How to deal with rare pediatric surgical diseases in the small developing country with limited resources: Insights from Bosnia and Herzegovina

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Title:

How to deal with rare pediatric surgical diseases in the small developing country with limited resources: Insights from Bosnia and Herzegovina

Running title:

Rare pediatric surgical diseases

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Conflict of Interest

The authors declare no conflict of interest.

Dear Editor:

The European Union Regulation on Orphan Medicinal Products defines a disease/condition as rare if it affects < 1 in 2.000 in the European population [1], making the prevalence data a key tool in creating health care policies for patients with rare diseases (RD) [2]. There is approximately 7.000 RD, mainly genetic [3], affecting approximately 30 million people in Europe and between 25 and 30 million in the United States [4].

Due to increased public awareness, improved understanding and treatment of the relatively more common disorders, elimination of nutritional deficiencies, and the development of laws related to the treatment of RD, pediatric rare diseases (PRD) have recently received increased attention [5]. The numerous challenges clinicians face in treating patients with PRD are due to the lack of standardized diagnostic criteria, referral pathways, and treatment guidelines [6, 7].

PRD in early childhood can be severe and life-threatening, and many require surgical treatment. The various types of rare pediatric surgical diseases have been reported and can generally be classified as congenital structural anomalies present at birth and those arising in early childhood and requiring surgical treatment in the first days or months of life [8]. Pediatric surgery is essential for the proper treatment of these patients. However, despite the huge gain in knowledge and the increased complexity of techniques that have fragmented adult surgery into multiple subspecialties, pediatric surgery remains the only true general surgery [9]. This is especially reflected in developing countries with limited financial and human resources, such as Bosnia and Herzegovina, where pediatric surgeons perform the full spectrum of pediatric surgical procedures as general pediatric surgeons since there is no possibility of obtaining a subspecialty in pediatric surgery, e.g., neonatal surgery. It is well-known that this is a highly skilled subspecialty dealing with complex pathology. The fact that the neonate is born with its unique physiological features within a very narrow range of

normalcy, beyond which it is helpless to cope with adverse settings, presents a special difficulty in neonatal surgery. Congenital anomalies can affect multiple organs/systems, requiring a deep knowledge of embryology and fetal biology and top-level expertise [9]. It also requires a high level of preoperative, operative, and postoperative management achieved in close multidisciplinary cooperation between physicians of various specialties to improve the survival and health of newborns. In developing countries with limited resources like Bosnia and Herzegovina, the rarity and complexity of various pediatric pathologies are additionally faced with limited training options, which represent another obstacle with potential management implications on PRD [10]. Additional problems are related to a perplexing political and fragmented healthcare system in the country that hampers centralized centers to treat the most complex PRD. Nevertheless, in some cases, our international collaboration with specialized centers may overcome the problem and save the patient's life (e.g., the treatment of pediatric encapsulating peritoneal sclerosis at a highly-specialized center) [11, 12]. However, much more effort (additional training and broader collaboration with specialized centers) is required to enable the proper management of PRD.

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