

Quality of care in end-stage renal disease: the importance of comparing “apples with apples”

Most patients with end-stage renal disease depend on dialysis treatment for their survival. To determine if the quality of dialysis care in one country or in one dialysis centre is different from that in another, it is essential to use comparable indicators to assess the quality of care. As such indicators were lacking at a European level, the European Renal Association - European Dialysis and Transplant Association (ERA-EDTA) initiated the NephroQUEST project. This project, that is being supported by the European Union under the Public Health Programme with more than half a million Euro, aims at a European wide consensus on the selection and standardization of quality of care indicators in end-stage renal disease and at further stimulating their availability. This ERA-EDTA initiative, that operates via its Registry in the Academic Medical Center in Amsterdam, was officially launched during a meeting of project partners and international nephrology researchers on November 10-11, 2007 in Amsterdam.

The wish to compare quality of care, so-called benchmarking, is not new. Already in the 1850s Florence Nightingale argued strongly that only by collecting and analyzing relevant data it was possible to determine the extent to which hospitals and other public institutions were effective in serving the patients who relied on their help.

In most European countries data on the frequency and outcome of patients with end-stage renal disease are collected by renal registries. Although registry information has contributed to the improvement of patient outcomes, there is an increasing need for information on the quality of care among clinicians, patients, health policy decision makers, insurance companies and hospital management to assist them in their choices and decision making. By comparing day-to-day clinical practice with clinical practice guidelines and with the performance of other centres (benchmarking), the resulting information may feed into local quality improvement programmes in an effective manner.

Many registries, however, experience considerable problems in the production of clinical databases allowing such comparisons. A huge problem is posed by the process of data collection, which in some countries still makes use of paper data collection forms or other labor-intensive methods. Another problem comprises the lack of standardization of methods to determine the data to be collected.

The NephroQUEST project addresses both of the above mentioned problems. Together with national renal registries and a large group of European experts the ERA-EDTA Registry in the Academic Medical Center in Amsterdam has taken up the task to produce a list of standardized quality of care indicators, including a priority for data collection for renal registries. Along the same lines, action will be taken to try and solve the problem of data collection itself by reducing the working burden for medical staff to collect these data. The answer to this problem is expected to be found in the automated data extraction from electronic hospital records. Given the enormous variety of such systems across Europe NephroQUEST will also take a standardized approach in this matter.

The project partners are confident that a standardized ‘European’ approach with room for some subsequent adaptation at the local level will contribute to the realization of a dream in which the majority of dialysis centres in Europe will receive the information they need to improve the quality of care provided to their patients. In this way the project will assist the improvement of health systems to the benefit of all European citizens.

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