

## Registries and Databases: the Importance of Collecting Information

### *Registros y bases de datos: la importancia de obtener información*

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Cardiovascular diseases, and particularly ischemic heart disease, are the leading causes of death in industrialized countries. In Argentina, public health statistics based on death certificates show a mortality rate of 239.4 per 100,000 persons, corresponding to one-third of total deaths. (1) Acute myocardial infarction (AMI) represents one of the most important entities of cardiovascular diseases. Several publications show the different therapeutic options and predictors of high risk in these patients. (2, 3) However, in Argentina, as well as in most other countries, there are no epidemiological registries to establish the long-term outcome and its relationship with the main clinical and therapeutic variables. Most registries include information limited to the hospitalization stage due to logistic and cost-related difficulties, encumbering the assessment of the prognostic value and the long-term benefit of different treatments. The American NRMI registry is an example, with more than 2 million patients from all regions and all types of hospitals, and the CONAREC XVII Argentine registry, with more than 1100 patients in 45 centers of our country. (4, 5) Only randomized studies with highly selected populations, including not more than 5-10% of total patients, show information during longer follow-up periods. Although they provide valuable information, the difficulty to generalize results is an important limitation.

The study by Álvarez et al., (6) published in this issue of the Journal, provides important information, as it evaluated both in-hospital mortality and long-term outcome in a significant number of patients undergoing primary percutaneous coronary intervention (PCI) in ST-segment elevation myocardial infarction (STEMI) in two community hospitals. This observational and retrospective study included 851 STEMI patients undergoing primary PCI at the Hospital Alemán and the Hospital Británico de Buenos Aires between 1993 and 2012. Of importance, all the patients were consecutively included in the registry, with a significant median follow-up of 7.8 years. Another remarkable aspect is that a high percentage of patients completed the long-term follow-up. The fact that the study

evaluated two consecutive decades is also relevant, as the characteristics of the population admitted due to infarction in both periods and the response to treatment could be analyzed and compared. The registry shows patients with clinical characteristics which represent those of the daily practice, and the information is similar to the one published by other local and international registries. Mean age was 61 years, most patients were men (77%), 50% were anterior wall infarctions and 83% presented with Killip and Kimball class A. Overall in-hospital mortality was 6% and was significantly lower than the one published in other Argentine registries, which ranged between 7.9% and 12.6%. (7, 8) This mortality was independently associated with 3-vessel disease, female gender, diabetes, age > 75 years and the presence of final TIMI flow < grade 3. These independent prognostic factors are similar to those previously published. (9, 10) The presence of Killip and Kimball class C or D at admission was not a predictor of in-hospital events but was associated with long-term mortality. Overall mortality was 14.3% and was lower than the one published in other international registries where it ranged between 17% and 22%. (11, 12) Age, diabetes and Killip and Kimball class C or D were independent predictors of long-term mortality. As expected, use of stents increased in the second decade, accompanied by a higher percentage of TIMI grade 3 flow. This observation was not accompanied by a significant reduction in mortality between both periods; yet, there was a strong trend towards lower mortality, though we cannot draw conclusions due to the limited number of patients. Important information provided by the study refers to the improvement in the time to reperfusion observed in the second decade, suggesting the implementation of protocols aimed at obtaining earlier revascularization. Time to reperfusion is accepted as one of the most relevant variables in the treatment of AMI due to its established association with mortality, and is included in most institutions as a marker of medical practice quality. (13) Thus, the registry demonstrates the importance of the retrospective collection of data and continuous monitoring to

determine the type and quality of medical care, as well as the development internal policies to improve it. It should be noted that the authors still have a long way to go to achieve a door-to-balloon-time < 60 minutes, as recommended by current guidelines. (14)

As Argentina lacks a continuously operating official population-based AMI registry, hospital registries are essential to become aware of the epidemiological reality of our country. However, the registries of individual institutions, as the one presented by Álvarez et al., (6) have the bias of representing a selected population (for example, all the patients included had medical coverage) so we would not know if these data could be extrapolated to or be representative of the general population. Great efforts have been made in Argentina to collect information about patients with acute coronary syndromes, as demonstrated by the CONAREC XVII Registry, which included more than 1100 patients from 45 centers nationwide; the Argentine Federation of Cardiology registry with information about 425 patients from 39 centers nationwide who voluntarily agreed to participate in an AMI Federal Registry; and the Epi-Cardio Registry, which prospectively included more than 50,000 patients. (5, 15, 16) However, none of these registries included long-term follow-up, and all of them lasted for limited periods of time without operating continuously. It is time for Argentina to enter the era of prospective and continuous collection of information from patients with cardiovascular diseases. The study by Álvarez et al.(6) could be used to make the scientific societies (SAC, FAC, CACI, FCA) participate actively with the health authorities in the development of prospective registries, due to the high prevalence of cardiovascular disease with great expenditure of health resources. In this way, information could be obtained about the different actors involved in the diagnosis and treatment of cardiovascular diseases in order to adopt a basic standard of care, provide adequate resources to all the sectors of the health care system and make a continuous evaluation of the efficacy of the measures adopted and their logical prospective adjustment.

In conclusion, the study by Álvarez et al. (6) provides significant information about the long-term follow-up of AMI patients. In addition, it shows the usefulness of collecting information demonstrating the type of medicine we practice, the changes over time, the resources used and the quality of health care. Undoubtedly, systematic and continuous collection of information is essential to understand medical practice. Its expansion to local and regional levels with the participation of scientific and public health care societies would be a great and extremely important challenge for the better health care of our patients

## Conflicts of interest

None declared

## REFERENCES

- Indicadores básicos 2012, [http://www.deis.gov.ar/publicaciones/archivos/indicadores\\_2012.pdf](http://www.deis.gov.ar/publicaciones/archivos/indicadores_2012.pdf)
- Keeley EC, Boura JA, Grines CL. Primary angioplasty versus intravenous thrombolytic therapy for acute myocardial infarction: a quantitative review of 23 randomised trials. *Lancet* 2003;361:13-20. <http://doi.org/c7p2r9>
- Conti C, Calandrelli M, Rodríguez Saavedra J, Muniz J, Rodríguez Alemparte M, Szwarczer E et al. Primary angioplasty in high risk patients with acute myocardial infarction, long term follow up and predictors of in hospital mortality. *Rev Argent Cardiol* 1997;65:515-22.
- National Registry of Myocardial Infarction (NRFMI). National Registry of Myocardial Infarction. Home page. Available at: <http://www.nrfmi.org/index.html>. Accessed on December 24, 2002
- Pérez G, Costabel J, González N, Zaidel E, Altamirano M, Schiavone M et al. Acute Myocardial Infarction in Argentina. CONAREC XVII Registry. *Rev Argent Cardiol* 2013;81:390-9. <http://doi.org/sg9>
- Álvarez JA, Migliaro G, Leiva G, Allin JG, Baglioni P, Fernández ML et al. Primary Percutaneous Coronary Intervention in Acute Myocardial Infarction: Long-Term Predictors of Adverse Events. *Rev Argent Cardiol* 2014;82:359-365.
- Zapata G. Comité de Cardiopatía isquémica. Registro Nacional de Infarto Agudo de Miocardio de la Federación Argentina de Cardiología. Etapa III. *Rev Fed Arg Cardiol* 2004;33:127-31.
- Gagliardi J, Charask A, Higa C, Blanco P, Dini A, Tajer C et al. Acute Myocardial Infarction in the Argentine Republic. Comparative Analysis of the Last 18 Years. Results of the SAC Surveys. *Rev Argent Cardiol* 2007;75:171-8.
- Michaels AD, Goldschlager N. Risk stratification after myocardial infarction. *Prog Cardiovasc Dis* 2000;42:273-309. <http://doi.org/fqqfqb>
- Champney KP, Frederick PD, Bueno H, Parashar S, Foody J, Merz CN, et al; NRFMI Investigators. The joint contribution of sex, age and type of myocardial infarction on hospital mortality following acute myocardial infarction. *Heart* 2009;95:895-9. <http://doi.org/cb6gx5>
- Kaneda H, Hiroe Y, Tanaka S, Shiono T, Inaba H, Miyashita Y, et al. Long-term outcome of acute myocardial infarction patients treated with stents versus balloon angioplasty: results from randomized trials. *Int J Cardiol* 2009;133:241-4. <http://doi.org/c2ffsk>
- Henriques JP, Zijlstra F, van 't Hof AW, de Boer MJ, Dambrink JH, Gosselink AT, et al. Primary percutaneous coronary intervention versus thrombolytic treatment: long term follow up according to infarct location. *Heart* 2006;92:75-9. <http://doi.org/cz36x3>
- Pinto DS, Kirtane AJ, Nallamothu BK, Murphy SA, Cohen DJ, Laham RJ, et al. Hospital delays in reperfusion for ST-elevation myocardial infarction: implications when selecting a reperfusion strategy. *Circulation* 2006;114:2019-25. <http://doi.org/d5bk4v>
- de Villers JS, Anderson T, McMeekin JD, Leung RC, Traboulsi M; for the Foothills Interventional Cardiology Service and the Calgary STEMI QIHI group. Expedited transfer for primary percutaneous coronary intervention: a program evaluation. *CMAJ* 2007;176:1833-8. <http://doi.org/fwc962>
- Comité de Cardiopatía Isquémica de la Federación Argentina de Cardiología. Registro Nacional de Infarto Agudo de Miocardio de la Federación Argentina de Cardiología. *Rev Fed Arg Cardiol* 2004;33:127-31.
- Gagliardi J, De Abreu M, Mariani J, Silberstein M, De Sagastizábal D, Salzber S et al. Chief Complaints, Procedures, Outcomes and Discharge Treatment Plan of 54,000 Patients Admitted to Cardiovascular Care Units in Argentina After Six Years of the Epi-Cardio Registry. *Rev Argent Cardiol* 2012;80:446-54.