PERSIAN REGISTRY OF CARDIOVASCULAR DISEASE (PROVE)

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ABSTRACT

Introduction: The Persian Registry Of cardioVascular disease (PROVE) aimed to study the demographic, clinical, diagnosis and treatment of patients with cardiovascular disease (CVD) and to follow them for 1 to 3 years, looking for short- and long-term outcomes. PROVE started in Isfahan in 2014 to test the feasibility of its implementation for later national dissemination. Therefore, we aimed to explain its design, methodology, development, validity of protocols and questionnaires of each CVD and its quality control (QC) design.

Methods: PROVE feasibility study is an observational (descriptive and analytical) open-label registry that collects patient’s data in hospitals or at population level, and follows them for between 1 to 3 years. Patients with acute coronary syndrome (ACS), ST Elevation Myocardial Infarction (STEMI), stroke, atrial fibrillation (AF), heart failure(HF); congenital heart disease (CHD), percutaneous coronary intervention (PCI) and recently, chronic ischemic cardiovascular disease (CICD) were enrolled. Four types of registered CVD (AF, STEMI, HF, CICD) had joined the European observational Research Programme (EORP). ACS and stroke registry started back in 1999 in the surveillance unit of Isfahan Cardiovascular Research Institute (ICRI) using the WHO MONICA (Multinational MONItoring of trends and determinants in CArdiovascular disease) protocol. Physicians and nurses who worked in each registry, received multiple training sessions based on the design of the registry. The development and validity of questionnaires, protocols, data collection, entry and management, and its analysis are supervised by a well-established QC protocol.

Results: PROVE subtypes followed different approaches. ACS, STEMI, stroke, HF and CICD are hospital based while AF and CHD are population based. The validity of questionnaires was performed by a QC committee before starting registry. More than 900 questionnaires of HF and 800 of STEMI, 350 of AF, 800 of stroke, more than 1000 of CHD and PCI and 9 of CICD were registered and all its data were managed by mid-September 2016. Using the WHO MONICA method for ACS and stroke since the year 1999, there were more than 150,000 and 37,000 patients registered and followed respectively. The follow up frequency, duration and method was different according to type of disease registry. The case report forms (CRFs) of AF, STEMI, HF, and CICD were sent to the EORP site.

Conclusion: PROVE implementation is feasible and can be considered as a valuable source of valid data to improving the management, treatment, prevention and control of patients with CVD. The data can be later used by policy makers and for future research.

KEYWORDS: Cardiovascular disease, Registry, Management of disease, Data collection