



Review

The care of adults with congenital heart disease across the globe: Current assessment and future perspective

A position statement from the International Society for Adult Congenital Heart Disease (ISACHD)



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ARTICLE INFO

Article history:

Received 22 April 2015

Accepted 29 April 2015

Available online 1 May 2015

Keywords:

Adult Congenital Heart Disease

Grown-Up Congenital Heart Disease

Position statement

World health

ABSTRACT

The number of adults with congenital heart disease (CHD) has increased markedly over the past few decades as a result of astounding successes in pediatric cardiac care. Nevertheless, it is now well understood that CHD is not cured but palliated, such that life-long expert care is required to optimize outcomes. All countries in the world that experience improved survival in CHD must face new challenges inherent to the emergence of a growing and aging CHD population with changing needs and medical and psychosocial issues. Founded in 1992, the International Society for Adult Congenital Heart Disease (ISACHD) is the leading global organization of professionals dedicated to pursuing excellence in the care of adults with CHD worldwide. Recognizing the unique and varied issues involved in caring for adults with CHD, ISACHD established a task force to assess the current status of care for adults with CHD across the globe, highlight major challenges and priorities, and provide future direction. The writing committee consisted of experts from North America, South America, Europe, South Asia, East Asia, and Oceania. The committee was divided into subgroups to review key aspects of adult CHD (ACHD) care. Regional representatives were tasked with investigating and reporting on relevant local issues as accurately as possible, within the constraints of available data. The resulting ISACHD position statement addresses changing patterns of worldwide epidemiology, models of care and organization of care, education and training, and the global research landscape in ACHD.

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1. Changing patterns of world-wide epidemiology of ACHD

1.1. Introduction

There are an estimated 150 million live births per year worldwide, of which 1.35 million are afflicted with CHD [1]. Approximately 85% of the world's population lives in low or middle-income countries (so-called developing countries), where considerable challenges impede access to appropriate CHD care. As such, hundreds of thousands of children with CHD die each year and millions more stand to benefit from specialized treatment. Developing countries vary greatly in their economic and infrastructural healthcare resources, with very limited to no access to potentially life-saving therapies in some. In others, advances in pediatric cardiac care and improved socioeconomic circumstances are allowing for increased survival to adulthood. As such, the worldwide burden of ACHD is expected to grow. In high-income countries, over 85% of children with CHD now survive into their adult years [2].

The World Health Organization (WHO) has stated that effective healthcare systems require robust financing, a well-trained workforce, and reliable information on which to base decisions and policies. There remains a paucity of data on population demographics of CHD in developing countries. As the field of CHD matures in developed countries, a new era of changing demographics has emerged, which presents challenges to proportionally matching services and infrastructure in a manner that is commensurate with the shifting realities. Thus, knowledge of the changing profile of CHD including demographic trends, disease severity, and solicited healthcare resources is essential in estimating needs and allocating specialized care.

1.2. Disease burden

Over the last decade, several studies have attempted to quantify the numbers of adults with CHD (as opposed to projections based on birth prevalence rates alone). A systemic review analyzed data from ten publications on the prevalence of ACHD in high-income countries between the years 2001 and 2011 [3]. Prevalence rates generally ranged from 1.7–4.1 per 1000 adults and have steadily increased over time, with the most recent statistics reaching 6.12 per 1000 adults [3,4].

The disease burden can also be estimated by comparing the proportion of adults to children with CHD. In most Western countries, adults now outnumber children with CHD by a margin that continues to increase. In Europe, from a total of 800 million people, the ACHD population is estimated to be 2.3 million, in comparison to 1.9 million children with CHD. Empirical estimates from Canada indicate that adults

outnumber children with CHD by a ratio of 2:1 and that the number of adults with CHD increased by 57% from nearly 100,000 in the year 2000 to over 160,000 in 2010 [4,5]. During this time frame, the proportion of children with CHD increased by a modest 11%. Estimates from Japan indicate an annual increase of 9000 adults with CHD from 1997 to 2007, with a prevalence of over 400,000 in 2007 [6]. Despite the lack of statistics, the growth rate of the ACHD population in developing countries is likely considerably lower given the overwhelming challenges to specialized CHD care.

1.3. Regional differences

Although regional disparities preclude a definitive tabulation of the global population of adults with CHD, applying a lower to mid-level prevalence range of 1.7 to 4.1 per 1000 adults to a world population of 7.2 billion yields an estimated 12 to 34 million adults with CHD worldwide. Fig. 1 illustrates the distribution of CHD in children and adults by region, when WHO population figures are indexed to age and a CHD prevalence rate of 12 per 1000 is applied to children [5].

Regional differences reflect varied and complex factors such as demographic population trends, socioeconomic status, infrastructure development including resource allocation, education of healthcare workers, access to pediatric cardiac care, competing causes of (non-CHD-related) mortality such as malnutrition and infection, and health behavior and awareness. Our best estimates indicate that, worldwide, adults comprise 22–26% of the total CHD population. Examples of the relative proportion of adults within the CHD population include 20% in Taiwan and 32% in Thailand. In Singapore, 2008 population statistics, albeit incomplete, suggest that adults outnumber children with CHD threefold, with 15,000 adults and 5000 children with CHD identified.

1.4. Disease severity

The distribution of lesion severity in the adult CHD population depends, in part, on the age category and available healthcare services. For example, in developed countries, most adults with CHD have had surgical palliation. In contrast, in an outpatient population of 1157 adults in New Delhi, India only 14% had had cardiac surgery (Fig. 2). Most had simple forms of CHD with a minority having more complex lesions conducive to natural survival, such as well-balanced tetralogy of Fallot and Eisenmenger syndrome. Similar findings were reported from a tertiary care center in Beirut, Lebanon [7]. In China, more than 50% of adults with CHD are untreated. In most high-income countries where care for adults with CHD is increasingly structured, the prevalence of severe

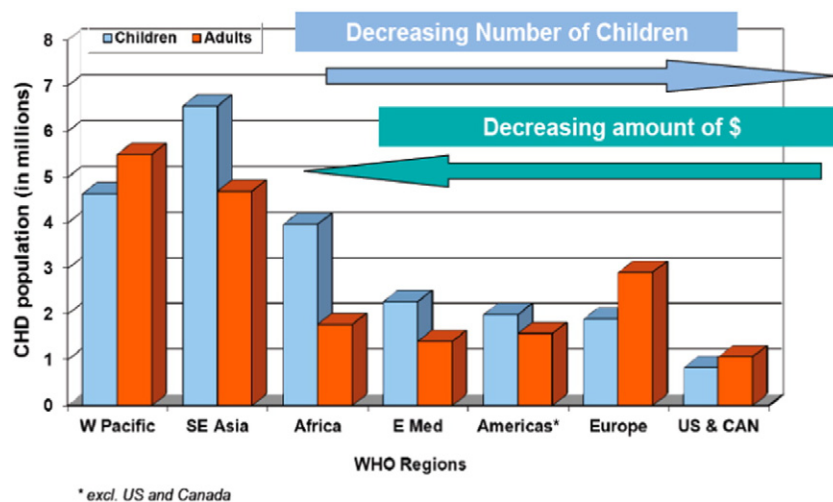


Fig. 1. The congenital heart disease (CHD) burden by WHO region indexed to regional population by age using a CHD prevalence of 12/1000 before and 4/1000 after age 18 years. This figure also illustrates countercurrent direction of resources and number of children with CHD. Where there are more children born and therefore more children with CHD likely to require services there are fewer resources allocated to CHD.

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