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SPECIAL ARTICLE

Celebrating the 10th anniversary of the Portuguese National Cardiology Data Collection Center: A reflection on its past, present, and future☆

A propósito dos 10 anos do aniversário do centro nacional de colecção de dados em cardiologia: uma reflexão sobre o seu passado, presente e futuro

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Introduction

In the statutes of the Portuguese Society of Cardiology (SPC), one of the Society's principal objectives is ''stimulating studies and research into scientific problems related to cardiovascular disease'' in Portugal.

The Board of the SPC for the biennium 2001–2003 decided that the time was right to take concrete steps toward achieving this objective by implementing a variety of initiatives.

One of these was a policy of translating international guidelines into Portuguese, particularly those published by the European Society of Cardiology (ESC) and endorsed by the SPC, and to distribute them to members. Another was the first prospective, non-randomized, multicenter international trial in the field of interventional cardiology to be sponsored and organized by the SPC (the PORTO Trial). This study, of sirolimus-eluting stents in small native coronary arteries in diabetic and non-diabetic patients, involved nine Portuguese and one Brazilian center.[1] The SPC encouraged the industry to establish a uniform system for management of hemodynamic data, to be made available to all cardiology departments.

Another initiative implemented during this period with the aim of stimulating multicenter studies and research was the creation of a coordinating center within the SPC to provide logistic support for joint national studies, based at the SPC's branch in Coimbra and equipped with the necessary technical, data management and human resources. This is the National Cardiology Data Collection Center (*Centro Nacional de Colecção de Dados em Cardiologia*, CNCDC).

The CNCDC was established to facilitate the development of studies on cardiovascular disease involving different elements of the Portuguese health system, including cardiology departments, coronary care units, catheterization laboratories, interventional cardiology centers, internal medicine departments, medical societies such as the Portuguese Societies of Hypertension and Atherosclerosis, the Ministry of Health, and health centers. These studies could be in the form of national registries, prospective multicenter trials, or epidemiological studies. The CNCDC also provides assistance with statistical analysis to SPC members.

The CNCDC began operating on January 1, 2002, and thus celebrates 10 years of existence this year. In the course of this period the Center has collected information on over 120 000 patients, which makes our program one of the largest in Europe.

The aim of this article is to present a reflection on what has been achieved in the first 10 years of the CNCDC, the

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current situation, and how to plan for the future, as part of the efforts to ensure that the Center's initial objectives continue to be fulfilled.

The past

In the course of its 10 years of existence, the CNCDC has supported two continuous registries, the National Registry of Acute Coronary Syndromes and the National Registry of Interventional Cardiology, which were established in January 2002. The participation of cardiology departments throughout the country in these registries was voluntary, although the SPC encouraged collaboration between departments in order to obtain sufficiently large datasets to have international impact. The Center is also involved in periodic registries on metabolic syndrome (beginning in 2006 and known as the VALSIM study) and on hypertension and dyslipidemia (beginning in 2005). The CNCDC also lent its support to the ESC's Euro Heart Surveys by assisting Portuguese investigators contributing to this important program, and is currently supporting its replacement, the EURObservational Research Programme. The numbers of patients included in these registries and in the Euro Heart Surveys are shown in Table 1.

Developments in the SPC's two main registries, of acute coronary syndromes and interventional cardiology, have been interesting. The former saw a progressive decline in the participation of the different centers, followed by a recovery in 2011 (Figure 1), which may be due to an increase in automated data export from some centers. In the Registry of Interventional Cardiology automated export of data from the departments' databases was introduced in 2008, which not only resulted in an increase in the number of patients included per year, but also made recording more consistent. This registry also saw a rise in patient numbers in 2011 (Figure 2). This development may also reflect the time it has taken for the centers to realize the importance of collecting clinical data and information on different experiences, which can then be used as the basis for improving clinical research in Portugal.

Table 1 Numbers of patients included in the SPC's national registries and in the ESC's Euro Heart Surveys.

National registries	n
Acute Coronary Syndromes	39 286
Interventional Cardiology	64 675
Hypertension and Dyslipidemia	285
Metabolic syndrome (VALSIM)	16 984
Sub-total	121 230
Euro Heart Surveys	
Diabetes and the Heart	209
Adult Congenital Heart Disease	192
Atrial Fibrillation	154
Acute Coronary Syndromes II	337
Heart Failure	109
Percutaneous Coronary Intervention	320
Sub-total	1321
Total	122 551

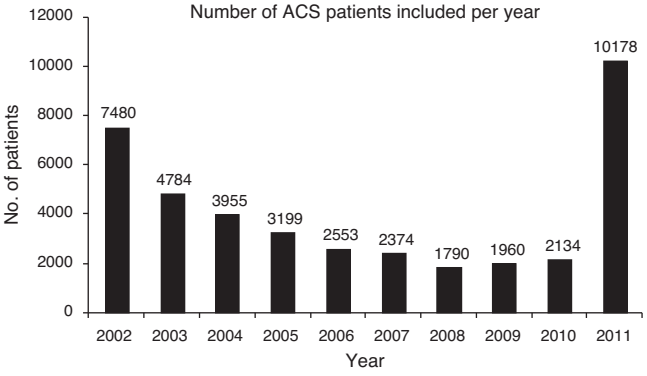

Figure 1 Number of patients in the National Registry of Acute Coronary Syndromes in the last 10 years. ACS: acute coronary syndromes.

The good results obtained with these two registries suggests that automated data export from the databases of cardiology departments should be encouraged in centers that do not yet use this facility, in order to further increase the number of patients included each year and to ensure systematic and consistent recording of data.

Since its launch in 2002, the CNCDC has given valuable support to SPC members through assistance in the production of studies, particularly in terms of statistical analysis of data. There have been numerous requests from SPC members over the last 10 years for assistance with statistical analysis of data both from the registries and from individual studies (Figure 3).

The analyses performed on data from the CNCDC registries has been the basis of a significant amount of research, as demonstrated by the large number of studies presented at Portuguese and international meetings. However, despite this limited success, it has to be acknowledged that little has been achieved in view of the potential and quality of the data available. The number of articles published on the basis of the CNCDC registries is small compared to the number of oral communications and poster presentations (Figure 4). To date, only 12 full-length articles have been published based on CNCDC data.[2–13] There are doubtless different reasons for this, two of the main ones being lack

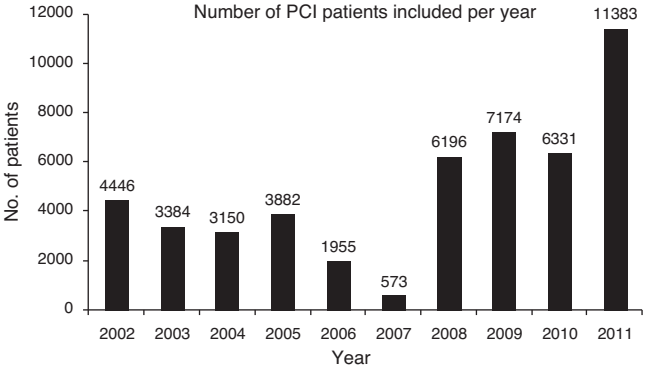

Figure 2 Number of patients in the National Registry of Interventional Cardiology in the last 10 years. PCI: percutaneous coronary intervention.

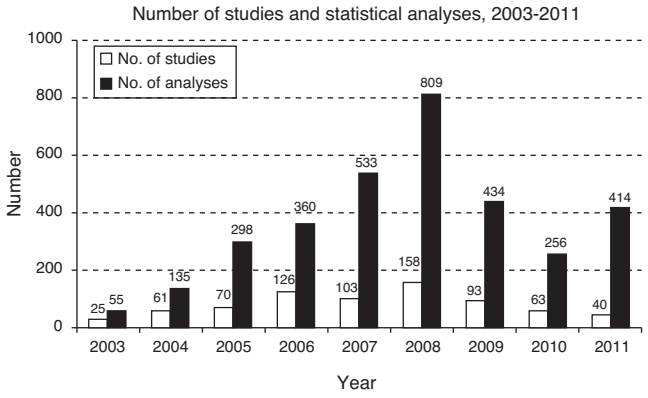

Figure 3 Numbers of statistical analyses (black bars) and studies (white bars) carried out at CNCDC, 2003–2011.

of time and pressure of work, among many others, but this situation needs to change; ways must be found to encourage the publication of CNCDC data in the form of full-length articles. One possible solution could be to offer SPC members who present their work at conferences and other meetings the services of a medical writer contracted by the SPC, who would help investigators to write up their work.

There has been a fall in recent years in the quantity of scientific works produced by Portuguese cardiologists, a trend that needs to be reversed. The decrease has been consistent, in the numbers of both statistical analyses and studies (Figure 3) as well as in communications based on CNCDC data (Figure 4). The number of full-length articles has remained very low throughout the last 10 years (Figure 4).

It is also interesting to analyze the data on papers submitted and accepted for ESC Congresses, which are a major showcase for the best in European and world research. Unfortunately, official data of the ESC are only available for

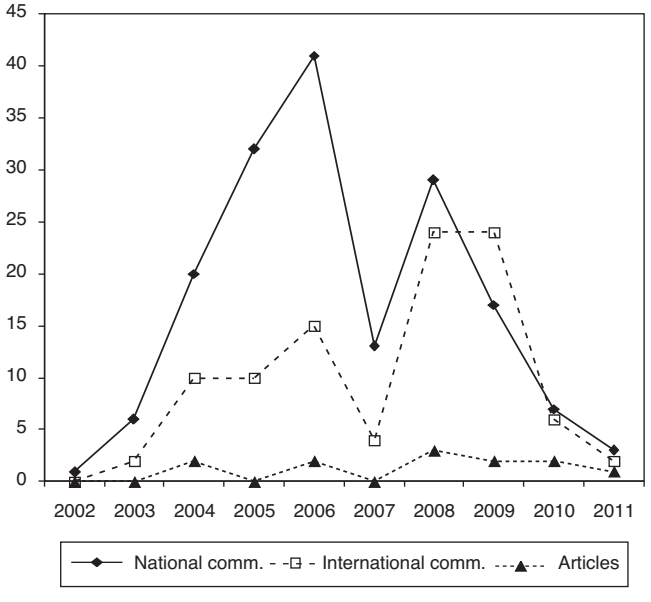

Figure 4 Numbers of national and international communications and articles published based on CNCDC data. Comm.: communications.

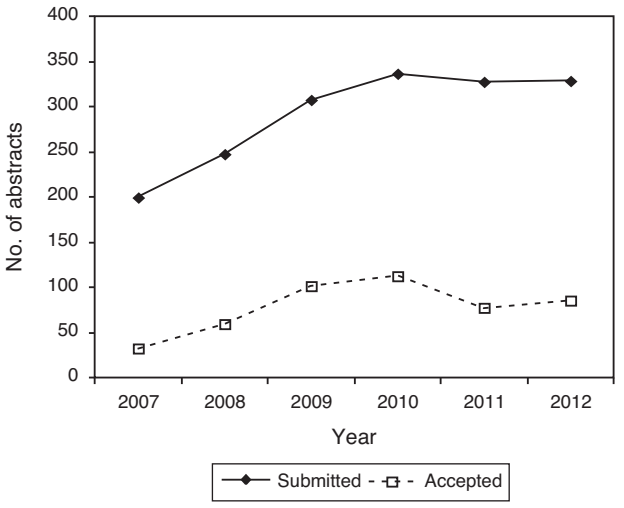

Figure 5 Numbers of abstracts submitted and accepted for ESC Congresses.

2007 onwards, but it can be seen from Figure 5 that there is a certain stagnation in Portuguese research, in terms of both numbers of papers submitted and of those accepted. These data merit close analysis by the SPC in general and future members of the Society's Board in particular, with a view to increasing the rate of acceptance of Portuguese studies in this important forum of world cardiology.

The present

The information in the CNCDC databases not only encourages scientific research; it also provides a clearer picture of cardiovascular disease in Portugal, analysis of which will help decide on actions that will lead to rapid and effective improvements in the situation, as well as to evaluate the impact that these measures have in practice. This information is of particular interest to public bodies in their decision-making processes, as well as in assessments of measures taken by the Portuguese health authorities. An example of this is the impact of the campaign, beginning in 2005, to promote the use of the *Via Verde Coronária* (coronary fast-track system) in the context of acute coronary syndromes in Portugal (Figure 6).

The establishment of the CNCDC enables individual cardiological centers to compare their results anonymously with the national average and, if necessary, take steps to improve the situation.

A major advantage of continuous registries is that they can be used to identify developments in treatment, changes in mortality and morbidity, and the extent of compliance with international guidelines in Portugal (Figure 7). Continuous registries are complicated to implement and maintain, but the quality and detail of the resulting information more than justifies the effort. Furthermore, they can pinpoint areas where specific training is needed, resulting in better management of the resources available for continuing education.

Continuous registries can be used to give a clear idea of changes in the form of presentation of disease and in changes in treatment patterns over time. For example,

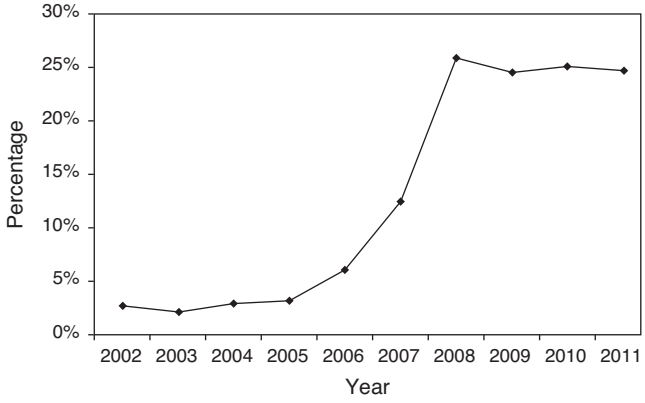

Figure 6 Use of the *Via Verde Coronária* (coronary fast-track system) in acute coronary syndromes in the last 10 years.

Source: National Registry of Acute Coronary Syndromes of the Portuguese Society of Cardiology.

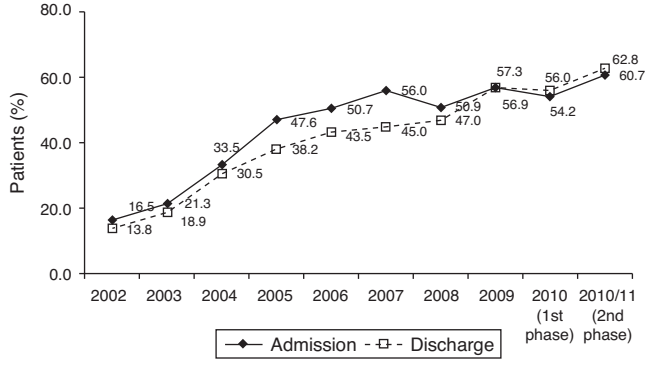

Figure 7 Changes in the use of drug therapies in acute coronary syndromes as recommended in the European Society of Cardiology guidelines.

Source: National Registry of Acute Coronary Syndromes of the Portuguese Society of Cardiology.

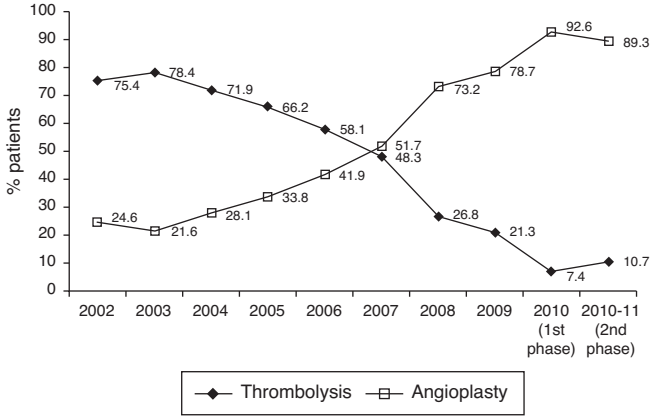

Figure 8 Treatment of ST-segment elevation myocardial infarction in Portugal: comparison of use of thrombolysis and primary angioplasty over the last 10 years.

Source: National Registry of Acute Coronary Syndromes of the Portuguese Society of Cardiology.

analysis of the data of the National Registry of Acute Coronary Syndromes shows changes in treatment of ST-segment elevation myocardial infarction in Portugal over the past 10 years (Figure 8); the paradigm shift that took place in 2007 is clearly visible, with primary angioplasty replacing thrombolysis as the preferred therapy.

The future

Considering the success of the CNCDC over the last 10 years, it can be foreseen that the Center's importance as one of the main tools to support research in the SPC will only increase, making Portugal more competitive internationally. However, for this to occur, members must take full advantage of its potential; all Portuguese cardiological centers should participate in this project, which belongs to all of them. Automated data export from local databases should be encouraged and extended.

It is essential for our registries to be known and their value to be recognized internationally as well as nationally. The first step in this direction came in 2012, when the National Registry of Acute Coronary Syndromes was registered on the www.clincaltrials.gov site. All of the SPC's registries should be registered on this site, particularly the National Registry of Interventional Cardiology, in order to gain official recognition at the international level. The recently initiated close collaboration between our program of registries and that of the Brazilian Society of Cardiology is another important strategic step.

There are epidemiological studies carried out in Portugal by SPC members in which the Society should be involved; it has already been seen that the CNCDC is able to support such studies while leaving the investigators in full control of how they are run, an excellent example of which is the VALSIM study. Use of the Center's services can significantly reduce the costs of a study, which will also enjoy the considerable advantage of being associated with the Society's independence and prestige. Members should be more willing to make use of these services, and similar advantages would accrue to the registries of pacing and electrophysiology if they were to become part of the CNCDC's program.

It is to be hoped that some bold SPC members will in the future design the first randomized prospective clinical trial supported by the CNCDC. This would be an extremely important step for the standing of the Society, which at the moment is entirely dependent on invitations to participate in international trials. Our colleagues in the Spanish Society of Cardiology have been carrying out randomized prospective trials for years. Why do we not do the same?

The CNCDC is likely to develop in various directions in the future. Firstly, it will continue to promote the participation of Portuguese cardiology centers in its various activities by promoting the export of data directly from local databases to the SPC's registries, which will increase the number of cases recorded and ensure systematic and consistent data collection. Secondly, it is important to implement a centralized follow-up program to assist centers that lack the logistical means to maintain comprehensive follow-up records. This is essential if we are to improve the quality of the data and thereby make our registries more competitive internationally. Finally, a quality control system must be implemented in the CNCDC, with data audits, in order to ensure the reliability of published data. Without such a system our registries will not be recognized internationally.

It is also important to increase the awareness of the Portuguese health authorities concerning the SPC's registries, both to improve the former's knowledge of the situation in Portugal and to help them design strategies to improve patient care. It would also be advantageous to have the health authorities' support in the further development of this project. This is especially relevant at a time when the Ministry of Health has begun publishing its Clinical Standards, which are mainly concerned with prescribing patterns and reduction of costs by use of cheaper or generic drugs. Only a medical society using continuous registries will be able to assess the long-term clinical results of this initiative.

The CNCDC was created with the goal of serving as a tool to support members of the SPC. In line with this philosophy, the Center should provide a medical writing service for members who wish to publish studies at the international level, whether based on data from the SPC's registries or using the databases of individual departments.

These and similar measures will make it possible to continue to fulfill the objective laid down in the statutes of the Portuguese Society of Cardiology: ''stimulating studies and research into scientific problems related to cardiovascular disease'' in Portugal.

Conflict of interest

The authors have no conflicts of interest to declare.

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