

Preface

Transitional Care Issues for the Adolescent with Congenital Heart Disease



Mary M. Canobbio,
RN, MN, FAAN



Sarah (Sally) Higgins,
PhD, RN, FAAN

Guest Editors

In 1984 the topic of adult congenital heart disease (ACHD) was first introduced in the *Nursing Clinics of North America*. At the time it was not clear what the prevalence of the population was, nor were adult cardiac practitioners convinced that there would be a need for a subspecialty of what was considered a pediatric problem [1]. Ten years later a second issue dedicated to the issues facing adults with congenital heart disease was presented [2]. In those first 10 years it became clear that children were surviving well into adulthood but were in need of specialized care, counseling, and education. By 1994 the subspecialty of ACHD was further defined, with estimates that there were up to 500,000 surviving adults who had CHD. Additionally, the important role that advanced practice nurses play within this subspecialty was acknowledged. Today, population numbers have doubled, and the subspecialty of ACHD is well established, having been recognized by both the American Heart Association and the American College of Cardiology.

In 2000 the American College of Cardiology organized a second Bethesda Conference on ACHD [3]. In their report, they addressed the need to create regional centers that are prepared to meet not only the medical and surgical needs of this population but also the training and preparation needs of the practitioners who would be managing these patients. Additionally, it was recognized that the preparation and counseling of adults with CHD must begin much earlier than when they turn 18; the transition from childhood

to adulthood is particularly difficult for patients with chronic disease, particularly if there are residual cognitive and physical disabilities. If not properly addressed, these patients are at risk for the loss of health care coverage and inadequate continuity of care, which may result in the development of secondary disability that can be not only emotionally damaging but financially costly.

Thus in 2004–2005 there has been a shift in focus, one that assists both the parent and adolescent to successfully transition into the adult world. Recognizing the importance of the transitional care model, we have pulled together a series of topics to introduce the concept of transitional care as well as key issues to guide pediatric as well as adult advanced practice nurses in developing transitional care programs within their practice settings. In three decades the subspecialty of ACHD has broadened to include adolescents so that we may continue to improve the delivery of care for adults with CHD in order for them to maintain the highest level of functional status and quality of life.

References

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Mary M. Canobbio, RN, MN, FAAN
Administrative Coordinator
Ahmanson-UCLA Adult Congenital Heart Disease Center
Lecturer, School of Nursing
University of California at Los Angeles
PO Box 951702, 700 Tiverton Avenue
Los Angeles, CA 90095-1702, USA

E-mail address: mcanobb@sonnet.ucla.edu

and

Sarah (Sally) Higgins, PhD, RN, FAAN
Professor and Chair
Department of Family Health
University of San Francisco School of Nursing
2130 Fulton Street
San Francisco, CA 94117, USA

E-mail address: higgins@usfca.edu