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EDITORIAL COMMENT

The fascinating world of clinical registries. Insights into current practice

O mundo fascinante dos registos clínicos. Um olhar profundo sobre a realidade

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Registries are an important piece in building the pyramid of evidence, with multicenter randomized clinical trials at the top of that pyramid. Within Europe, the European Society of Cardiology has led this movement with the Euro Heart Survey, a major program comprising registries to investigate clinical conditions such as acute coronary syndromes, heart failure, chronic stable angina, among others, as well as treatments including revascularization.[1]

In Portugal, the Portuguese Society of Cardiology started a great program of national registries in 2002 headquartered at the National Center for Data Collection in Cardiology.[2] Acute coronary syndromes and interventional cardiology are two of the most important registries showing real-world data in Portugal over more than 20 years.[3–5]

In the current issue of the Portuguese Journal of Cardiology, Calé et al. published the Official Report of Percutaneous Coronary Angiography and Intervention from 2014 to 2023.[6] The time frame between 2004 and 2013 was covered in a previous publication by Pereira et al.[7] These two publications are absolutely fascinating, not only as part of the history of cardiology in Portugal, but especially because they show the long road traveled to where we are today. It is also important not to ignore the unquestionable role and vitality of an independent scientific society creating the conditions for producing good science.

The current registry provides information that reflects current practice in Portugal in the field of interventional cardiology. The registry is robust, collecting data from almost all procedures performed in the country, not only in the mainland but also in the islands. Data are collected through a national platform migrating the information to the National Center for Data Collection. The entire process is centralized, and public access is regulated.

The good news arising from the registry is that despite a clear stabilization in the number of annual therapeutic percutaneous coronary interventions (PCI) in the last decade (1360/million inhabitants in 2014 to 1322/million in 2023; R2=0.0399, p=0.276), the number of primary PCIs increased 22% (306/million inhabitants in 2014 to 374/million inhabitants in 2023; R2=0.759, p<0.001) and there was a decrease, although not an elimination, in the geographical disparities.

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It is important that everyone have access to quality health care regardless of their economic condition, social status or geographical location.

One of the biggest advantages of registries is to provide benchmarking not only within the country, but also to compare the data with comparable countries. This makes it possible to assess local practices, correcting errors and deviations. Spain and France are good comparators with Portugal if we take into consideration cultural issues and healthcare systems. The Spanish National Registry, published by Jurado-Román et al. in 2023,[8] like the Portuguese Registry is nationwide and representative of the country, collecting data from 111 centers. The number of PCI is slightly higher in Spain (1573/million inhabitants vs. 1322/million in Portugal), as well as the number of primary PCI/million inhabitants goes in the same direction (452/million in Spain vs. 374/million in Portugal). This is an intriguing issue even when we look at the regions of Spain closest to Portugal, which share the same culture and habits (Galicia 475/million; Extremadura 497/million: La Rioja 499/million).

France also published its local experience with coronary intervention, unfortunately it was not representative of the country.[9] Between 2014 and 2022, only 47 centers collected data inside the registry. In almost the same time period, the total number of reported angiography procedures was slightly higher (176 030 in France vs. 160 101 in Portugal), nevertheless the number of primary PCI is lower (31 631 in France vs. 36 892 in Portugal). These are interesting findings which reveal a better use of urgent angiography in Portugal (23% of total angiography proceed to primary PCI) than in France (17.9%).

In the Portuguese report,[6] nothing is mentioned about the success of the procedures nor about data on complications that may be relevant for the qualification of the registry. I hope this information will be the subject of future publications. The quality of our clinical practice and the way in which we comply with international recommendations are measured by the registries since they have been designed for this purpose and should contain all required information. This is why all information is important to evaluate clinical practice.

Clinical registries are a new science inside the world of clinical research. A good registry with emphasis on quality, identifying gaps and difficulties in the implementation of good practices, is a crucial tool for health authorities. As Parker concluded,[10] methodologically rigorous, clinical quality registries demonstrate the translation of data to knowledge, knowledge to practice, and then practice back to data. The cooperation between scientists, represented by their scientific societies, and policy decision makers, represented by health authorities, is essential. Both parties should sit at the same table and data from the real world should be the basis for the necessary planning.

Looking toward the future

Randomized clinical trials (RCTs), the most prized scientific evidence, have several limitations. One of the most important limitations is that they involve patients who are rigorously selected and treated according to protocols that might not represent real-world practice, as well as real-world populations. An interesting solution designed within the last decade may be registry-based randomized clinical trials (RRCTs). In brief, this new concept involves the inclusion of a randomization module in a large clinical registry.[11,12] RRCTs may deliver answers to key clinical questions efficiently and at a lower cost, and they may have a key role in evaluating important clinical questions where funding is difficult to access.

There are good examples of this novel approach in cardiovascular medicine. The TASTE (Thrombus Aspiration in ST-Elevation myocardial infarction in Scandinavia) study published in *The New England Journal of Medicine* is one of the pioneers of this research technique, clarifying the use of thrombus aspiration in patients with myocardial infarction. It is the largest clinical trial conducted on this matter.[13,14]

The second step is the future focus on artificial intelligence (AI) and its contribution to a better understanding of real-world data. AI comprising techniques is an integral part of our life and is present in many applications which help us in the process of decision making.[15] Maru et al.[16] searched for published studies based on AI techniques and machine learning between 2010 and 2023 and found only 3106 articles on ClinicalTrials.gov. They found there were more observational studies (61.6%) than interventional studies (38.4%) and the topic cardiovascular diseases represented 11% of all studies.

We are taking the first steps in this fascinating world, but we should recognize how AI will be changing our practice and how it will be a potent tool to interpret our experiments. The future is surely brilliant.

Conflicts of interest

The author has no conflicts of interest to declare.

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