
Clinical Psychology and Congenital Heart Disease



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Edward Callus • Emilia Quadri
Editors

Clinical Psychology and Congenital Heart Disease

Lifelong Psychological Aspects
and Interventions

Forewords by
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 Springer

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Foreword

The concept of health care as pure therapy has changed due to the discoveries in the last 20 years. The overall goal of medicine has shifted towards an approach that is concentrated on health, meant as a necessity requiring the availability of a service which is more focused on the patients as persons and on their multiplicity of needs. Medicine cannot be considered only in terms of “survival” anymore, but in a more broad perspective of the meaning of existence, which also encompasses and enhances the subjective psychological aspects of health itself.

A development of the process which involves the humanization of health care structures can be seen in the national and international hospital organization, and this can also be observed from the improved qualification and awareness of the medical and nursing staff.

It is therefore important to give the necessary relevance to the humanization of health care, where there is not only the cure of the pathology, but also attention to the global, psychophysical well-being of individuals.

The primary objective of the San Donato Hospital Group is for patients to be considered at the center of health care, being respected in all their dimensions including their personal stories, their culture, their emotions and feelings.

The IRCCS (Istituto di Ricovero e di Cura a Carattere Scientifico – Scientific Institute for Research, Hospitalisation and Health Care) Policlinico San Donato University Hospital is one of the three IRCCS of the San Donato Hospital Group: the Group is constituted by a total of 18 hospitals, and it is currently one of the first hospital groups in Europe, besides being the most important one in Italy.

Apart from being the most important reference point in Italy when it comes to cardiac pathologies, it is one of the outstanding centers in the world for the treatment of pediatric and adult congenital heart disease. In fact, in 2013 alone, approximately 550 cardiac catheterisms (both interventional and diagnostic) and 460 heart surgeries were performed for the benefit of patients affected by this condition.

It is a source of great pride for me to present this volume, the first of its kind, designed and developed at our Policlinico San Donato.

San Donato Milanese, Milan, Italy

Gabriele Pelissero
President of the San Donato Hospital Group

Foreword

For several years in our clinical practice, we have observed the psychological support to patients and families in the Pediatric and Adult with Congenital Heart Disease Center of the Cardiovascular Center “E. Malan” of the IRCCS (Istituto di Ricovero e di Cura a Carattere Scientifico – Scientific Institute for Research, Hospitalization and Health Care) Policlinico San Donato University Hospital. For the patients and their families who are involved in the difficult path of dealing with complex pathologies, like some conditions of congenital heart disease can be, it is essential to be adequately welcomed and listened to.

When it comes to providing assistance to hospitalized children, the necessity for humanization manifests itself more strongly. In fact, the hospitalization process can have important repercussions on the psycho-developmental processes in the child.

This happens because children and their families find themselves having to handle the condition and all that its treatment involves, which is often inevitably traumatic. Furthermore, they are often distanced from an environment which they are familiar with. There are also occasions in which children or adolescents are also necessarily separated from one or both parents for some time during their hospitalization. Having a congenital heart disease can also entail dealing with life-long health issues during adulthood, which can have an important impact on all areas of life.

The objectives of the humanization of the hospital setting and its integration with the surrounding territory have led us to conduct a series of psychological and cultural projects coordinated by two psychologists and psychotherapists (Dr. Emilia Quadri and Dr. Edward Callus), which also include research activities, in collaboration with the NGO AICCA (Associazione dei Cardiopatici Congeniti Adulti – Italian Grown Up Congenital Heart Disease Organization).

That is why I am very pleased to write the foreword for this book, in which the psychological aspects linked with congenital heart disease in all stages of life are considered.

San Donato Milanese, Milan, Italy

Mario Carminati
Director, Pediatric and Adult
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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.

San Donato Milanese, Italy

Edward Callus
Emilia Quadri

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