
Preface

Although congenital heart disease is the most common inborn defect, with an approximate prevalence of eight newborns for every 1,000 births, it is a not well known condition in the general population. One possible reason for this is that in the past these patients used to carry a very poor prognosis; however nowadays most of them survive reaching adulthood.

In fact, the number of adults with congenital heart disease is growing rapidly due to the advances and triumphs of cardiovascular medicine and surgery in the twentieth century. Since this population is on the constant increase, it is especially important to concentrate research efforts on the improvement of the management of these patients, including psychological aspects as well, which are an essential component of care in medical and chronic conditions.

Like all the other pathologies, although technological, scientific and medical progress has brought many benefits, it also entails the risk of potentially developing less personal and less humanized processes, systems and institutions, especially when it comes to medical institutions. Specialized psychological care in institutions, in which these patients are taken care of, is not to be taken for granted – there is a huge diversity of situations in Europe and the world.

In our role as psychologists and psychotherapists at the IRCCS Policlinico San Donato University Hospital with patients with congenital heart disease of all ages and their families, we have often asked ourselves in which way the hospitalization experience could be improved. In this context there is often a contact with suffering and emotions, which are often labelled as “negative”.

In these situations, some of the conditions which cause immediate suffering cannot be changed, but a lot can be done when it comes to the attitude towards suffering. One of our main objectives was to create an environment where it was possible to legitimate and give the possibility to express what one was going through.

This was possible also through the collaboration with the nonprofit organizations in this sector, both locally and on a European level. Also in this case, our contribution was that to help create occasions, also outside of the hospital setting, in which problems can be shared, and support given, focusing not only on what is wrong but also on the incredible resources and potential of these patients and their families.

This book was conceived as a guide for the psychologist and other professionals who deal with these patients and their families. Firstly, the medical condition of congenital heart disease is described and the humanization of the health care context in general is explored. In the following parts of the book, the psychological characteristics of patients with congenital heart diseases are considered from childhood to adult age, focusing in particular on specific issues, which emerge as important in this population; for example, neuropsychological aspects, psychological functioning, quality of life, life experiences and end of life care. Apart from citing the most important literature on the various topics, there has often been an effort to describe clinical case studies, in order to give specific indications when it comes to the management of these patients.

There is plenty of literature regarding the psychological aspects of acquired heart disease, also under the name of psychocardiology. In this textbook the reader will find the results of an effort to find which aspects of psychocardiology might also be applied to congenital heart disease patients. In addition, specific examples of psychological interventions are described, such as Medical Art Therapy for these patients. Finally, the importance of associations and peer to peer support is outlined, by focusing on the development of European associations and by exploring specific examples of peer to peer support.

We are very happy and thankful that some of the top experts in the psychosocial management of these patients have contributed to the creation of this manual, and we sincerely hope that it will be a valuable tool, which improves the care provided to these patients.

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