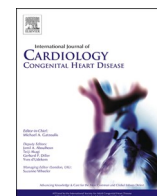




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Position statement for the development of adult congenital heart disease units in Latin America and the Caribbean: Recommendations by the adult congenital heart disease chapter and pediatric cardiology council of the interamerican society of cardiology ...[☆]

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ABSTRACT

In 2020, there was an estimated prevalence of more than 1.8 million adults with congenital heart disease (ACHDs) living in South America, and 677,000 in Central America and the Caribbean. The ACHD mortality is higher in developing countries, compared with developed countries, and it has been shown that concentrating this population in specialized ACHD units improves their survival and prognosis. Currently, Latin American (LATAM) and Caribbean countries have an insufficient number of specialists and specialized ACHD units. Analyzing this situation, the Inter-American Society of Cardiology's (IASC) ACHD chapter and Pediatric Cardiology Council have prepared the first recommendations for developing ACHD units in LATAM and Caribbean

[☆] Dedicated to the memory of Dr. Gary Douglas Webb, mentor and friend of the ACHD community in Latin America and the Caribbean nations.

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countries. This article is the first collaborative work between South American, Central American and Caribbean countries. It describes the main points for organizing and developing ACHD units adapted to our own reality. Each point has been discussed in terms of barriers and challenges, followed by specific recommendations for improving and developing ACHD care. They have been reviewed and endorsed by the International Society for Adult Congenital Heart Disease (ISACHD), and the goal of their implementation is for each ACHD unit in the region to have the standards of quality and efficiency to improve the prognosis and survival of ACHDs in the region.

1. Introduction

With a global prevalence of 8–13 cases per 1000 live births, congenital heart disease (CHD) is the most prevalent birth defect worldwide [1]. Advances in diagnosis, surgical and hemodynamic treatment, as well as rehabilitation and follow-up of CHDs in childhood have achieved a more than 90% survival in most Latin American (LATAM) and Caribbean countries, and as a result of all this effort, many children with CHD reach adulthood.

The prevalence of adults with congenital heart disease (ACHDs) in LATAM and the Caribbean can be extrapolated to 3000 ACHDs per one million inhabitants [2,3]. By 2020, 1.8 million were estimated in South America and 677,000 in Central America and the Caribbean, with a 5–6% annual growth [4].

Adults with congenital heart disease have a higher morbidity and earlier mortality, not only due to their own constantly evolving CHD, but also due to the comorbidities which can contribute to disease progression or worsen the prognosis and make this population more fragile, with more serious health problems and more complex care needs. The international consensus and guidelines recommend that ACHD patients be centralized and managed in special units, known as adult congenital heart disease units (ACHD units) [5,6], which should be duly organized in regard to infrastructure, technological resources and human resources. The ACHD units should be the main launching point for improving medical care, and should consist of various specialists responsible for providing all the necessary and specialized support for solving the health problems of this growing population.

Aware of our current situation, we recognize the challenges and opportunities we face in developing and centralizing ACHDs. We emphasize four fundamental principles which helped us understand the need to develop ACHD units. These were previously raised in Brazil in 2015 and are known as **ROCK** [7].

The “**ROCK**” principles are:

Recognize the need to organize and structure ACHD units.

Organize, to face big challenges.

Centralize the facilities and specialists in order to not lose important resources.

Knowledge: create a multidisciplinary team of specialists and sub-specialists (nursing, intensive care, cardiac surgery, complex imaging, anesthesia and social work).

This paper provides the first recommendations for forming, structuring and developing ACHD units in LATAM and the Caribbean, developed by the emergent ACHD chapter and the Pediatric Cardiology Council of the Inter-American Society of Cardiology (IASC). These recommendations have been reviewed and are endorsed by the International Society for Adult Congenital Heart Disease (ISACHD).

2. Justification

“The response to a forced necessity to improve ACHD care in LATAM and the Caribbean”

More than 57,000 children with CHD are born every year in LATAM, and close to 45% have moderate and high complexity defects, which must be repaired during childhood. This has created a demand for specialized care in the pediatric population, a goal which many LATAM countries are meeting with the development of specialized CHD centers

in the region. Efforts focused on the pediatric population have achieved a significant improvement in life expectancy in middle and high-income countries (MICs and HICs, respectively) in LATAM and the Caribbean, although it continues to be an unresolved problem in low-income countries (LICs) [8].

The emergent ACHD population is a reality which warrants the development of specialized centers, motivating us to consider our current situation and work on two simultaneous fronts: the pediatric and ACHD populations, as a necessary goal.

Our healthcare systems must develop public policies for health care and coverage to reach the ACHD population and thus improve their quality of life, providing the best care with the proper resources.

Adult congenital heart disease mortality is seven times higher in developing than in developed countries (20% vs. 3%, respectively) [9]. This difference can be explained by better healthcare infrastructure, more financial resources, the existence of advanced and consolidated ACHD programs, and the efficiency of transitional and transfer programs in developed countries.

To achieve better access to care for the patients, an adequate number and availability of ACHD units must be ensured. The European Union (EU) recommendations state that there should be one ACHD care unit per 10 million inhabitants [10]. According to a study by Kempny A et al., in South America, there are only 0.4 ACHD care units per 10 million inhabitants [11]. Extrapolating this information, we also recognize that there are very few ACHD units in Central America and the Caribbean.

This concerning situation and the growing number of ACHDs motivated the creation of the ACHD chapter in 2018, which is part of the IASC’s Pediatric Cardiology Council. Since then, this group has actively worked on the development of ACHD care in the region. Given the geographic diversity of LATAM and Caribbean countries, the extensive land and maritime borders which separate them, the remote and hard-to access areas, as well as the decentralized healthcare systems and developing river, sea, air and land transportation systems in many countries, we recommend one ACHD unit for every 4–6 million inhabitants. This is also based on the recommendations provided by the Congenital Heart Disease Committee of the European Association for Cardio-Thoracic Surgery (EACTS), which established the need for one hospital with cardiovascular surgery capacity for every four million inhabitants [12,13].

3. Main points for organizing the care of adults with congenital heart disease

3.1. Strengthen transition and transfer programs

The success of ACHD follow up and care lies in an adequate transition and transfer of pediatric patients with CHD to adult care. This is a critical point and, unfortunately, many patients have serious difficulties in this process, resulting in losses and gaps in specialized care [14,15]. Some studies also show that more than 40% of patients experience gaps in specialized care, increasing the risk of greater morbidity, urgent interventions and a deteriorated quality of life [16].

The recent meta-analysis by Monns et al. shows that the discontinuity in cardiac follow up in young people with CHD transitioning to adulthood ranges from 3.6% to 62.7%, with a combined estimated proportion of 26.1% [17]. Unfortunately, this is a weakness in LATAM

and the Caribbean, where there may be up to 60% losses to follow up.

3.1.1. Recommendations

- a. Implement and develop transition and transfer programs. Due to the reasons explained in the previous section, it is crucial for pediatric cardiovascular centers to begin to efficiently develop these programs. Currently, this responsibility falls to pediatric cardiologists who are directly responsible for the care of the pediatric CHD population. The educational activities should be implemented at all levels of care, following the international recommendations for transition and transfer, applied to our region as was recently attempted to be confirmed [18].
- b. Transitional pediatric cardiologist. This professional profile model is proposed, in which a group of pediatric cardiologists should focus on adolescent patients with CHD (*"an adolescent medicine topic"*). These professionals should work closely with ACHD specialist cardiologists. A slow transition is recommended, in which the patients interact with both providers to be familiar with both. The participation of members of both groups will express adequate care continuity. The task of transferring to the ACHD unit should be duly coordinated and occur at the most opportune time.
- c. Cardiovascular centers with advanced CHD programs should conduct at least one meeting or medical transfer board meeting per month. The group should consist of pediatric cardiologists and ACHD specialists. The goal of this medical board will be the transfer of new ACHD youths to the ACHD unit. The young people who have reached the age of 18 years and have completed a transition program should be presented by the pediatric cardiologists to the ACHD cardiologists, along with a detailed medical report summarizing their disease course, all interventions and complications, and their current functional-anatomical clinical condition. For high-complexity cases, both the pediatric and adult cardiologists may need to be present either at the first visit to the ACHD unit or the last pediatric visit.

3.2. Physical and structural resources

The ACHD units should ideally function within the same hospital center in which a pediatric cardiology service exists. They should function separately from pediatric care, in an environment adapted and outfitted for the new ACHD patients. When the ACHD unit functions within a hospital center without pediatric cardiology services, there should at least be a nearby reference hospital with a pediatric cardiology service to foster the transfer to the ACHD unit. Or as an alternative strategy, telemedicine assistance should be implemented between the ACHD units and hospitals with pediatric cardiology services that are far away. This will reduce the loss of patients and improve transfers.

3.2.1. Recommendations

- a. The ACHD unit should be equipped with diagnostic and assessment resources including an electrocardiograph machine, ambulatory heart monitor (Holter), cardiopulmonary stress test, ambulatory blood pressure monitor, scale, stadiometer, pulse oximeter, stethoscope, blood pressure machine and digital thermometer.
- b. The ACHD unit should function within a complex tertiary care hospital center with advanced cardiovascular labs with experience in CHD (heart catheterization, hemodynamics, electrophysiology, ambulatory and intrasurgical transesophageal echocardiography, radiology, tomography, magnetic resonance and nuclear medicine). They must all work together, collaboratively, to promote the comprehensive and highest quality care of ACHD patients (Fig. 1).b. Ideally, the ACHD unit should function within a complex tertiary care hospital center with advanced cardiovascular laboratories with expertise in CHD (cardiac catheterization, hemodynamics, electrophysiology, ambulatory and intraoperative transesophageal

echocardiography, radiology, tomography, magnetic resonance imaging, and nuclear medicine). Everyone must work together, collaboratively, to promote the highest quality comprehensive care for patients with ACHD (Fig. 1). If any of these specialized laboratories are not available, the ACHD unit must have strategic alliances with other more advanced cardiovascular centers that can provide the laboratory services needed by the patients to handle their conditions.

3.3. Professional resources

This is another critical point in ACHD care in LATAM and the Caribbean. If the number of ACHD units in the region is low, the number of cardiologists with specialized ACHD training is extremely low. Currently, the ratio of ACHDs/specialized providers does not cover the demand for this population. Consequently, the availability of specialized care is extremely limited for many patients. This has raised the awareness and interest of several cardiologists in the region to acquire specialized training and formal education in ACHD. These have become pioneers and leaders in their respective countries, promoting the development of the specialty, with the common goals of educating and training more providers.

3.3.1. Recommendations

- a. Joint work between pediatric cardiologists and adult cardiologists: as long as there is a limited number of ACHD-trained cardiologists in our region, the best strategy for managing ACHD patients will be teamwork between pediatric cardiology and general adult cardiology. Undoubtedly, while pediatric cardiologists understand CHDs and are familiar with their management in childhood, the changes in their evolution and behavior in adults require a change in the assessment focus.

This new profile of the adult cardiovascular patient with CHD demands a professional duly trained in how to approach and solve problems in this population. Thus, our recommendation for now is for the two specialties to work together.

- b. Multidisciplinary groups: understanding that heterogeneous CHDs are a characteristic of ACHD patients, it is easy to understand that such a varied clinical phenotype between patients with the same CHD depends on many factors such as the time of diagnosis, prior surgical or palliative hemodynamic procedures, the severity of sequelae and complications related to previous repairs, and associated comorbidities, among others.

When dealing with a complex case, close collaboration with other specialists significantly helps decision making. This is especially true in our region, given that late CHD diagnosis continues to be very prevalent in many countries. The decisions regarding surgery, clinical management and related complications provide an opportunity for developing a multidisciplinary group. Any invasive cardiovascular or non-cardiovascular procedure should be guided by direct consultation with ACHD experts, after discussion in multidisciplinary sessions.

We recommend that the multidisciplinary meetings consist of a cardiologist with ACHD training and certification, a specialist in cardiovascular imaging, an electrophysiologist, an interventional cardiologist, a cardiovascular surgeon, a cardiovascular anesthesiologist, a cardiovascular nurse, an intensive care specialist, a radiologist and a social worker; all with experience in managing CHD patients.

- c. Leadership of the ACHD unit: the unit should be led by a cardiologist with specialized ACHD training. If this specialist is not available, it should be led by the cardiologist with the most experience in and knowledge of CHD.

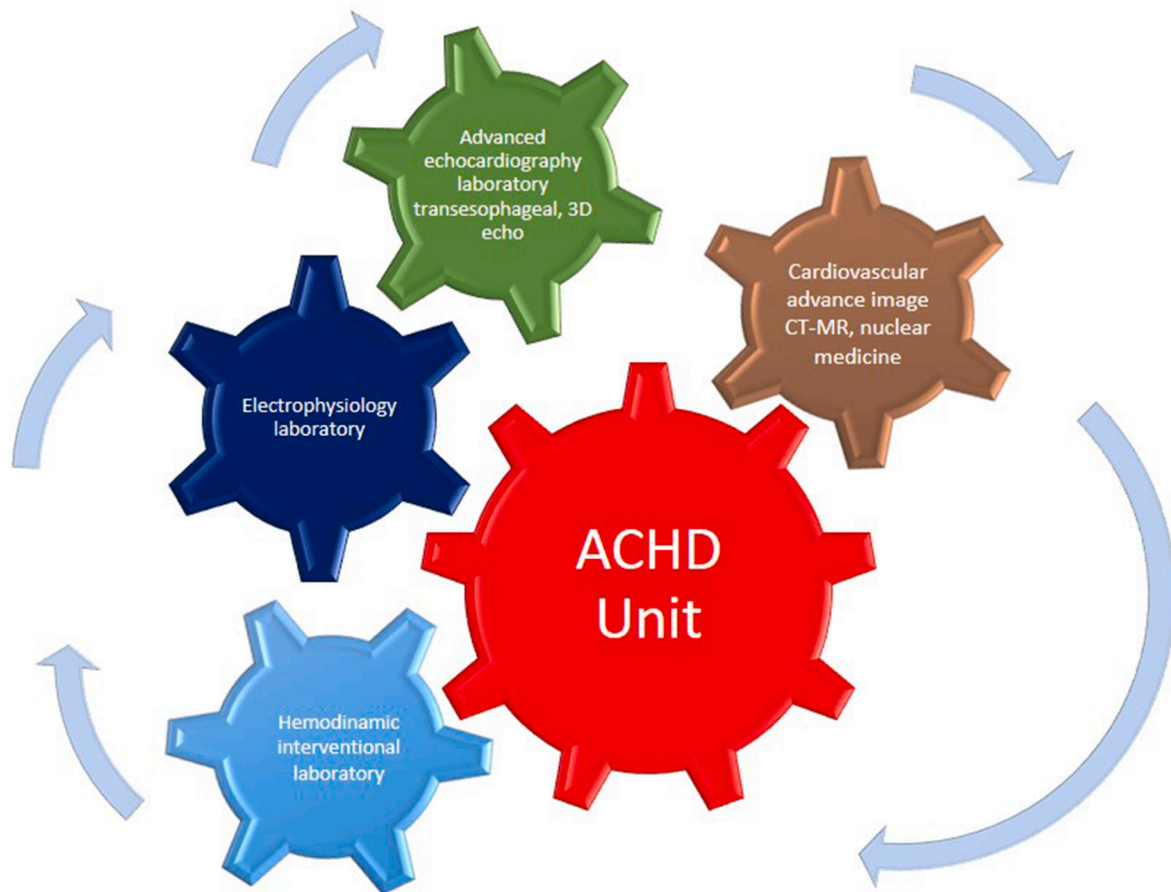


Fig. 1. Cardiovascular support labs specialized in congenital heart disease for the adult congenital heart disease unit (ROCK principle).

- c. Hospital centers with an active pediatric cardiology program should work together with adult cardiologists to solve complex CHD problems when there is no ACHD specialist available. This point is very important, especially in our region where there is still a limited number of ACHD specialists, and therefore the emergent ACHD services in several hospital centers are led by adult cardiologists. The interrelationship and cooperation with pediatric cardiology programs provides the benefit of CHD experience for an appropriate solution to ACHD problems.
- d. The ACHD unit should rely on other cardiovascular and non-cardiovascular specialized units functioning within the same hospital center (Fig. 2) which support the management and solution of noncardiac medical problems. These include the emergency room, high-risk obstetrics unit, heart failure and transplant unit, pulmonary hypertension unit, coronary unit, renal unit, and critical care unit, among others. Given the state of advanced hemodynamic decompensation reached by many ACHDs who have not received specialized care or even CHD repair, the palliative care unit provides important support for cases considered terminal.
- e. Telemedicine support and assistance, because some Latin American and Caribbean countries have a limited number of pediatric cardiology services and many are far away from the cardiovascular centers where the ACHD unit operates. We recommend implementing and using telemedicine between pediatric hospitals and ACHD units.

d. Support from non-cardiac specialties: just as with other chronic diseases, the health problems of ACHDs require the participation and cooperation of other medical specialties, including internal medicine branches (pulmonology, endocrinology, infectious disease, nephrology, oncology, hematology, hepatology, gastroenterology, and radiology) as well as surgical branches (general surgery, obstetrics-gynecology, and general anesthesia), among others (Fig. 3). Specific protocols and referral pathways should be established with obstetrics and gynecology for the care and follow up of women with CHD.

This is very similar to what has been recommended by other international consensus on the organization of ACHD care [19–21]. Once more, the importance of the pediatric cardiologist is highlighted in the transition, as a constant support for the ACHD unit, along with the social worker's cooperation which is extremely necessary due to access and financial barriers and even the exclusion and discrimination often faced by adult patients with CHD. The support of hepatologists and gastroenterologists is increasingly important for ACHDs with Fontan

circulation [22] and other types of complex congenital heart defects.

Since some LATAM and all Caribbean countries lie close to the equatorial zone, these patients are exposed to infectious agents which cause endemic tropical diseases like malaria, yellow fever, dengue, Zika virus and Chagas disease [23]. These tropical diseases have cardiovascular manifestations including myocarditis, pericarditis, heart failure and arrhythmias which, when they affect people with CHD, increase their morbidity and lethality. Maternal transmission of the Zika virus is also known to cause congenital defects like interatrial or interventricular septal defects [24,25]. Therefore, we emphasize that, unlike HICs in Europe and North America, our region needs the participation of tropical medicine specialists to strengthen the multidisciplinary teamwork previously described.

3.4. Development of ACHD training programs

Since the current number of ACHD specialists is very low, it is essential to increase the number of cardiologists with complete training in the specialty in all LATAM and Caribbean countries.

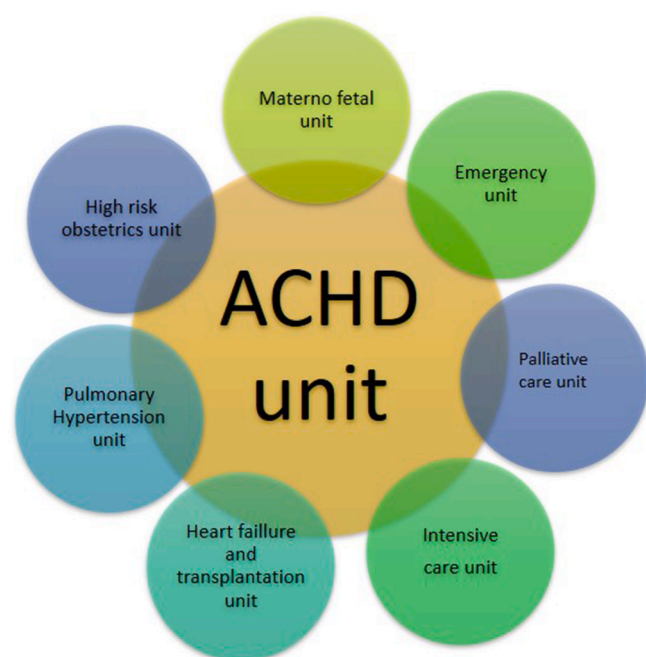


Fig. 2. Cardiovascular and non-cardiovascular specialized units that support the adult congenital heart disease unit (ROCK principle).

3.4.1. Recommendation

- a Promote the formation and development of ACHD training programs: this is already being implemented by some countries like Mexico and Argentina, who have developed an intensive year-long program in specialized training supported by universities and aimed at pediatric and adult cardiologists. Colombia and Chile are also considering this. The rest of the region's countries should take the programs which have already begun as models and develop their own programs adjusted to the local needs.

3.5. Strategic alliances with international ACHD units

This point is essential for strengthening the ACHD units created in the region, given the greater development and experience of high-level programs in North America and Europe. We understand that strategic alliances allow us to advance with our units. Currently, several countries are doing this; for example, the Commonwealth of Puerto Rico has an alliance with Boston Children's Hospital and seeks to promote and increase the experience of the island's cardiologists in ACHD management. Other countries like Colombia, Mexico, Argentina and Brazil are supported by other ACHD units in North America and the EU for counseling or consults to resolve complex ACHD cases.

3.5.1. Recommendation

- a Currently, the local ACHD leaders in each country, who have had the opportunity to be trained in ACHD centers outside of their countries, are the ones responsible for making these types of alliances. The experience of having learned at these centers provides the opportunity to continue ongoing supportive alliances at the hospitals in which ACHD units are being developed.

3.6. Latin American and caribbean alliance

The ACHD chapter of the IASC was founded under the slogan "All adults with congenital heart disease under the same banner." One of its objectives was for LATAM and Caribbean nations to join forces and work

together on ACHD. This goal is being built day by day and is growing stronger.

3.6.1. Recommendation

- a The already established and more advanced ACHD units can support the countries in the region that do not have an ACHD unit and are in the initial formation stage. For example, Argentina provides support to other nearby countries like Paraguay, Bolivia and Uruguay; Colombia supports nearby countries like Ecuador, Peru and Panama; Chile does this with some cases in Peru and Bolivia; and Mexico with Guatemala, El Salvador and Honduras.

4. Monitoring and constant development of the adult congenital heart disease units

We are aware that the formation and structuring of ACHD units is a big challenge for our region. There are particular barriers for each country, limited financial healthcare resources, and a small number of ACHD specialists, among many other challenges, which should not be an impediment. The first step is to start with each country's available resources, following the recommendations previously suggested in this paper.

4.1. Recommendations

- a. According to the complexity of the population cared for, each cardiovascular center responsible for creating an ACHD unit should have parameters for measuring quality and institutional performance to allow corrective measures to be taken in their functioning (for example, indices of mortality, complications, reinterventions, hospitalizations, and financial statements, among others).
- b. The IASC's ACHD chapter is carrying out an interamerican census of the actual number of ACHD units in our territory. Our task is to identify and include new units formed in the region on the list, and promote their growth and development.
- c. The ACHD chapter and Pediatric Cardiology Council is made up of a group of CHD experts who are not only able to emit recommendations for the organization and structuring of ACHD units, but also can provide constant monitoring of their quality and performance.
- c. ISACHD backing and ongoing support: recognizing that ISACHD is the most important and influential international community of ACHD professionals, strengthening our relationship with the international ACHD leaders in various regions of the world will allow us to reach our objectives.

5. Adult congenital heart disease unit certification

This is the goal we want to reach at the end of this whole process. Each ACHD unit in LATAM and the Caribbean should be duly certified by the Pediatric Cardiology Council and ACHD chapter of the IASC.

In 2020, the IASC developed a program for creating and certifying cardiometabolic prevention units (CMPUs) [26]. This was a strategic proposal to reduce the impact of atherothrombotic cardiovascular disease, recognized to be the main cause of morbidity and mortality in all America [27]. This proposal encourages us to follow the example of other IASC councils.

5.1. Recommendations

- a. Following the initiative proposed by IASC for the CMPUs, it is now the Pediatric Cardiology Council and ACHD chapter's mission to develop the tools to train the various ACHD units in LATAM and the Caribbean, and determine the parameters to achieve certification.
- b. The Pediatric Cardiology Council and ACHD chapter are currently carrying out continuing education, updating, and training activities

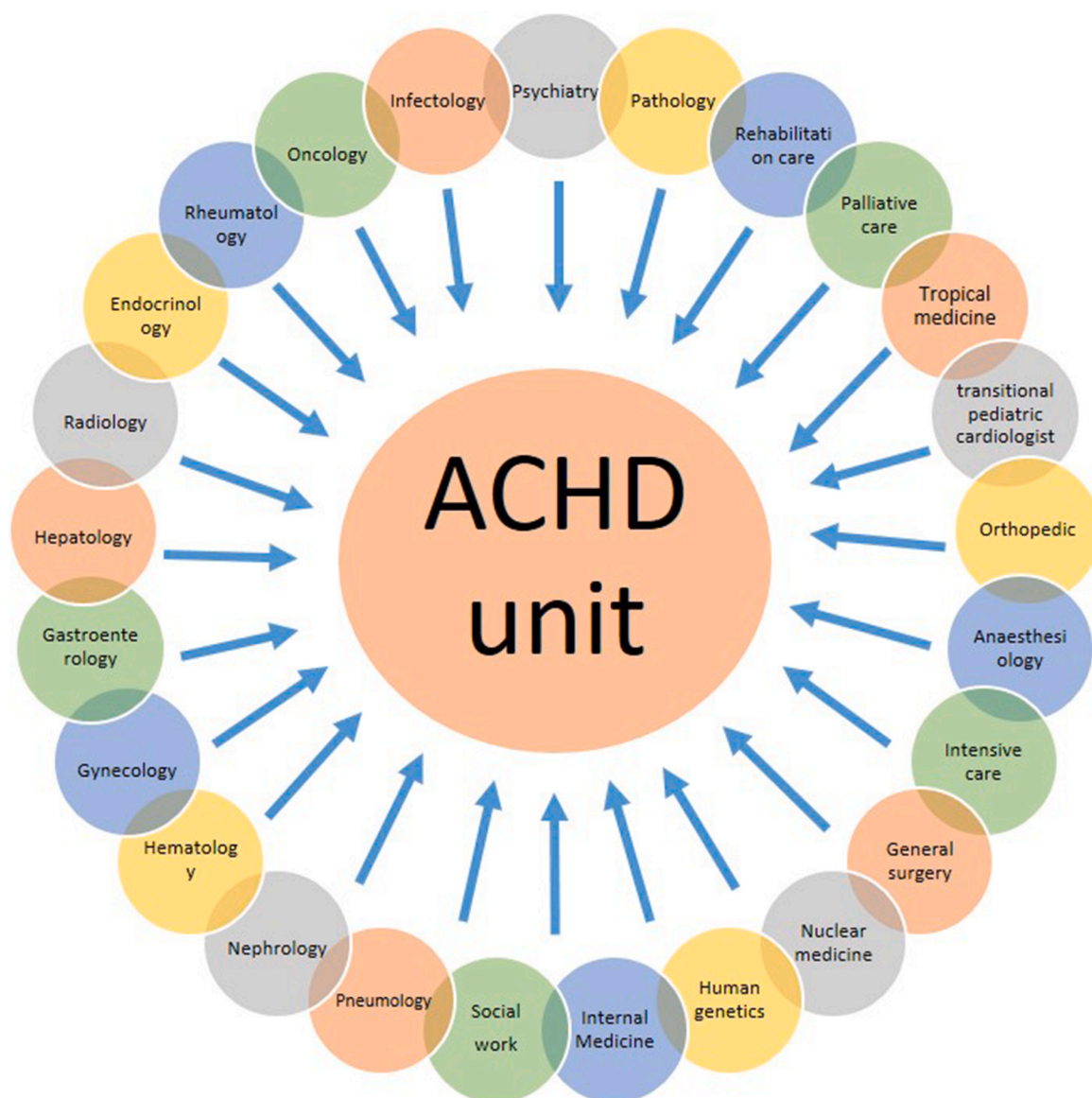


Fig. 3. Adult medical specialties supporting the ACHD unit (ROCK principle).

through the group of experts in the ACHD chapter. These activities are the basis for training the emergent ACHD units in LATAM and the Caribbean. We also recognize that the support of ISACHD will be essential for achieving this purpose.

- c. Foster ACHD research. To achieve certification and excellence in care, it is important for the new ACHD units to actively participate in local, national and international ACHD research projects. This will allow a deeper understanding of our own reality and help adapt ACHD training programs aimed at responding to the needs of the population.

6. Limitations

This paper attempts to be a reference point for LATAM and Caribbean countries. Its recommendations are the product of the consensus of experts and leaders from the participating countries. However, we recognize that not all countries have the same level and development in ACHD care. Thus, we have tried to be inclusive and impartial. While most of the region's countries are represented, there are some in which we have not yet found leaders in this field, and therefore we do not

thoroughly understand the ACHD care situation. We recognize that the implementation of these recommendations will help but will not solve all the problems. We have tried to address the most relevant topics, and some topic may have been left out at this time.

7. Conclusions

Currently, CHD survival is more than 90% in developed countries, and this is also occurring in LATAM and the Caribbean. Consequently, the rapid growth of ACHDs has taken many countries by surprise, and LATAM and the Caribbean are not the exception. Adults with congenital heart disease are a special and vulnerable population who need lifelong monitoring and care. Concentrating and centralizing this population in special units is a challenge. Recognizing the weaknesses and confronting the barriers is the first important step to take in the region. These recommendations are the first collaborative work between LATAM and Caribbean nations, and we believe that follow up and adaptation to the needs of each country will significantly improve this population's prognosis.

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Declaration of competing interest

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