilities for studying special rare indications that need the multi-centre approach to collect enough material. Locally, it is possible to use the audit forms as a basis for a study, e.g. comparison between two operation methods, introduction of new types of rehabilitation and so forth. The motivation is especially strong when someone can use the register for his/her thesis work.

Performance

In RIKSHÖFT detailed functional parameters are registered, as this is important in the short-term perspective of these elderly patients. Previous studies have shown that over 80% of the complications needing reoperation occur within 2 years after the hip fracture. The registered hip fracture patients also have a considerable mortality with time due to high mean age and concomitant diseases [13–15].

In Sweden all persons have a social security number e.g. 050315-1649. This person was born as child number 164 in Sweden on the 15th of March 1905. The last digit is a control based on the other digits. Due to this social security number, which is unique to the person, it is possible to trace the patient. The number is generally used for all kinds of identification in Sweden. This is a great advantage when checking data with files from different departments and when patients change their address.

Computing and Feed Back

The use of PC programs and handling of data on desk top computers, were early used by the Swedish Hip Fracture Register RIKSHÖFT which is now using direct on line web registration accessible through its home-page www.rikshoft.se. The possibility for the participating centres to make their own calculations on their data is important. Permits for the registration from the Swedish Data Inspection have been given. Access to the data is limited on several levels of aggregation to protect individual patients.

Feedback to the participants with regular reports containing their own data as well as comparative mean values for the whole country is necessary. The hip fracture register makes a yearly report. To keep the enthusiasm for the project on a high level, regular discussion meetings are required, e.g. in connection with the Swedish Orthopaedic Societies meetings.

Funding

Great amounts of energy and idealism are necessary to start a large-scale registration project. Furthermore, economic resources are necessary to print forms, to communicate with the other centres and to register data on computer, as well as to do calculations and print reports. The Swedish Medical Research Council has funded this project during the initial years. From 1990 the Swedish Government has decided to fund the national registers, which are still to be run at the original centres. It has been decided to be advantageous that the profession itself outlines the guidelines for a register and keeps it running. The goodwill and enthusiasm of the orthopaedic community has been the basis for managing the Swedish audit projects.

References