ACCESS TO ORPHAN DRUGS IN GREECE DURING ECONOMIC CRISIS

Tsiantou V1, Mylona K1, Karampli E1, Boubouchairopoulos N1, Kyriopoulos I1, Athanasakis K1, Gavril E2, Makridaki D3, Kyriopoulos J1

1 Department of Health Economics, National School of Public Health (NSPH)
2 Institute for Pharmaceutical Research and Technology (IFET)
3 Panhellenic Association of Hospital Pharmacists (PEFNI)

Background & Objectives

Orphan Drugs (ODs) are medicinal products intended for diagnosis, prevention or treatment of rare diseases. Access to ODs is crucial for patients' health and quality of life. However, patients claim that access to orphan drugs is sometimes restricted, a phenomenon that has grown during the economic crisis. The aim of this study was to identify current problems and future challenges of patients’ access to ODs in Greece.

Methods

A qualitative study took place between December 2013 and January 2014. Data were retrieved through policy documents identified through web searches using keywords “orphan drugs” and “rare diseases” in Greek. The selected documents were content analyzed and based on the first results, an interview guide was developed in order to be used in semi-structured interviews with six representatives of key stakeholders in Greece. The interviews were content analyzed and the main problems that the patients with rare diseases face were identified. Furthermore, patients' pathway to access ODs was depicted.

Results

There are two main channels through which the patient can have access to an OD and it is depending on whether it is licensed in Greece or not. In the first case the patient can take the drug through the hospital (Figure 1) or the pharmacy of the National Organization for Healthcare Services (EOPYY) (Figure 2) if it is not available at the hospital pharmacy and in the second case through a public sector organization (IFET) (Figure 3). All cases are characterized by extensive bureaucracy and involvement of up to three organizations in order to receive the approval, a procedure which creates delays in patients' access and risking their health.

Conclusions

Ensuring patients’ access to ODs in Greece is challenging especially during the economic crisis. Financial constraints and continuous legislative changes in the health system and the pharmaceutical market constitute important barriers to patients' access. The national action plan for rare diseases that was developed in 2008, addresses many of the barriers that our study identified and its implementation can improve patients’ access to ODs.

The study was supported by Actelion

The major barriers in patients’ access to ODs according to stakeholders

- Delays in pricing and reimbursement of ODs in Greece
- Budget cuts to the hospitals
- Absence of patient registries
- Absence of a well-described procedure, lack of cooperation between the organizations and committees