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Review

Access to Specialized Care Across the Lifespan in Tetralogy of Fallot

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ABSTRACT

Individuals living with tetralogy of Fallot require lifelong specialized congenital heart disease care to monitor for and manage potential late complications. However, access to cardiology care remains a challenge for many patients, as does access to mental health services, dental care, obstetrical care, and other specialties required by this population. Inequities in health care access were highlighted by the COVID-19 pandemic and continue to exist. Paradoxically, many social factors influence an individual's need for care, yet inadvertently restrict access to it. These include sex and gender, being a member of a racial or ethnic historically excluded group, lower educational attainment, lower socioeconomic status, living remotely from tertiary care centres, transportation difficulties, inadequate health insurance, occupational instability, and prior experiences with discrimination in the health care setting. These factors may coexist and have compounding effects. In

RÉSUMÉ

Pour les personnes qui vivent avec la tétralogie de Fallot, des soins spécialisés en cardiopathie congénitale (CC) sont nécessaires pour surveiller et prendre en charge toute complication tardive éventuelle. Toutefois, l'accès à des soins en cardiologie demeure difficile pour de nombreux patients, tout comme aux services en santé mentale, aux soins dentaires, aux soins obstétriques et à d'autres soins spécialisés dont cette population a besoin. Des inégalités dans l'accès aux soins de santé ont été mises en lumière lors de la pandémie de COVID-19 et continuent d'exister. Paradoxalement, de nombreux facteurs sociaux agissent sur les besoins d'une personne en matière de soins, et limitent en même temps son accès à ces soins. Le sexe et le genre, l'appartenance à un groupe racial ou ethnique ayant vécu une exclusion par le passé, un niveau de scolarité ou un niveau socio-économique plus faible, l'éloignement géographique des centres de

Timely access to appropriate health care has become a pressing concern for Canadians, Americans, and people all over the world in recent years. Problems pertaining to inadequate access to family doctors as well as long wait times and overcrowding in emergency departments are regularly identified by the media, patients, and health care professionals.[1,2] The COVID-19 pandemic amplified inequities within health care systems[3,4] as well as urgent issues regarding health care worker burnout and retention,[5] both of which can further undermine access to primary care and subspecialty services.

Access to care is defined as "the timely use of personal health services to achieve the best possible health outcomes."[6] This paper, as part of a focused issue from the *Canadian Journal of Cardiology—Pediatric and Congenital Heart Disease*, addresses issues relevant to access to specialized care among individuals with one of the more common forms of congenital heart disease (CHD), namely tetralogy of Fallot (ToF). Despite excellent outcomes from surgical repair that are typically achieved in infancy, late complications are common, and timely diagnosis allows for effective interventions. These include but are not limited to pulmonary regurgitation requiring pulmonary valve replacement, branch pulmonary artery stenosis requiring balloon dilation and/or stenting, endocarditis, and tachyarrhythmias requiring catheter ablation.[7] Individuals with ToF require access to a primary care clinician, typically a physician or nurse practitioner, who can serve as the medical home, in addition to lifelong specialized CHD care.[8] Several other health care services are also relevant

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addition, many patients believe that they are cured and unaware of the need for specialized follow-up. For these reasons, lapses in care are common, particularly around the time of transfer from paediatric to adult care. The lack of trained health care professionals for adults with congenital heart disease presents an additional barrier, even in higher income countries. This review summarizes challenges regarding access to multiple domains of specialized care for individuals with tetralogy of Fallot, with a focus on the impact of social determinants of health. Specific recommendations to improve access to care within Canadian and American systems are offered.

soins tertiaires, les difficultés de déplacement, une protection inadéquate en matière d'assurance de soins de santé, la précarité professionnelle et des expériences antérieures de discrimination en contexte de soins de santé font partie de ces facteurs, qui peuvent coexister et avoir un effet cumulatif. De plus, de nombreux patients croient être guéris et ne sont pas conscients qu'un suivi spécialisé est nécessaire pour eux. Pour ces raisons, les interruptions des soins sont fréquentes, en particulier au moment de la transition entre les soins pédiatriques et les soins destinés aux adultes. La pénurie de professionnels de la santé formés pour intervenir auprès d'adultes présentant une CC est un obstacle supplémentaire, même dans les pays à revenus élevés. Notre article de synthèse résume les obstacles vécus par les personnes vivant avec la tétralogie de Fallot dans l'accès à plusieurs types de soins spécialisés, en portant une attention particulière aux déterminants sociaux de la santé. Des recommandations concrètes pour améliorer l'accès aux soins en contexte canadien et américain sont présentées.

to the ToF population; for example, approximately 20% of affected individuals have identifiable chromosomal defects, the most common being 22q11 deletion syndrome.[9] Access to obstetrical care coordinated with adult CHD (ACHD) clinicians is essential to optimize maternal and fetal outcomes. Mental health comorbidities such as anxiety and depression often coexist in the ToF population,[10] yet access to mental health care is a major challenge for many individuals, particularly for those with limited financial resources. Figure 1 highlights factors that contribute to access to health care and desirable ToF outcomes as well as factors, such as adverse social determinants of health, that serve as barriers to optimal CHD care.

This review addresses factors that influence access to care across the lifespan and offers mitigation strategies for individuals living with CHD, with a primary focus on ToF. This is written from the perspective of an interdisciplinary group of health care professionals, including one who has lived experience with ToF, with an emphasis on Canada and the United States. We note, however, that access to CHD care is an unmet need for many individuals around the world, particularly those in low- and middle-income countries.[11] We begin with a review of social circumstances that influence access to health care and then elaborate on access to unique elements of health care across the life trajectory for people born with ToF.

Social Determinants of Health

Social determinants of health (SDOH) are defined by the World Health Organization as the circumstances in which people are born, grow, live, work, and age, and the systems put in place to manage illness.[12] SDOH are formed by the distribution of money, power, and resources, and are largely responsible for avoidable differences in health status.[13] SDOH are highly inter-related and have been cataloged into 5 domains: economic stability (including employment, food insecurity, housing instability, and poverty), education access and quality (including language and literacy), health care access and quality (including health literacy and access to health services), neighbourhood and built environment (including access to healthy foods, crime and violence, environmental conditions, and quality of housing), and social and community context (racism, discrimination, and social cohesion).[13,14]

Recognizing that SDOH are not similarly distributed in the population highlights an important difference between equity and equality. *Equality* occurs when people experience or receive the same amount of something regardless of what they need, whereas *equity* exists when people experience or receive something based on what is needed in an impartial and fair way.[15] The COVID-19 pandemic unmasked glaring racial inequities, which are a product of structural and overt racism and have also affected cardiovascular disease (CVD) risk and outcomes, especially among Black, Hispanic/Latino, and other historically excluded racial and ethnic groups.[4] Significant health disparities affecting these groups are the product of staggering adverse SDOH and do not reflect biologic factors but reinforce that race is a social construct.[16] Thus, patients with CHD from historically excluded racial and ethnic groups are more likely to experience lower socioeconomic status (SES), inadequate insurance, food insecurity, occupational instability, transportation barriers, and racism, among others, which puts them at significant disadvantage throughout their life beginning before birth.

The epitome of adverse SDOH is manifested in higher age-adjusted mortality attributed to CHD affecting Black people in the United States,[17] although health disparities have also been documented throughout the lifespan. From a prenatal standpoint, women in low-income and lower education neighbourhoods have 29% and 34% higher adjusted odds of having infants with CHD.[18] Families from lower SES, Hispanic ethnicity, or rural residence experience 15%-22% lower likelihood of prenatal detection of complex CHD,[19] which influences future educational attainment[20,21] and opens a pervasive maelstrom of increasing adverse SDOH. Adverse neonatal and infant postsurgical outcomes as well as CHD-related infant mortality are more common among Black patients; lower neighbourhood income and disease complexity magnify this association.[22] As surviving patients age, we observe further influence of adverse SDOH, including loss to follow-up,[23] endocarditis-related hospitalizations among adults with ToF,[24] and in-hospital mortality in ACHD

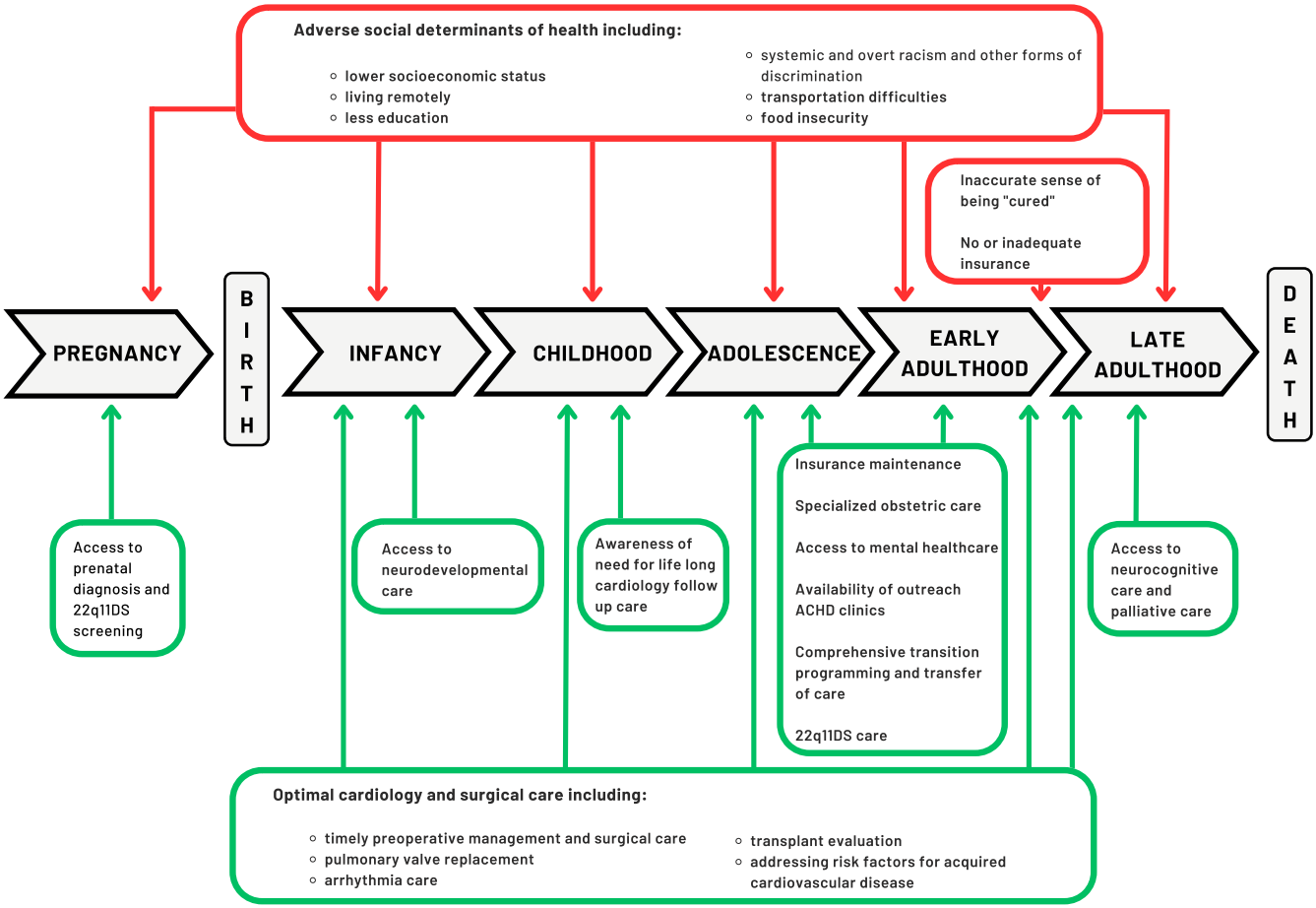

Figure 1. Access to optimal tetralogy of Fallot care across the lifespan. Clinical services and factors in (**green boxes**) reflect ideal access to care. In contrast, factors in (**red boxes**) represent barriers to care. ACHD, adult congenital heart disease.

surgery.[25,26] Furthermore, adverse SDOH and childhood adversity predispose individuals to CVD risk factors such as obesity, hypertension, metabolic syndrome, and to experience CVD in early adulthood.[27,28]

Access to Health Care

Access to prenatal diagnosis

Prenatal diagnosis of ToF is readily available in tertiary care centres and allows for immediate postnatal management and intervention among newborns with ToF and pulmonary atresia or critical pulmonary stenosis. Fetal echocardiography is highly sensitive and specific for predicting the need for a neonatal intervention in ToF.[29] Access to fetal echocardiography, however, is reduced among Hispanic[19] and Black[30] people, those living remotely from tertiary care centres,[31] lacking private medical insurance,[30] and of lower SES,[32] even in jurisdictions having universal access to health care.[32] Furthermore, access to prenatal diagnosis relies on effective obstetrical screening; detection of ToF requires an outflow view, as the 4-chamber view is typically normal. Therefore, factors that reduce access to prenatal care and effective screening will in turn influence the likelihood of prenatal diagnosis. Fetal telecardiology, with remote interpretation of images by paediatric cardiologists, was adopted during the COVID-19 pandemic without compromising diagnostic accuracy,[33] and is one model after the pandemic to reduce the need for patient travel to tertiary centres and improve access to this vital service.

Access to prompt postnatal diagnosis

Neonates with critical CHD, including ToF variants with pulmonary atresia or critical pulmonary stenosis, require prompt recognition and management after birth when a prenatal diagnosis has not been made. Data from Texas demonstrate that Black and Hispanic neonates are more likely to have a late referral (>4 days of age) and have higher neonatal mortality relative to their White counterparts.[34] Routine adoption of screening pulse oximetry in all neonates reduces the likelihood of a late diagnosis, though is not sensitive for some forms of CHD (eg, coarctation of the aorta) and may not reduce mortality when birth occurs remote from a surgical centre (eg, transposition of the great arteries).[35] Therefore, access to fetal echocardiography and prenatal diagnosis is critical.

Access to timely corrective surgery

Although data specific to ToF are lacking, population-level data from Canada have shown that among children with moderate or complex CHD, lower SES quintile is associated

with later age at first intervention.[36] In the United States, a study from the 1990s showed that children with private insurance underwent ToF repair at a median age of 8.7 months compared with 11.4 months for those with Medicaid insurance.[37] However, race and ethnicity were not directly associated with age at repair in that study. A more recent literature review by Ross et al.[38] did not find a conclusive impact of race or ethnicity on age at CHD surgery, likely because literature on this topic is very limited.

Infant mortality and outcomes of corrective surgery

Although CHD-specific infant mortality is decreasing over time, non-Hispanic Black infants continue to have the highest mortality attributable to CHD in the United States, followed by Hispanic infants.[17] Relative to White infants, mortality rate ratios for Black and Hispanic infants have increased slightly over time, reflecting increasing disparities in CHD-specific infant mortality.[17] Mortality in this age group is often perioperative. Reasons for these disparities are complex and multifactorial. However, it is worth noting that Black patients are less likely to be managed with extracorporeal membrane oxygenation after congenital heart surgery than White patients.[39] Furthermore, patients of lower SES may be more likely to be referred to low-performing hospitals.[40,41] Gonzalez et al.[42] recognized 20 years ago that racial differences in mortality in the United States are due to inequitable access to care, rather than biology.

Individual, institutional, system-level, and population-level factors may all contribute to the persistence of these racial and ethnic mortality disparities. For example, implicit bias and unconscious decisions may impact patient management decisions, and access to transportation may impact the ability of parents to seek urgent postoperative care when complications arise. Implicit bias training and understanding CHD centre quality and associated referral patterns are all necessary to address disparities in CHD mortality.[17]

Access to cardiology follow-up care in childhood

Loss to follow-up of children with CHD is well documented, even within the context of a government-funded health care system.[23,43,44] Risk factors for loss to follow-up include male sex,[44] lower SES,[23] lack of medical record documentation regarding the need for follow-up,[23] lack of awareness of the need for follow-up,[23] absence of symptoms, race (higher risk among patients from historically excluded racial and ethnic groups),[45] having Medicaid insurance,[45] and less severe disease.[44] Reid et al.[43] reported that 22% of patients with moderate or complex CHD at the Hospital for Sick Children in Toronto had not been seen after the age of 10 years. Likewise, Quebec data that included simple CHD demonstrated that 47% of children did not receive care after age 13.[44] In the United States, among a sample of >1000 children with moderate or complex CHD, only 42% returned to the cardiology clinic by age 5, and non-White children were at higher risk and experienced a lapse in care at younger ages than White children.[45]

Geographic remoteness from tertiary care centres is a reality for many children in Canada and the United States and reduces accessibility to cardiology care. Population-based data in Canada demonstrate that 30% of children with CHD live >100 km from the closest paediatric cardiology programme and 10% live >300 km away (straight-line distance).[36] Travel time and costs to access inpatient and outpatient care, and time away from work for parents, may be prohibitive. Among children with moderate CHD, including ToF, mortality in the first year of life was 43% higher among those living >300 km from the closest surgical centre relative to those living <100 km away.[36] This may reflect delays in diagnosis and referral, and/or suboptimal cardiology follow-up.

These data highlight the need for clinical programmes to take action to mitigate lapses in care and disparities in access to care. Some tertiary care programmes offer outreach clinics whereby a cardiologist, nurse, and sonographer travel to a smaller community hospital, significantly reducing the distance that patients and families need to travel. Virtual visits, which became commonplace during the COVID-19 pandemic, allow patients and clinicians to connect without any travel and can be an efficient method of conducting follow-up assessments for patients not requiring a physical examination. However, the importance of the physical examination in cardiology care limits the broad uptake of this approach.

Other strategies to facilitate follow-up during childhood include relying on clinics rather than parents to schedule appointments and emphasizing with parents the need and rationale for follow-up. This messaging should begin in infancy and be repeated throughout childhood.

Paediatric to adult transfer and retention in care in adulthood

Adolescents and young adults commonly experience gaps in care during the transfer from paediatric to adult CHD specialists, with 42% of patients in the United States with moderate CHD (including ToF) experiencing gaps of >3 years.[46] The lack of awareness of the need for lifelong care and a false sense of being cured are common contributing factors,[46] as are practical barriers including lack of insurance,[47] relocations with lack of awareness of how to find an ACHD clinic, and limited availability of ACHD-trained cardiologists. Black and Hispanic people with CHD are at higher risk of becoming lost to follow-up at this life stage.[48,49] Patients with simple lesions are at higher risk of lapses in care,[50] as are patients who had a scheduled follow-up of >12 months from the last encounter.[47] Strategies to improve timely arrival and retention in ACHD care include the following:

- Messaging regarding the importance of lifelong specialized CHD care that begins in infancy and is repeated throughout childhood, adolescence, and adulthood.
- Joint transition clinics, attended by both paediatric and adult clinicians.
- Detailed information about the ACHD programme, including location and team members, with positive endorsement from paediatric cardiologists.
- Direct inquiry into barriers to attendance at ACHD clinics (eg, transportation, distance, beliefs about the necessity of adult care).
- Comprehensive transfer letter prepared by the paediatric team that includes all available patient contact information, recommended time interval to the first

adult appointment, complete medical history in addition to pertinent psychosocial and neurodevelopmental history; to be sent to the ACHD team, primary care clinician, and patient.
- The ACHD clinic initiates the scheduling of the initial visit rather than relying on patients to do so.
- Appointment reminders are provided in multiple ways and according to patient preference (mail, telephone, email, text messaging, etc).
- Beginning in the paediatric setting and continuing after transfer to adult care, education and assistance regarding maintenance of health insurance; social work consultation availability.
- Collaboration with community-based and national patient and family CHD organizations to develop meaningful strategies focused on the importance of retention in care.
- Strong advocacy by paediatric and ACHD teams for policies to eliminate health care inequity (eg, lifelong health insurance independent of pre-existing conditions).

Challenges to Accessing ACHD Care in Canada

Although Canada has a universal health care system, equal access to health care resources is a fallacy that grossly underestimates the burden of living with a chronic disease.[51] Lack of access to primary care, being young, and being a woman are all examples of risk factors that lead to unmet health care needs for systemic reasons in Canada.[52] For adults with ToF, these unmet health care needs can be insidious and lead to worse long-term outcomes.[53]

Relative to paediatric cardiology programmes, adult CHD programmes in Canada are typically less resourced with respect to numbers of cardiologists, nurses, and allied health care staff including psychologists and social workers. As of 2010, there were 50% more adults than children living with moderate-complex CHD, including ToF,[54] and that discrepancy is likely even higher in 2023. Therefore, a much greater societal investment in ACHD care is needed.

A common barrier to long-term care for adults with ToF is the dearth of ACHD-trained specialists.[55] As the population of adults living with ToF has grown, the physician workforce required to care for these complex patients has not kept pace.[54,55] Although the number of physicians with formal training in ACHD in Canada has increased over the past 15 years, the absolute number of physicians caring for this patient population, which has grown more than 50%, has remained stagnant.[55] The Royal College of Physicians and Surgeons of Canada recently recognized ACHD as an area of focused competence with set training requirements.[56] Although this standardizes the training and provides recognition for specialists, it does not overcome the small number of available training spots, the lack of funding for training, and the length of training (up to 9 years after medical school) required to become an ACHD specialist.

In addition, physician expertise in managing long-term complications of ToF is clustered in large urban centres, leaving patients living in rural areas to travel long distances for care.[57] For other diseases in Canada, such as colon cancer, an urban-rural disparity in care has led to reduced overall survival for rural dwelling patients.[58] The recent increased uptake of virtual care models for ambulatory care may reduce this rural-urban disparity, and several review articles on this subject have recently been published.[59–62] The advantages of virtual care include convenience for patients and families, lower care delivery costs for providers, and the potential to link to devices that provide remote physiologic monitoring. There are also disadvantages; virtual care requires ongoing IT support, may result in compromised confidentiality, has less reach to rural areas, and can exacerbate disparities for patients with lower SES who may not have the resources needed to receive virtual care.[63]

Also contributing to the problem is the limited education of family doctors and general cardiologists regarding the possible long-term consequences of living with ToF, such as heart failure, arrhythmia, and multiorgan dysfunction.[64] This means that patients must rely heavily on specialists, as their family physician or local emergency department may be uncomfortable in managing their disease.[65] All of these factors combine to leave adults with ToF struggling to receive guideline-based care.[57] As many adults with ToF live with neurocognitive differences, advocating for their own health care may be an undertaking too daunting to achieve and drive lapses in care.[57,66]

In addition, the lack of universal pharmacare in Canada is a barrier to access for many adults with ToF.[67,68] As patients with CHD age, heart failure and arrhythmias contribute to morbidity and mortality.[69] Regarding novel therapeutics, patients with CHD who lack workplace benefits are left to shoulder the cost of expensive medications or do without.[70] Finally, access to advanced therapies, such as heart transplant, is limited to several large urban centres in Canada. This leaves some adults with ToF with the difficult choice between relocating to a different province or accepting a lower level of care.

We know that patients with ToF who do not have genetic syndromes have similar intelligence as age-matched controls.[66] Their lower educational attainment and incomes are, therefore, often largely attributable to systemic and societal factors.[71] This lower income status can be both the originator and the result of poor cardiovascular outcomes. Even in older Canadian patients with atrial fibrillation with pharmacare (>65 years of age), living in economically deprived neighbourhoods portends worse cardiac care and outcomes.[72] Quantifying the financial strain of living with ToF and the challenges to receiving guideline-based care in Canada are the first steps in rectifying these inequities and improving the lives and longevity of adults with ToF.

Challenges to Accessing ACHD Care in the United States

The US health care model creates additional barriers to accessing ACHD care for disenfranchised patients, above and beyond the barriers experienced within publicly funded health care systems. These include lack or inadequacy of health care coverage and inability to afford care.

Despite referral to ACHD centres being associated with mortality reduction,[73] acceptance of these referrals must

overcome insurance screening and contracting. Health care systems negotiate prices with insurance companies, and these are generally higher than Medicare or Medicaid and vary widely.[74] Hospital participation in Medicare and Medicaid is voluntary; however, not-for-profit hospitals are required to care for Medicare and Medicaid beneficiaries as a condition to receiving federal tax exemption.[75]

Strategies focused to improve access to ACHD care included Medicaid expansion, which was adopted by some US states as part of the Affordable Care Act. Full Affordable Care Act implementation has been associated with improved insurance coverage for all ACHD groups, but Hispanic patients and those in transition ages still face disparities.[76] When uninsured patients with CHD obtained insurance, there was an associated lower risk of emergency encounters, increasing efficiency of used resources.[77]

Affordability of CHD care remains a significant challenge even for those with private insurance. Parents of children with CHD are more likely to report food insecurity and delaying care due to inability to pay medical bills.[78] Many families may need to relocate to areas with lower cost of living to prioritize coverage of CHD care costs; however, insurance portability across state lines is variable and needs to be taken into account when making these decisions. These factors impact paediatric to adult transfer and continuity with ACHD care. Collaboration with social workers and financial counsellors within ACHD practices would help address these challenges.[79,80]

As in Canada, there is also an inadequate number of ACHD-trained specialists.[81] The scarcity of ACHD physicians (475 board-certified physicians up to May 2023 in the United States)[82] relative to the large ACHD population (estimated to be 1.4 million in 2010)[83] plays a significant service-demand mismatch and accentuates health disparities. Some factors influencing the low ACHD physician recruitment include the length of training (at least 8 years for Pediatrics or Internal Medicine residency-trained physicians and 9 years for Internal Medicine-Pediatrics residency physicians), lack of compensation compared with general cardiology practice, faculty positions available in limited geographic locations and restricted to large academic centres, the challenging landscape for building new programmes, and limited exposure to ACHD clinical and procedural care, likely exacerbated by the COVID-19 pandemic.[84] Some strategies aimed to improve this situation include increasing early ACHD exposure, curriculum innovation, and higher compensation derived from ACHD-specific taxonomy.

In the United States, almost half of the population lives more than 1 hour away from an ACHD centre, and those living in remote areas are more likely to be of Hispanic ethnicity, live below the federal poverty level, have lower educational attainment, and lack health insurance.[85] Living far from an ACHD centre is associated with gaps in care and higher resource utilization in emergency or inpatient services.[86] Efforts to overcome these problems should be multipronged and coordinated, including individuals, institutions, and systems. Priorities such as increasing and diversifying ACHD physician and health care professional recruitment,[84] decentralizing ACHD practices using geolocation,[87] and establishing partnerships with primary doctors and local cardiologists represent some initiatives to close current gaps in ACHD care. Decentralization can help increase access to care by reducing transportation distance and costs, and for some patients, avoiding hotel costs. Decentralization can also help offset patient volumes seen at the specialized ACHD centre. The disadvantages of decentralization include the potential for higher costs associated with care delivery necessitating a cost-effectiveness evaluation and the need to refer more complex patients on to the main referral site.

Access Challenges for Indigenous Children and Adults

Indigenous (First Nations, Inuit, and Métis) children and adults in Canada and the United States experience many adverse SDOH as described above. However, Indigenous persons face additional unique barriers to accessing health care. Reasons for this include systemic anti-Indigenous racism within Western health care,[88–92] the resulting distrust and fear of health care providers and systems, and the lasting effects of colonialism including intergenerational trauma resulting in part from the legacy of residential schools. At the same time, the burden of CVD is higher among Indigenous adults compared with the general population. For any given income level, Indigenous people have higher rates of cardiovascular risk factors and CVD than people of European origin.[93] Although data specific to ToF are lacking, the incidence of other types of CHD, including ventricular septal defects[94] and total anomalous pulmonary venous connection,[95] is higher in Indigenous children.

Gaps in understanding of Indigenous persons and negative attitudes toward them exist even among health care professionals who are motivated to pursue health equity.[88] Steps to address this have included the development of mandatory antiracist and anticolonial continuing professional education in some jurisdictions. However, learning about and reflecting on stereotypes and biases is not enough. When caring for Indigenous persons with ToF or other forms of CHD, health care professionals should self-correct when encountering their own biases, recognize that resources are often not the same for Indigenous persons with respect to transportation to appointments or access to primary care, and that perception of stereotypes can be inadvertently activated by words and actions, regardless of intent. At the hospital and/or department level, creation of an Indigenous health navigator or liaison programme can help inpatients and outpatients feel supported and can help improve communication and follow-up care with health centres in Indigenous communities. Inclusion of Indigenous persons on patient and family advisory councils is another step that can improve health care systems' understanding of the needs of the local Indigenous community that they serve.

Access to Reproductive Care

A specific challenge for women living with ToF is access to specialized reproductive and gynaecologic care. Although Canadian guidelines for the establishment of cardio-obstetrics programmes have been published, these specialized programmes are based in tertiary centres and therefore are less accessible to some women and do not encompass all gynaecologic concerns.[96]

The majority of general cardiologists are not well versed in contraception options.[97] Although estrogen-containing birth control is safe in those with ToF, concerns about thromboembolism and hypertension may be overestimated, resulting in suboptimal contraceptive options being presented.[98] Intrauterine devices are also safe in ToF, but should be inserted by a clinician with an understanding of the patient's underlying heart disease. Bradycardia and hypotension (cervical vasovagal response) can be triggered by cervical manipulation during intrauterine device insertion and could be especially problematic in those with a preload-dependent circulation (right heart failure) if not carefully considered in advance.[99]

All patients with ToF should receive preconception counselling if they are considering pregnancy.[96] They are at risk of right heart failure and arrhythmia but, as adult complications are heterogeneous, individualized counselling should be provided by an ACHD cardiologist with expertise in pregnancy care. Some will benefit from intervention or surgery before pregnancy (pulmonary valve implantation or replacement, device therapy), and this should be carefully considered.[100] Women with ToF should be provided with education regarding the elevated risk of CHD in offspring and should undergo fetal echocardiography, as should pregnant partners of men with ToF.[100] During pregnancy and at the time of delivery, patients with ToF require obstetricians and anaesthetists with expertise in high-risk cardiac conditions.[96] This may necessitate travel for care, which places an additional hardship on a pregnant person and their support system.

Some with ToF and high-risk anatomy may choose to terminate a pregnancy or be counselled to do so for the sake of their own cardiac health. Although access to a full spectrum of reproductive choices is less legally fraught in Canada than it currently is in the United States, availability of these services remains far from universal and judgement-free.[101]

Another source of inequity in the longitudinal care of women with ToF is the lack of research regarding nonreproductive gynaecologic care. Many important questions remain unaddressed in the ACHD literature. Research on dysmenorrhoea is sparse, with one study finding significantly different menstrual patterns in patients with cyanotic CHD and another identifying a higher rate of menorrhagia in all complex CHD.[102,103] Menopause and the impact of hormone replacement therapy for menopausal symptoms have not been studied in women with ToF or other forms of CHD. Despite the lack of evidence, short-term, low-dose, combined estrogen/progestin therapies are generally considered safe for women with CHD.[104] The impact of hormonal therapy on the long-term cardiac health of transgender persons with CHD remains unstudied. Research encompassing gynaecologic health throughout the lifespan of a person living with ToF, and not just focused on pregnancy, is sorely needed.

The recent overturn of Roe v Wade in the United States may disproportionately affect women with TOF from disenfranchised communities. In abortion-restrictive states, the proportion of women of childbearing age is higher among Hispanic women compared with non-Hispanic White women.[105] In addition, the strain on the health care system will be significant as abortion restriction is estimated to add 539 congenital surgeries in the first year after the overturn of Roe v Wade[106] and has the potential to widen health disparities, affecting historically excluded racial groups in the years to come. Strong advocacy is necessary to ensure that the full spectrum of obstetrics care is available to all women with CHD.

Access to Noncardiac Surgical Care

Children and adults with CHD having residual haemodynamic abnormalities, such as repaired ToF with significant pulmonary regurgitation, are at higher risk of perioperative morbidity and mortality.[107–111] Accordingly, the American Heart Association has published perioperative considerations for noncardiac surgery in children[112] and adults[8] with CHD. Patients require surgical care provided by interdisciplinary teams having expertise in CHD. Cardiologists, intensivists, and anaesthetists versed in CHD must provide input on the best location for safe conduct of noncardiac procedures and specify a qualified team (eg, cardiac anaesthesia, recovery in intensive care unit, etc). With respect to access, many patients are expected to travel farther to a cardiac centre than to a local noncardiac surgical facility.[113] Further, advocacy with insurance companies and government payors to ensure that individual patients access the right care at the right place may be necessary.

Noncardiac surgical requests, such as cosmetic reconstruction of prior cardiac surgical scars, and fertility and reproductive care, are examples of noncardiac surgical needs one may encounter throughout the lifespan. Access to other health care specialties, such as gender affirming care for transgender and gender nonconforming patients, is also highly disparate and limited by geographical and legislative barriers, expertise, stigmatization, and market availability.[114]

Access to Dental Care

Oral care is an integral part of overall health. Despite prevention programmes that have contributed to improvements in children's oral health in recent decades, dental caries remains common in children with CHD.[115] Dental health is important in the CHD population, as CHD represents a risk factor for the development of infective endocarditis (IE)[116] and approximately 30%-40% of IE cases are caused by oral streptococci. Individuals with cyanotic lesions including ToF, particularly ToF with pulmonary atresia, are at high risk relative to individuals having other CHD lesions.[116,117] Prosthetic material commonly used in repair of ToF, such as Contegra xenografts and transcatheter pulmonary valves, presents a risk factor for IE.[118,119] Poor dentition resulting in pulmonary valve endocarditis is a major contributor to morbidity and mortality in this patient population.[120–122]

Dental care in Canada and the United States is primarily delivered through private dental practices, with lack of public funding. This poses a significant challenge for adults with ToF.[123] The American Heart Association emphasizes the importance of biannual access to dental care.[124] Although children, seniors, and those on long-term disability are provided with some basic dental coverage in several Canadian provinces, many adults with ToF are required to pay out of pocket.[123] Accordingly, there are inequities in access to dental health, with individuals with lower SES often unable to afford care; 34% of the lowest income quintile Canadians report

avoiding dental professionals because of the cost.[125] Those without dental insurance of any kind, public or private, do not visit a dentist regularly.[125] Not surprisingly, these same disadvantaged individuals have the highest level of oral health problems.[125] Many patients with ToF stumble into this funding gap because they cannot afford the dental care that could prevent expensive hospitalizations and surgeries. The Canadian Dental Association recommends alternative funding and models of care to reduce inequities in access, coordinating public health programmes including outreach programmes, adding oral health as a part of early childhood development programmes, and fluoridating public drinking water.[126]

The use of antibiotic prophylaxis has been associated with a reduced IE incidence following invasive dental procedures in high-risk individuals, including those with prosthetic cardiac valves, common in individuals with ToF.[127] The morbidity is high in all cases of IE related to device implantation. For these reasons, cardiologists should routinely inquire about their patients' access to dental care, remind patients of symptoms that would suggest possible IE with an action plan for prompt medical evaluation with blood cultures before initiating antibiotics, and advise about the use of antibiotic prophylaxis for those that warrant it. Although patient education regarding the symptoms of endocarditis can improve promptness of care, it cannot prevent infections from developing in the first place.[128] Finally, cardiologists should connect patients who lack dental insurance or are unable to afford dental care with a social worker or other services to facilitate access.

Access to Mental Health Care and Neurocognitive Care Across the Lifespan

There is growing recognition that the care of individuals with ToF and other forms of CHD extends beyond medical surveillance and treatment and also includes optimization of neurocognitive and psychological outcomes. Although reviewed separately below, the multifactorial interplay between neurocognitive and psychological outcomes is well accepted.[129,130]

A 2011 Scientific Statement from the American Heart Association summarized the elevated risk of neurodevelopmental deficits among children with CHD, particularly across the domains of language, speech, attention, executive functioning, and behaviour.[131] Risk factors for neurodevelopmental and neurocognitive deficits and disabilities can present *in utero*, in the infant perioperative period, and across the entire lifespan, from childhood through adulthood.[130] Although contributing factors can be cumulative and interactive, the strong impact of SES on neurodevelopmental outcomes among children with CHD merits special note in this paper focused on access to care.[132] Further, only a minority of children with CHD undergo neurodevelopmental evaluation, and nonattendance has been associated with lower family income and insurance barriers.[133]

Neurocognitive deficits do not diminish in adolescence and adulthood, and in fact their impact can become more pronounced as they are expected to take a more independent role in daily living. Further, there are additional adult-onset cardiovascular risk factors for neurocognitive deficits including hypertension, coronary artery disease, stroke, diabetes, arrhythmias (including atrial fibrillation), and heart failure.[66,134,135] Adults with CHD also have greater susceptibility to early onset dementia.[136]

Although most individuals with ToF have neurodevelopmental outcomes within the normal range, as a group, there is an elevated prevalence of neurodevelopmental impairment.[137] Many individuals with conotruncal defects such as ToF also have 22q11.2 deletion syndrome,[9] which is associated with an increased prevalence of autism spectrum disorder and attention deficit-hyperactivity disorder.[138,139] Based on findings from a systematic review of 14 studies, the odds of structural brain abnormalities detected on magnetic resonance imaging were 7.9 times higher among adolescents and adults with CHD compared with comparison groups.[140] Imaging has similarly revealed signs of brain injury specifically within the ToF population.[141]

Sound strategies have been proposed to optimize neurodevelopmental and neurocognitive outcomes across the lifespan. The management algorithm for paediatric CHD includes risk factor stratification and guidelines for surveillance, screening, evaluation, re-evaluation, and management with patients' medical homes.[131] Proposed strategies to monitor and prevent progressive neurocognitive decline among adults with CHD include physical activity promotion, weight management, aggressive guideline-based management of acquired CVD, and earlier screening for dementia.[66] However, the success of these strategies depends largely upon who may access them, and evidence suggests that they are being underused. Further, even when offered, most adults with CHD with self-reported neurocognitive deficits do not pursue formal neurocognitive testing.[142]

With respect to psychological outcomes, children with CHD, particularly more complex forms, are at elevated risk of neurodevelopment impairment as well as internalizing and externalizing behavioural difficulties.[131,143,144] Adolescence is often characterized by personality development, identify formation, and a focus on peer relationships, each of which may entail additional challenges for youth with CHD.[80] Psychosocial distress can impede successful transition and also result from transition. Within middle and late adulthood, potential sources of psychological distress include medical factors (eg, surgeries and other medical interventions, the onset of arrhythmias and heart failure, and declining health status) and social factors (eg, relationship challenges and difficulties maintaining employment).[130] The lifetime risk of a mood or anxiety disorder among adults with CHD is approximately 50%.[130] However, there is evidence to suggest that adults with CHD $\geq$60 years have better mental health and less anxiety than younger patients.[145]

Compared with healthy peers, adolescents with ToF have a higher lifetime prevalence of attention deficit-hyperactivity disorder and worse outcomes on patient/parent-reported anxiety and behaviour ratings.[146] Further, youth with ToF and a genetic diagnosis are particularly at risk, as they have an increased lifetime prevalence of anxiety disorders and lower global psychosocial functioning compared with patients with ToF without genetic diagnoses.[146] In adulthood, individuals with TOF and 22q11.2 deletion syndrome have a markedly higher prevalence of schizophrenia and other psychotic disorders.[138,139]

In a study of over 4000 adults with CHD across the globe, patient-reported outcomes were compared between patients

within different diagnostic subgroups.[147] In terms of physical functioning, mental functioning, anxiety, and depression, the subgroup of patients with ToF were generally in the mid-range, whereas those with cyanotic subtypes of CHD reported poorest outcomes.[147] Based on analyses of the Taiwanese National Health Insurance Research Database, patients with ToF had approximately triple the risk of psychiatric disorders compared with individuals without ToF.[10] Even after excluding psychiatric disorders recorded before the age of 5 years, patients had elevated risks of anxiety, depression, bipolar disorder, and sleep disorder.[10]

Concerningly, the majority of individuals with CHD who report clinically significant psychological distress do not receive mental health treatment.[146,148] Some patients may not be interested in psychological services. However, others will face barriers including stigma, the availability of mental health professionals in one's geographic area, or financial limitations. In the United States, many individuals do not have adequate insurance coverage for mental health care; co-pays may be prohibitive. In Canada, despite the characterization of universal health care, it is rare for psychological counselling to be covered unless it is provided by a physician. For patients already navigating the system-level obstacle course to obtain ACHD care in Canada, accessible mental health supports can be few and far between.[149] This leaves patients struggling on their own or taking on an additional financial burden to receive needed care.

Equitable access to mental health professionals is thus key to optimizing the full spectrum of CHD outcomes. A recent Scientific Statement from the American Heart Association included a call to action for CHD programmes to embed mental health professionals within CHD teams to comprehensively support patients' quality of life.[130] We echo this call for including mental health professionals with interdisciplinary care teams in order to improve access, ideally at no cost to patients and families. This can achieve multiple goals including reduction in stigma (due to normalization of psychological distress and treatment) and improved access to care independent of financial status.[130]

Patient and Family Perspective on Barriers and Facilitators of Accessing Congenital Cardiology Care

Living with CHD is a unique experience of intermittent and unpredictable instability; cardiac status can quickly change and is typically interspersed with extended periods of stability. Key themes among qualitative research exploring the experiences of children and young people with CHD include disruptions in normal living, a sense of powerlessness during times of declining health, ongoing medical adversity and uncertainty, and hampered efforts to achieve life goals.[150]

When considering strategies to improve successful transfer to and retention in ACHD care, the perspectives of patients and families must be incorporated. Anxiety about transfer of care may involve loss of long-standing therapeutic relationships with paediatric clinicians, differences between the paediatric care environment and the adult care environment, and premature transfer before emotional readiness.[151] Other patient-related factors include perception of the severity of one's heart status, acceptance or denial of CHD, lack of support with health care facilitation, connectedness with health care clinicians, excessive health care expenses, geographic distance from CHD providers, and health literacy including knowledge of long-term complications.[152] Patients who entered adulthood before the mid-to-late 2000s often received misinformation that their prior cardiac surgeries were curative or the need for ongoing follow-up in adulthood was not discussed with them.[153]

Patient preference for parental involvement in adolescence and young adulthood varies; some patients express frustration with parents' continued involvement in such activities as scheduling and attending appointments, answering questions on the patient's behalf, and promoting life-style restrictions, whereas others continue to rely on parents for transportation, insurance/financial support, CHD knowledge, and support in making medical decisions. The varying and dynamic patient-parent relationship may serve as either a barrier or a facilitator of care, and therefore, an individualized assessment of patient preference and tailored interventions to foster patient independence is recommended.

From a logistical perspective, there are changing life circumstances that may impact access to care, including moving to a new geographical area, changes in employment or health insurance, increasing family or work demands, changes in family dynamics including the death of primary caregivers, and retirement or relocation of an ACHD provider. Many patients also confront programmatic operational barriers, such as limited clinic locations and schedules, lack of scheduling invitations or reminders, ill-timed follow-up, long wait times for appointments, and scheduling systems that make it challenging to cancel and reschedule clinic visits. They are also expected to manage health care system—related factors including high cost of care, limited number of available ACHD specialists, difficulty navigating the health care insurance system, and lack of digital or virtual options for care delivery.[152] Language can serve as an additional barrier to accessing care. In a recent US study, patients in an unsupportive environment from a language perspective felt more guilt and dismissal and rated their health as worse than English-proficient patients.[154]

Finally, it must be acknowledged that CHD and other forms of health care do not occur in a vacuum. Patients and families experience additional chronic and acute life stressors, including but not limited to educational and employment challenges, financial pressures, relationship and parenting difficulties, racism and other forms of discrimination, and the death of loved ones. At various times, the management of these other stressors might supersede the need to access CHD care. Therefore, it is important to engage in a nonjudgemental manner with patients and families when they do re-establish CHD care after a missed clinic visit or extended lapse in care. A holistic and patient-centred approach to understanding barriers and facilitators of consistent access to CHD care is essential across the lifespan.

The Important Roles of Nurses in Engaging Patients and Improving Access to CHD Care

Nurses are uniquely positioned to create ancillary therapeutic relationships with patients and families. Nurses can provide comprehensive care coordination, assess health

literacy and educational needs, conduct individualized patient education, and develop holistic assessment intake forms. For patients with ToF and other forms of CHD, nurses can also implement motivational interviewing and goal setting for adherence with lifestyle recommendations and maintain engagement with patients by assisting with tasks such as filling prescriptions and attending appointments.

Nurses are well positioned to develop programmatic tracking strategies to ensure timely completion and communication of results. The creation of patient databases, including active patient lists for review with the ACHD team at regular case conferences, helps ensure programmatic communication and prevent lapses in care.[155] Nurses can facilitate community outreach to raise awareness of the CHD programme, support patient advocacy events, collaborate with other CHD programmes, and facilitate transfer of care for patients who are relocating. Nurses help create protocols for programmatic operations that standardize and streamline high-level patient care.

Nurses have been shown to be effective facilitators of transitional programmes, and nurse-led transition interventions have proven beneficial in terms of improving patient knowledge and self-management skills in randomized trials.[156–159] Nurses can serve as the bridge between paediatric and ACHD programmes and provide the patient and their family with continuity during this high-risk time period. As a central part of the interdisciplinary team, nurses are integral to preserving access to care.[160]

Potential Strategies to Improve Access to Care

Throughout this paper, we have highlighted many obstacles to access to the full spectrum of CHD care, with a focus on individuals with ToF. It must also be noted that several pivotal facilitators of access to care have emerged over the past decade. For example, the incorporation of transition programmes bridging paediatric cardiology and ACHD care has been shown to decrease discontinuity rates.[50] Further, there have been efforts to clearly designate individuals and programmes with the necessary ACHD expertise to provide optimal care to individuals with ToF and other forms of CHD. Examples include board certification within the American Board of Internal Medicine, US programme

Table 1. Potential strategies to improve access to care

Level	Strategies targeting health equity[4,15,161,162]	Strategies to improve awareness and availability of specialized care[80,163–165]
Individual clinician	• Engage in implicit bias and cultural sensitivity training • Learn about and reflect on stereotypes and biases • Identify and properly address microaggressions • Maintain equity mindset: inquire about and address social determinants of health in outpatient and inpatient settings	• Educate patients and families about the importance of lifelong CHD care, during childhood, adolescence, and adulthood
Institutional	• Make implicit bias (and follow-up) training mandatory • Provide clear messaging to employees, patients, and families that racism, sexism, ableism, and other forms of discrimination impact health and health care • Provide access to local community resources available for historically excluded racial and ethnic groups • Involve racially concordant health system navigators in discharge and follow-up planning • Introduce policies to reduce barriers for patients with lower financial means (eg, free parking and transit tickets) • Establish a diverse patient and family advisory council to guide decision-making and prioritization of strategies to make the institution a welcoming environment for historically excluded racial and ethnic groups, members of the LGBTIQA+ community, people with disabilities, etc. • Lead advocacy work within the community to improve access to housing and other social supports • Lead advocacy work at the national level to challenge policies that reduce access to evidence-based health care	• Coordinate obstetrical sonographer training in CHD screening, especially in remote locations • Have tertiary centres provide fetal telecardiology services to remote community hospitals • Provide technology (eg, remote physiologic monitoring of oxygen saturation before ToF repair) to optimize home-based monitoring. • Offer shared care with satellite clinics and partnerships with primary care providers and local cardiologists • Offer virtual follow-up visits when physical examination is not essential (eg, to discuss test results) • Have the clinic schedule follow-up visits rather than relying on patients/families to do so • Partner with patient and parent advocacy groups to identify local barriers to accessing care • Increase the number and diversity of CHD health professionals • Ensure that the number of adult CHD clinicians within a programme reflects the growing patient population
Population	• Promote education on racism and colonialism	• Establish a national CHD registry • Encourage community-based participatory research • Support public awareness campaigns re: prevalence of CHD and importance of lifelong specialized care
Policy/system	• Ameliorate hidden socioeconomic burdens of health care (eg, parking, other transportation costs, days of work lost, and childcare) • Introduce mandatory sick leave coverage • Implement policies to protect insurance coverage (including pharmacare, dental and eye care, and mental health care) across the lifespan • Increase funding for people with disabilities • Offer the full spectrum of family planning and obstetrics care, regardless of geographic location • Implement social programmes that mitigate neighbourhood-level disparities	• Regionalize diagnostic, medical, and surgical care, with equitable and transparent referral patterns • Offer no-cost medical transportation services for remote residents • Approve telemedicine services across provincial/state lines • Increase reimbursement for visits focused on patient and family educational needs (eg, transition from paediatric to adult care) • Support the integration of neurodevelopmental, mental health, and dental services • Implement national licensing for health care professionals

CHD, congenital heart disease; ToF, tetralogy of Fallot.

accreditation by the Adult Congenital Heart Association, and Canadian programme accreditation by the Royal College of Physicians and Surgeons of Canada. The Adult Congenital Heart Association provides a very useful ACHD directory of all clinics in North American (https://www.achaheart.org/your-heart/resources/clinic-directory/) as well as a travel directory listing international programmes (https://www.achaheart.org/media/3080/traveldirectory13thedition.pdf).

Table 1 offers strategies to improve access to care, at individual, institutional, population, and health care system levels. It is essential to develop sustainable strategies to increase the supply of ACHD clinicians. Other strategies include optimizing the geographical distribution of programmes and satellite clinics relative to where patients live, expand clinic offerings to include late or weekend clinics for patients who are working, shortening follow-up intervals during high-risk time periods, and using advance practice providers and team-based care approaches to ACHD care.[160] Within CHD programmes, the incorporation of mental health services, nursing care coordination, social work assistance with insurance and transportation needs, patient-led support and advocacy programmes, and dedicated administrative support for complex scheduling may all serve to reduce discontinuity of care. Of note, most strategies that are commonly offered, here and elsewhere, are based on expert opinion from clinicians, researchers, and patients rather than robust empirical investigation.

Conclusions

Medical guidelines for the management of individuals diagnosed with ToF are well established, yet their implementation relies on patients being able to access this care. A concerted effort to addressing adverse SDOH, eliminating health inequity, and ensuring access to the entire spectrum of health care needs is essential for the field of CHD to continue to reduce morbidity and mortality and to provide patients with ToF and their families the best possible quality of life.

Ethics Statement

This review article has adhered to the relevant ethical guidelines.

Patient Consent

The authors confirm that patient consent is not applicable to this article. They performed a review of the literature summarizing challenges regarding access to multiple domains of specialized care for individuals with tetralogy of Fallot. No patient medical records were used.

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