How Important Can the Finnish Registry for Kidney Disease-Report Be For Us?

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Our newly elected Direction has decided, as one of his first contacts with the Society’s members, to send us the Finnish Registry for Kidney Disease-Report 2020. With no analysis and no comments. They know that the most important thing is to read them.

Sending documents like this is a worthwhile activity and the reading of which contributes in a very significant way to our knowledge. What was sent to us was the website where we can find it, consult, analyse, print and, if we desire, compare it with similar registries. As any other citizen can freely do: French, Greek, Latvian, Portuguese.

In my opinion, the message is clear: the need to enter a new cycle where a considerable number of problems in our field – nephrology – awaits solution.

Could there be a better incentive for this than a careful reading of such a document? Unfortunately, for reasons we should not be proud of, our data is cited on several occasions in this document.

For example, the data on incidence and prevalence in renal replacement therapy (RRT) in Finland and other European countries. Figure 8 shows that “In Cyprus, Greece and Portugal the incidence was more than 2.5-fold than in Finland” and in figure 12 that “Relative to Finland… the prevalence in Portugal was more than two-fold”.

As nephrologists, we know this data very well. Mainly through a huge number of international references. This data is disturbing and I cannot fail to state the discomfort that it causes me. Mainly because we know that something is wrong and that little or nothing has been done to change this situation.

There is something that seems interesting to me: Finland and Portugal are divided into five regions and, in both countries, there are significant differences in RRT incidence and prevalence between them. Understandably, the Finnish researchers sought to find an explanation and, for that, they analysed the clinical and laboratory characteristics of patients who entered RRT in 2010-2020. While recognizing that the decision to start RRT is not based on GFR alone, they concluded that “Research on timing of KRT start has not supported a very early start (at high estimated GFR). In 2010 the median estimated GFR was 7.4 mL/min/1.73 m2 and in 2020 it was 7.7 mL/min/1.73 m2”.

Although in Portugal the difference between regions is much higher – for example, Lisbon and Tagus-Valley have an incidence in dialysis two to three times higher than the others – there are no studies such as the one carried out in Finland. However, in Portugal there is also a national registry where the demographic, clinical and laboratory data of all patients, before RRT, must be included. For reasons hardly understandable they are not available.

The annual Finnish Registry, allows doctors, nurses, health technicians and citizens in general – those who are interested – to be informed about the most important quality markers of the treatment performed. The possibility of knowing these data will certainly be useful for patients in deciding the modality of treatment and where to be treated in the future.

One of the most important characteristics that we feel while reading the report, is the sense of responsibility of the Entities that produce it. They address not only the health community but seek to involve the entire population in general. There is a clear intention to keep it correct and fully informed, to contribute to the literacy, and to promote a possible and desirable intervention. This, despite the well-known high level of health literacy that the Finnish people already have, is considerable higher than what we know to exist in other countries.

Simply, those Entities have long since realized that keeping the data confidential, or restricted, does not help people, families and society in general, and does not allow to clarify problems or improve clinical results.

We all certainly agree that a chronic kidney disease registry, like others in any area of Health, is a fundamental and indispensable
instrument. It allows to know what is happening in the different regions, in the entire country and to compare them with other regions and countries around the world.

And, allows corrections when necessary and can be an important tool to change our current paradigm.

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