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EDITORIAL COMMENT

Finally, a continuous national multicenter registry: Primary angioplasty in Portugal[☆]

Finalmente um Registo Multicêntrico Nacional contínuo: a propósito da angioplastia primária em Portugal

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When the 2001-2003 Governing Board of the Portuguese Society of Cardiology (SPC) decided to establish the National Registry of Interventional Cardiology (RNCI), registries were generating intense interest. There was a perceived need to analyze clinical practice in different countries in the light of randomized clinical trials and to determine whether guidelines were actually being implemented. In Portugal, little was known beyond overall cardiovascular mortality, and information on coronary angiography and angioplasty was missing or woefully incomplete.

The establishment of the RNCI was a challenge that we believed could be overcome. The SPC would play a central role in motivating member physicians and in organizing the registry and the collection and statistical analysis of the data. With the assistance of a German colleague with extensive experience of registries in his own country (Anselm Gitt), the RNCI began operating in January 2002, using data records sent to the National Center for Data Collection in Cardiology (CNCDC), which was established in the same year in the SPC's branch in Coimbra.[1] However, the aim of the project from the beginning was much more ambitious: to set up a continuous registry, such as that in Sweden, which would provide more information than the partial registries organized by the European Society of Cardiology known as the Euro Heart Surveys.[2] Enthusiasm for registries grew in various countries, and in order to standardize data collection, in 2004 the European Union approved the Cardiology Audit and Registration Data Standards (CARDS) project, which defines which data should be collected on coronary interventions, and in which I was involved.[2]

The RNCI as implemented was a multicenter, voluntary, prospective and continuous registry. The intention was to achieve complete adherence, because not only would this provide information on coronary intervention from the whole of Portugal, but it could also be a source of data for clinical research and for comparison with other countries.

If I have described in some detail how the RNCI was conceived and implemented, it is because the article by Pereira et al. published in this issue of the *Journal*[3] presents data from the RNCI between 2002 and 2013, and in the last two of these years continuous data from all 20 public and five private centers were included. This is an excellent achievement that must have taken a great deal of effort on the part of the Portuguese Association of Cardiovascular Intervention (APIC), and all the heads of the centers and the co-authors are to be congratulated. There are few European countries with such a continuous multicenter registry.

The path to this achievement cannot have been easy, entailing as it did exporting and standardizing data from the many databases involved and being prepared to share different experiences while maintaining strict confidentiality. The support of information technology has been crucial to APIC over the years. With a continuous registry covering the entire country, all those involved should be proud, and there

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is now an opportunity to make significant progress in clinical research. As Pereira et al. acknowledge, not all patients are followed systematically, the registry does not currently have either internal or external auditing, and recent advances in techniques and drugs used in the treatment of myocardial infarction (MI) and in coronary intervention have yet to be reflected in the registry data.

The article by Pereira et al.[3] presents data on 99% and 95% of patients who underwent primary percutaneous coronary intervention (p-PCI) for MI in 2012 and 2013, respectively, in 18 public and four private centers, compared with 37% of patients in six centers in 2002. The numbers of p-PCIs for MI rose from 1118 in 2002 to 3524 in 2013, an annual rate of 106 and 338 per million population, respectively ($p<0.001$). Although the number of p-PCIs is still less than the target (600 per million population per year), through initiatives such as the coronary fast-track system and Stent for Life, Table 1 of the article shows that we are treating more patients, and more severe patients, and thereby helping to reduce cardiovascular mortality in Portugal. Since not all centers participated in the registry until 2012/2013, it will only be possible to evaluate some of the information reported, such as type of stent, access route, use of aspiration thrombectomy, and other recent developments, in the future.

However, the most important data missing in the article concern in-hospital complications of p-PCI.[4] Other studies have shown no apparent differences in mortality between women and men[5] or between centers with and without cardiac surgery,[6] but for some reason no numbers were given. This is particularly important for comparisons between p-PCI rates and statistics on mortality in mainland Portugal from the Portuguese Directorate-General for Health. It would be interesting to analyze mortality in patients who underwent p-PCI compared to those who were treated by fibrinolysis or were not reperfused, and in those treated by p-PCI admitted through the coronary fast-track system, although more MI patients still die before they reach the hospital.

Now that the dream of a continuous registry including all interventional cardiology centers in the country has been realized, for which the members of APIC and the SPC are to be congratulated, it is time to look to the future. Progress in clinical research is hindered by the high costs of clinical trials, which are the basis of evidence-based medicine, and decreased investment from industry. An alternative approach is based on 'big data'[7] derived from computerized clinical records and continuous disease registries, which changes how clinical research is done in data-rich areas such as cardiology. This applies not only to interventional cardiology and continuous registries with constantly updated data; in the future, it will apply to all types of information on cardiology, which is already being collected in order to be combined and analyzed as a whole. In my view, it is increasingly important to collect continuous clinical data on all patients and to be able to compare them on an individual basis, as part of an iterative process that will profoundly change both the scientific method and clinical practice, and will in the future inevitably lead to structural and institutional change.

Conflicts of interest

The author has no conflicts of interest to declare.

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