An EDTA Registry for the year 2000?

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Why registries?

Close collaboration between various centres, covering large populations has become a prerequisite for progress in medicine. Critical assessment of therapeutic developments, a hallmark of Western medicine, relies more and more on large, expensive multi-centre studies, an impressive example of which is given by the recent Modification of Diet in Renal Disease (MDRD) study [1]. Evaluation of health care delivery also depends on the survey of large patient populations as illustrated by the study of Parker et al. on the prognostic value of urea reduction ratio in dialysed patients [2]. The introduction of peer review of the performance of individual centres relies on the availability of adequate information on predefined populations in the same geographic area. The natural history of a variety of rare diseases can be defined only by gathering information scattered in different hospitals. Finally, information on the distribution of health care facilities has become a priority for health authorities.

It is within this context that several national and international registries have been developed during the last 30 years. They have proved to be unique tools for the advancement of medicine.

The contributions of the EDTA Registry

The story of the EDTA Registry illustrates the benefits accruing from close international and national cooperation. The Registry was the first to accumulate detailed information on the demography of renal replacement therapy. For many years it remained the only source of documentation available world-wide and helped thus shape this rapidly expanding young speciality. The Registry’s yearly reports provided the basis for British nephrologists to argue that British authorities did not provide adequate means to cover their population’s needs. Individual centres became aware of the overall European trend in expanding therapeutic modalities such as bicarbonate dialysis or anti-hepatitis vaccination. Survival curves for different groups according to age, comorbidity, therapeutic mode have provided a large body of reference to which each group could measure itself. Many more similar examples could be quoted. These examples are but a few among the EDTA Registry’s accomplishments.

A changing environment: a challenge to registries

Whatever their past success, registries have to cope with a changing environment. Both the motivation of the initiators and the returns expected by participants have profoundly changed over the last 30 years. This is again illustrated by the history of the EDTA’s registry.

The Registry was initiated at a time dialysis facilities were scarce, the long-term prognosis of patients on renal replacement therapy was almost unknown and the treatment modalities were restricted to conventional hemodialysis and renal transplantation. Nephrologists were eager to have demographic data and to learn about the fate of patients. A simple structure coped with these demands and the founding fathers’ eagerness guaranteed an adequate return of simple questionnaires.

Today’s environment has changed drastically. It requires a dramatic revision of the EDTA Registry’s concept. The number of centres and the covered geographical area have exploded. The nephrologists in charge are not interested any more in rough demographic data or in overall patient survival curves. By contrast, government agencies are concerned with the economic implications of an expensive, widely available technique. They thus require accurate demographic data allowing reasonable projections as well as precise information on patients’ survival, distribution of renal care between various treatment modalities whose cost-effectiveness should be documented. Furthermore, public health authorities expect quality control of ESRF treatment. Together with the profession, they support the development of peer review processes based on accurate information on patient mix and survival in the various centres.

Nephrologists in charge of dialysis units are now eager to obtain several other types of information. The first relates to their individual performance: an adequate feedback of their unit’s results should allow a comparison with those observed in their area, especially in view of a possible peer review system.
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The second should provide some guidelines on treatment modalities: only co-operative studies within the Registry will put in perspective the benefits expected from shorter or longer hours of dialysis, from newer methods such as hemofiltration, hemodiafiltration, from a diversity of therapeutic strategies aimed at the prevention of cardiovascular, osteoarticular, nutritional or infectious complications.

Still, another type of expected information relates to the fate of subgroups of patients such as the elderly or those with some rare diseases. Registries such as ours will have to face this new environment if they are to survive.

Which strategy for the year 2000?

The validity of the overall demographic data depends critically upon the return of reliable information. In the future, an adequate voluntary return will rely much more on the satisfaction of the nephrologist’s present needs than on the enthusiasm of the founding fathers. That will be obtained only by a flexible, user-friendly system—such as the one outlined by Shalom Mendel [3] and by the use of simple, straightforward questionnaires.

More pointed epidemiological studies require a response rate of at least 90%. Such high rates cannot be expected throughout an area as large as that covered by the EDTA Registry. Newer epidemiological and biostatistical tools should thus be utilized relying on those centres who provide a complete information. In addition to simple questionnaires covering basic information, special questionnaires could be sent to units known for the quality of their response. Obviously, this endeavour will require the collaboration of expert epidemiologists and biostatisticians.

The cultural change expected from the Registry is enormous. The Registry has to move away from a ‘black hole’ concept in which a highly centralized, dense team absorbs the energy of the various dialysis and transplant units without returning them individually useful information. It has to develop a customer friendly, flexible approach, designed to validate the incoming information and to provide each customer with needed information. In other words, the Registry has to inform, to involve and to impress its constituency.

We should nurture no illusion, changing the culture of the EDTA registry is comparable to changing the culture of an international enterprise. It is a long-term process that demands enormous efforts from the Registry’s office, a progressive shift in the attitude and the requests of the participating units and countries. It will only slowly yield results.

Conclusions

‘Failure is the foundation of success’ wrote Lao Tseu 2500 years ago. We have to transform today’s difficulties into opportunities to launch a rejuvenated Registry on the path of the future. As a matter of fact, we have no alternative but to go in that direction as quickly and as determinedly as possible. Government and public health authorities demand it for economic reasons. The profession needs it to improve its performance and meet peer review requirement. Lastly, and perhaps most importantly, the future of renal replacement therapy relies on a rapid, critical, objective assessment of newer developments that only well-organized Registries can provide: medical science and the benefit of our patients are indissociable here. As a result, the care of end-stage renal failure will once more be on the cutting edge of medicine, leading the way for many other, as yet less structured, medical endeavours.

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References