



Congenital Heart Disease in Canada: The Need for Comprehensive and Accessible Care

Fregonas A¹_{HBSc} & Kugamoorthy P^{2*}_{MD}

¹University of Ottawa Faculty of Medicine, MD 2025 Candidate, Secretary and Board Member, Canadian Congenital Heart Alliance, Canada.

²Vice-President Canadian Congenital Heart Alliance, Department of Cardiology and Translational Research, University Health Network, Canada.

*Corresponding author: **Priyanka Kugamoorthy**, Vice-President Canadian Congenital Heart Alliance, Department of Cardiology and Translational Research, University Health Network, Canada. **E-mail:** p.kugamoorthy@gmail.com

Received: November 17, 2023; **Accepted:** October 29, 2024; **Published:** November 05, 2024

©Copyright 2024: Fregonas & Kugamoorthy. This is an open access article distributed under the terms of the Creative Commons Attribution License [CC-BY 4.0.], which permits unrestricted use, distribution, and reproduction in any medium, provided the original author and source are credited.

Abstract

Advancements in the medical management of congenital heart disease (CHD) have considerably improved prognosis and outcomes for affected individuals. However, significant gaps remain in ensuring lifelong, multidisciplinary care for the CHD community. Approximately 1 in 100 newborns will be diagnosed with CHD in Canada. CHD is a chronic condition that requires continuous follow-up with trained providers. Yet, access to comprehensive care remains limited across the country. This commentary addresses the disparities that exist within the field of CHD, highlighting the lack of available providers, the need for more accessible ACHD centers, the vulnerable populations in Canada, as well as the gaps that exist within CHD research. The authors urge the medical community to prioritize the expansion of accessible care, consider social determinants of health in the context of CHD, and employ strategies to meet the needs of Canadians living with CHD, advocating for a national approach to bridge these critical gaps.

Keywords

Congenital Heart Disease (CHD); Adult Congenital Heart Disease (ACHD); Health Disparities in Canada; Social Determinants of Health

Introduction

Congenital heart disease (CHD) is a chronic disease that requires continuous monitoring throughout one's life. Despite successful interventions that seek to repair the anatomical anomalies of the heart and diminish immediate risks to one's health, those with CHD should still be monitored throughout their lives [1]. This is necessary to mitigate any changes in their cardiac health and prevent other comorbidities. The incidence of CHD in newborns is approximately 1 in 100 within Canada [2]. Medical advancements in the early diagnosis of CHD and improved treatments have extended the lives of those with CHD, meaning that the vast majority of individuals will live until adulthood [3]. The population of adults living with CHD is increasing, thus presenting a unique set of concerns and risk factors to the future cardiovascular health of Canadians. Therefore, there is a growing need for CHD-specific resources and CHD specialists that are widely available across the nation, equitable services for vulnerable populations, and comprehensive research on the health outcomes of Canadians with CHD.

Lack of Providers

Following pediatric cardiac care, those with CHD should be transitioned to follow-up care with an adult CHD (ACHD) specialist. Nevertheless, the lack of follow-up care is a pertinent issue in this population. A recent Canadian study published in 2022 found that only two-thirds of their pediatric population had a successful transition into adult care [4]. Although it is an increase from a 23% follow-up rate in 2007 [3], there is still a large population of individuals with CHD who are not receiving adequate care. Even those that would prefer to be followed more closely by their Cardiologists may not be able to achieve this due to a lack of accessibility and wait times that surpass Canadian recommended guidelines [3]. Survey results based on data from 2020 indicate that only 46% of physicians treating ACHD patients in Canada have had formal ACHD training, and 3% of all Cardiologists practicing in Canada have received ACHD training [5]. The growing population of adults with CHD have not been met with adequate improvements in the accessibility of care, and in fact, resources have decreased in proportion to patient growth when examining data between 2007 to 2020 [5]. Individuals living with CHD also face challenges with mental health that can impact their quality of life, with approximately one-third of patients reporting clinically significant anxiety, depression, or both [6]. The psychological needs of this 1 of 8 populations are not adequately addressed, and should be met with a greater integration of mental health professionals into the CHD circle of care [7].

Disparities in Access to Care

As seen in Figure 1, there are only 16 specialized ACHD clinics in Canada, 6 of which are located in Southern Ontario. Given that 44% of the active Canadian ACHD patients reside in Ontario, it is necessary to have a considerate amount of resources directed there [5]. However, these centers are concentrated in Southern Ontario, leaving the rest of the province with a paucity of resources. Additionally, Prince Edward Island, New Brunswick, Yukon Territory, Northwest Territory and Nunavut do not have a single, specialized ACHD center. Atlantic Canada accounts for 9% of the active ACHD cases, but the active cases in the territories have not been reported [5].



Figure 1: Distribution of ACHD centers across Canada [9].

The sparsity of ACHD centers makes it extremely difficult, both from a financial and logistical perspective, for individuals with CHD in more rural and remote regions of Canada to travel long distances to receive care. Additionally, children are less likely to receive a prenatal diagnosis of critical CHD if they are a part of families who face long commutes to healthcare centers [8,9].

A lack of accessible centers may be more concerning in provinces with higher poverty rates, such as Nova Scotia and British Columbia, which both had poverty rates of 9.8% in 2020, well above the Canadian average of 8.1% [10]. An Ontario-based study found that mothers within a region with a higher rate of material deprivation, a proxy for measuring poverty, were found to have an increased risk of having an infant with CHD [11]. Employment flexibility and the cost of travel poses a significant barrier to Canadians who require close monitoring, especially those of a lower socioeconomic status. Further, despite the role of virtual care in attempting to break the barriers in healthcare accessibility, specialized tests such as echocardiograms, ECGs and cardiac stress tests are often necessary to determine the state of one's health and appropriately counsel individuals on the future direction of their medical care.

Given that the COVID-19 pandemic has imposed further difficulties with obtaining primary care, numerous individuals with CHD have the potential to go years without receiving any kind of medical review. This lack of follow-up is occurring in the context of an aging population that is at risk of acquiring other comorbidities. The susceptibility of adults with CHD to various comorbidities will vary based on their diagnosis [12]. Further, adults with CHD may require surgical or percutaneous procedures later in life (12) which may pose additional complications to their care. For example, about 10-20% of those with coarctation of the aorta will develop a re-coarctation [12], which may subsequently need to be repaired. The effects of these circumstances not only impact the individual's health in the long-term, but they also impose a cost to the Canadian healthcare system. From 2004 to 2013, the cost of CHD care has risen by 21.6%, resulting in \$121 million being directed towards CHD care in 2013 [13]. Therefore, a concerted effort should be directed towards the analysis of the economic impacts of an aging CHD population and the strain it may impose on the Canadian healthcare system.

Vulnerable Populations in Canada

Racialized individuals with CHD may experience poor outcomes as a result of bias and structural racism [8,14]. Those that experience perceived bias and a lack of respect towards their cultural practices may be less likely to obtain pre-and post-natal medical attention [8]. Additionally, there are certain populations, such as individuals of South Asian descent, that are known to have higher rates of cardiovascular disease [15], which is independent of their CHD lesion. It is increasingly important for close surveillance to be maintained within this population to monitor for acquired heart disease in addition to one's CHD. Particularly vulnerable populations in Canada are Indigenous peoples, who have higher rates of cardiovascular disease, and unique barriers to accessing cardiac care in comparison to other Canadians [16]. An additional complicating factor is the perpetuated racism towards Indigenous people [17]. The fear instilled into these communities as result of the negative healthcare encounters experienced by individuals, and those that have been highlighted in the media, make it even less likely for an Indigenous person with CHD to elect to receive follow-up care. Therefore, the root cause of this 3 of 8 issues is twofold; the limited access to appropriate resources, and the need for the structure of the Canadian healthcare system to be more culturally competent and safe. Although there are some online resources that provide information on Indigenous health and culture this education must be incorporated into everyday practice [18]. There is limited literature on the immediate and long-term outcomes of racialized and Indigenous individuals with CHD in Canada. Without research directed towards delineating these answers, Canada as a nation will not be meeting the needs of these populations.

Addressing Gaps in Research

To ensure that all individuals with CHD are monitored appropriately, regardless of their area of residence, there must be a unified effort across Canada to address the current gaps in research and care. The Canadian Cardiovascular Society has published new guidelines for common congenital heart lesions in 2022 that may serve as a point of reference for clinicians to take into account within their practice [12]. An important point of consideration to highlight is that clinical guidelines are created on the basis of high quality research such as randomized clinical trials. However, the majority of cardiovascular clinical trials that have been conducted either will not contain a sufficient number of participants with CHD to analyze their data independently, or choose to exclude participants with CHD from the study altogether (12). There are scant randomized clinical trials dedicated to CHD, and the majority of lesions, and medical therapies used to treat them, lack these robust forms of investigation [12,19]. Notably, there is a lack of longitudinal data that provides insight on health outcomes in those with CHD which is increasingly valuable in the aging CHD population. Curating this data in the CHD population faces notable challenges, including a lack of resource allocation, and a small subset of potential participants given the low rates of follow-up care [19]. ACHD centers across the country should collaborate with one another to achieve an appropriate sample size and diverse population of participants to aid in the conduction of this research.

Future Directions

There are many potential strategies that can be utilized to improve care for those with CHD. A method of increasing access to care can include more exposure to ACHD within traditional cardiology training, as well as internal medicine residencies as a whole. This may increase CHD-specific knowledge in non-ACHD physicians that are practicing in more rural regions of Canada, and accommodate patients that may have difficulty accessing tertiary care centers. More information can also be given to medical students to increase their awareness of this area of medicine prior to entering a residency program. Further, training can be provided to other clinicians, such as Primary Care Physicians, to help bridge the gap in care for those subjected to extensive wait times to see their Cardiologists. Allied healthcare workers such as Nurse Practitioners and Psychotherapists may be integrated more broadly into the care of those with CHD to address their healthcare needs from a multidisciplinary standpoint. To ensure that the culture of those at the clinic is respected, staff may be asked to engage in training courses or modules centered on cultural competency. Additionally, patients can be asked about their preferred language prior to their appointment to eliminate barriers to communication with their healthcare team. Clinics can also aim to become more welcoming by providing educational resources in multiple languages, while highlighting any cultural considerations that are relevant to one's cardiac health. These resources can include information about CHD, in addition to mental health resources and guidelines for maintaining a healthy lifestyle.

Conclusion

CHD is a heterogeneous disease, and the prognosis and course of treatment will vary greatly between individuals. Social factors can influence not only an individual's ability to seek care, but their risk of complications in the future. These social factors are not uniform across Canada, and the intersectionality of these social components may vary in a unique way for each individual. Therefore, it is essential to obtain as much information as possible on the social aspects of one's life that can influence their cardiac health in the future. This information should be gathered and synthesized from a pool of participants that are diverse in their CHD presentation, ethnicity and race, geographical location of residence, and social determinants of health (14). This is vital information that must be made available to physicians to deliver evidence-based care, and also to those living with CHD to offer them a sense of autonomy. Healthcare for those living with CHD has been significantly advanced by the medical community. However, there are still important steps to take to address the social components of CHD care, while ensuring that it is equitably available. Advocating eradicating existing barriers must be at the forefront of patient care whilst addressing the ever-

evolving medical challenges faced by those living with CHD.

Contribution

PK and AF researched literature and wrote this commentary. All authors reviewed and edited the commentary and approved the final version of the article.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Ethical Approval

Ethical approval was not sought for this article because this research commentary did not use any patient data.

Funding

The authors received no financial support for the research, author-ship, and/or publication of this article.

Informed Consent

Informed consent was not sought for this article because no patient data was used.

References

1. Baumgartner B, Backer JD, Babu-Narayan SV, Budts W, Chessa M, et al. (2020) ESC guidelines for the management of adult congenital heart disease. *Eur Heart J* 42(6) 29: 563-645.
2. Marelli AJ, Ionescu-Ittu R, Mackie AS, Guo L, Dendukuri N, et al.(2014) Lifetime Prevalence of Congenital Heart Disease in the General Population from 2000 to 2010. *Circulation* 130(9): 749-756.
3. Beauchesnea LC, Judith Therrienb J, Alvarezc N, Mackien AS, Silversides CK (2012) Structure and Process Measures of Quality of Care in Adult Congenital Heart Disease Patients: A Pan-Canadian Study. *Int J Cardiol* 157: 70-74.
4. Suliman A, Ruochen Mao R, Hiebert B, Shah AH, et al. (2022) The Critical Transfer from Paediatrics to Adult Care in Patients with Congenital Heart Disease: Predictors of Transfer and Retention of Care. *CJC Pediatric and Congenital Heart Disease* 1(3): 129-135.
5. Ducas RA, Mao T, Beauchesne L, Hayami D, Kells C, et al. (2023) Adult Congenital Heart Disease Care in Canada: Has Quality of Care Improved in The Last Decade? *Can J Cardiol* 40(1): 138-147.
6. Kovacs AH, Luyckx K, Thomet C, Budts W, Enomoto J, et al (2024) Anxiety and Depression in Adults with Congenital Heart Disease. *J Am Coll Cardiol* 83(3): 430-441.
7. Kovacs AH, Brouillette J, Ibeziako P, Jackson JL, Kasparian NA et al. (2022) Psychological Outcomes and Interventions for Individuals with Congenital Heart Disease: A Scientific Statement from the American Heart Association. *Circ Cardiovasc Qual Outcom* 15(8): 672-688.
8. Jackson JL, Grant V, Barnett KS, Texter K, Laney B, et al. Structural Racism, Social Determinants of Health, and Provider Bias: Impact on Brain Development In Critical Congenital Heart Disease. *Can J Cardiol* 39(2): 133-143.
9. Available at: Canadian adult congenital heart (CACH) network. Canadian Adult Congenital Heart CACH Network, Canada
10. Xuelin Z, Andre B (2022) This Census in Brief Article Focuses on the Experiences of Poverty in Canada Based on Data from the 2021 Census. It Examines Disaggregated Poverty Trends by Age, Gender, Family Situation, Immigration Status as Well as by Indigenous Identity and for Racialized Groups. When Possible, Comparisons Are Madeto Data from the 2016 Census. Government of Canada, Statistics Canada, Government of Canada, Statistics Canada, Canada,
11. Qun M, Dunn S, Wen SH, Lougheed J, Maxwell C et al.(2022) Association of Maternal Socioeconomic Status and Race with Risk of Congenital Heart Disease: A Population-Based Retrospective Cohort Study in Ontario Canada. *Epidemiology*12(2):

12. Marelli A, Beauchesne L, Colman J, Mulder BJ, Warnes CA, et al. (2022) Canadian Cardiovascular Society 2022 Guidelines for Cardiovascular Interventions in Adults with Congenital Heart Disease. *Can J Cardiol* 38(7): 862-896.
13. Mackie AS, Tran DT, Marelli AJ, Kaul P (2027) Cost of Congenital Heart Disease Hospitalizations in Canada: A Population-Based Study. *Can J Cardiol* 33(6): 792-798.
14. Bayne J, Garry J, Albert MA (2023) Brief Review: Racial and Ethnic Disparities in Cardiovascular Care with A Focus on Congenital Heart Disease and Precision Medicine. *Curr Atheroscler Rep* 25(5): 189-195.
15. Ahmed ST, Rehman H, Akeroyd JM, Alam M, Shah T, et al. (2018) Premature Coronary Heart Disease in South Asians: Burden and Determinants. *Curr Atheroscler Rep* 20(1).
16. Vervoort D, Kimmaliardjuk DM, Ross HJ, Fremes SE, Ouzounian M, et al. (2022) Access to Cardiovascular Care for Indigenous Peoples in Canada: A Rapid Review. *CJC Open* 4(9): 782-791.
17. Kitching GT, Firestone F, Schei B, Wolfe S, Bourgeois C, et al. (2019) Unmet Health Needs and Discrimination by Healthcare Providers among an Indigenous Population in Toronto, Canada. *Can J Public Health* 111(1): 40-49.
18. All Courses: Ontario Health E. Learning, elearning.ontariohealth.ca/course/index.php?categoryid=20.
19. Diller GP, Arvanitaki A, Opotowsky AR, Jenkins K, Moons P, (2021) Lifespan Perspective on Congenital Heart Disease Research. *Journal of the American College of Cardiology* 77(17): 2219-2235.