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Chapter 1. Introduction

Congenital heart defects occur in 8-10/1,000 liveborn neonates worldwide, representing the most common structural malformation, and are the leading cause of death in infancy among all congenital malformations (1-3). Improved prenatal and postnatal diagnostic methodologies, advanced perinatal and perioperative managements, and enhanced intensive care have achieved lower mortality rates following neonatal heart surgery over the last few decades (4,5). Over the last decades, most children born with complex congenital heart defects can reach adulthood (4). The substantial improvement in survival rates after neonatal heart surgery has resulted in a shift in the focus of research studies from short-term survival to long-term outcomes, which are related to morbidity and quality of life, generally defined by neurological and developmental outcomes (6,7). In parallel, the improved survival of neonates and infants with congenital heart defects has also attracted the attention on endless issues in the ethical and social fields.

Among them the most evident are the aspects of the fetal diagnosis with all relative consequences on the decision-making processes following the prenatal discovery of a congenital heart defect, the responsibilities of decisions after a fetal diagnosis, the complicated situations resulting from the presence of genetic disorders, or the association with other cardiac and/or non-cardiac malformation, or the cultural, religious, socio-economic status of the families.

More complicated are the aspects related to the involvement of children in the consent for surgical procedures, and the way to proceed to make them informed about the plans for the management of their health, not to mention the delicate issues of disclosure and confidentiality when involving children in prospective long-term clinical research projects.

Other ethical and social issues occur when negative outcomes occur, resulting in the death of the children or severe permanent lesions, complicating the role of decision-making in life for life threatening and/or end life situations, not to mention the care of parents and families after the death of their child.

In the modern era new issues appeared, like the utilization of the available resources and the discrepancies among environments in low versus high-income countries, as well as the introduction of artificial intelligence and remote consultations

The purpose of this book is to try to analize all the above aspects, with reports from different perspectives, to provide the readers with the possibility of forming an opinion based on the available knowledge or dogmas, more than on evidence, considering the absence of true scientific approach and quantification in these matters.

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