

Guest editorial

National registration of hip fractures

Based on my experience of having started the first national registration (audit) of hip fracture patient care in Sweden in 1988 (named RIKSHÖFT) (Thorngren 1993, 1995, 1998, Thorngren et al. 1993, 2002, 2005) and of having later broadened the concept to Europe in 1995–98 by initiating and leading the European Commission supported project (BIOMED 2) called Standardised Audit of Hip Fractures in Europe (SAHFE) (Parker et al. 1998), I have been asked to comment on the editorial by Martyn Parker and two articles from the Norwegian Hip Fracture Register in this issue of *Acta Orthopaedica* (Gjertsen et al. 2008a, b, Parker 2008). The latter started in 2005 and is now reporting its early results. Our Norwegian colleagues have achieved something great in starting a national registration of hip fractures. This has had extremely good coverage even from the start, with all hospitals treating hip fractures in the country starting to report during the first year. Now an interesting study based on this registration has appeared—involving questionnaires to patients with displaced femoral neck fractures.

Parker rightly points out the basic prerequisites and problems in performing a successful audit (registration). The possibility of performing national registration does, however, appear to differ between different countries in Europe. Most of the problems have been overcome in Scandinavia, and the solutions may be of some help in starting registers elsewhere. In Sweden, after the start in 1975 with the Knee Arthroplasty Register, followed by the Total Hip Arthroplasty Register in 1979 and the Scandinavian Sarcoma Group Register in 1986, the interest from other disciplines mainly started in the early 1990s—with several registers such as the Swedish Heart Surgery Register in 1992, the Swedish National Cataract Register in 1992, Riksstroke

in 1994, and the registry on Cardiac Intensive Care in 1995. Now Sweden has 56 national registers; after application on an annual basis, they receive financial support from the Swedish Association of Local Authorities and Regions together with the National Board of Health and Welfare. Several other registers are currently trying to obtain financial support.

Knowledge about operative procedures in orthopedics has been acquired in different ways. Usually the inventor of a new operative technique presents his own series, as a consecutive study or sometimes also in a randomized study. Later, others organize multicenter randomized studies or, as in one hospital in Peterborough, one surgeon operates most patients and can have his own consecutive series. All this usually shows the results under optimal conditions (the inventor, the individual surgeon). When national guidelines are written, they are usually based on systematic reviews of randomized investigations, such as the extensive work of the Cochrane collaboration. The randomized investigations are excellent in compensating for many factors, but one drawback is the selection bias that usually exists both concerning choice of patients and predominance of skilled centers. The results from national registers cover everything that is done within a country, even in remote places and also with less trained surgeons. They therefore give a true picture of everyday practice. That is the advantage of national registers as well as the large materials. Furthermore, by including outcome in terms of mobilization and rehabilitation as well as patient satisfaction the efficiency of the whole chain of treatment is shown.

Hospital administrators have long been collecting data regarding organization and costs of medical care, but in terms of clinical outcome there

had been little or no organized collection of data at the hospital or regional levels—or on a national basis—until the Swedish orthopedic registers were started by the medical profession. With the heightened interest in registration, such data have been much in demand over the past few years, and the registries have won the support of county councils. There is now a need to know not only how much medical treatment costs, but also what the quality of the care is. It is widely acknowledged that the registers also are helping to improve medical care by showing what can be obtained with different procedures. Nowadays, the basis of improvement of daily care has become open comparisons between regions and now also between hospitals. For these open comparisons, the data must be calculated and interpreted by the medical profession to avoid misjudgements based on case-mix considerations and incomplete data. There is general agreement that the registers should be run by the medical profession. At the beginning, some examples of poor results from the cataract register were published by the Swedish press because the journalists did not realize the importance of case-mix and random variation. A small hospital with low volumes might seem to have poor figures, even though these data may not be statistically significantly different from average data taken from several hospitals. During recent years, the public and press have come to understand the complexity of these data and there is much less risk of sensation-making on false premises.

In Sweden, our experience after decades of national registration is that the patients are not against the idea of registration. Instead, most of them want to gain some benefit from the registers by knowing the results of different procedures. After receiving such information, a patient seldom refuses registration. In the case of patients with dementia, the relatives or guardians have the same attitude. No written consent is required.

One particular factor that facilitates registration in Scandinavia is the system with national personal identification numbers, which makes it possible to trace patients through the medical system, and also the fact that each city usually has only one hospital. There are national arthroplasty registers also in Norway, Finland, and Denmark. Many Swedish registers are now internet-based, and an authorized

person can gain access to the data using a user-name-password security system.

Parker suggests that in the future, patient administration systems may provide an alternative and easy way of obtaining the information required. This will, however, only be possible when electronic patient filing systems have the capacity to extract data for the purpose of making calculations. As most of Sweden has now gone over to electronic patient filing systems, intense work has started to determine whether it would be possible to unify the nomenclature. The traditional patient file has very little systematic content and lacks structure. On the technical side, there are unfortunately several types of electronic data filing systems in use—and also different versions of the same system. This leads to more problems than one might expect. In the meantime, the solution to knowing not only the diagnoses and some figures of times and costs, but also functional variables and patient satisfaction variables, is to have national registration. As Lord Kelvin said “when you can measure what you are talking about and can express it in numbers, you know something about it”. Now, medical auditing can be performed on a national basis. The fields of national audits and national guidelines have started to develop rapidly.

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