Are we united enough to come down with common charter of demands: the health professionals’ perspective

Antonis Kattamis

Hematology-Oncology Thalassemia Unit, First Department of Paediatrics, University of Athens, ‘Agia Sofia’ Children’s Hospital, Athens, Greece

Abstract

Providing optimal care for patients with hemoglobinopathies is a common goal for all the health professionals working on the field. The medical community has adopted best practices guidelines to provide similar therapeutic plans. The pre-requisites for an effective health system cover all aspects from infrastructure to organization flow, staffing and public interventions. If economic resources are limited, best available option, which will not differ from 'optimal care', need to be found.

The health professionals’ perspective

The undisputable common goal of the all the health professionals is to provide optimal treatment for all patients. Even though, there is a consensus in this goal, there may be different clinical approaches in many medical issues. Evidence-based medicine (EBM) is the conscientious, explicit and judicious use of current best evidence in making decisions about the care of individual patients. The adoption of evidence-based medicine has been a major breakthrough in the daily clinical practice. EBM is based in the results of randomized clinical trials and meta-analyses. Unfortunately, there are many limitations, mainly as EBM does not cover all the clinical dilemmas, especially in chronic and rare diseases. To bridge these gaps, guidelines and expert opinions have been proposed. These are still not a panacea, as they have elements of subjectivity and may occasionally be misleading. Nevertheless, the medical community has overall accepted the ‘patronage’ of EBM, guidelines and expert opinions and has moved to more unified therapeutic approaches. The establishment of network of physicians taking care of patients with hemoglobinopathies, usually with respective professional societies in a local or international level, is a proof of the willingness to collaborate and adopt common practices. Thus, ‘optimal care’ can become from a vague, philosophical term to a measurable identity with specific endpoints.

For best achievements, health professionals need to work in an appealing and efficient environment. The requirements for these purposes are:
- Improvement of available infrastructure to adapt to the constantly-evoluting needs of the patients.
- Application of an organization structure in the public health system to cover the needs of patients with hemoglobinopathies. In this respect, we need legislation to cover how the individual units and reference centers should be organized. Recent EU resolution on developing reference centers for rare diseases can be taken into account.
- Dedicated Staff. The need for adequate and motivated health professionals to cover the care of the patients is of extreme value. The perplexity of the clinical phenotype of patients with hemoglobinopathies necessitates a multidisciplinary team approach. Continuing medical education is also essential to provide constant update on the medical issues.
- Policies with focus on public education / prevention programs / blood donation need to be implemented

Hierarchical categorization of specific needs may be an issue of variability among professionals, as it is dependent on personal beliefs and specific and occasionally transitory conditions.

Finally, the goal of providing the best available care can be achieved only if there is full coverage of medical expenses, including medications and transfusions.

In the real world where the budget is limited, this may eventually become unfeasible. Thus, the medical community needs to work in a non-dogmatic way with the providers to find the best solution, with an attempt to implement more economic alternatives of equal efficacy and safety.

References