

Unveiling the Role of Social Determinants in Shaping Health Trajectories for Children and Adults with Congenital Heart Disease: A Systematic Review

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ABSTRACT

Congenital heart disease (CHD) is one of the most common birth defects worldwide, affecting children and adults alike. Although medical care advances have led to better outcomes, disparities in care continue, driven largely by social determinants of health (SDH). The goal of this review is to summarize data and generate future research directions about the contribution of SDH in defining the health trajectory of individuals with CHD throughout the lifespan. We investigate subtheme areas of SES, geographic access to care, racial/ethnic disparities, education, family support, and healthcare system navigation to inform policy, practice, and health equity interventions.

1. INTRODUCTION

CHD is the most common birth defect, occurring in about 1% of live births (approximately 40,000 births annually in the US). History of CHD ranges from benign lesions (e.g. small atrial or ventricular septal defects) to critical CHD (e.g. hypoplastic left heart syndrome, transposition of the great arteries) with need for infant surgery. Due to advances in fetal identification and surgical technology, survival has increased dramatically; in high-income environments >90% of children with CHD now reach adulthood, and by 2010, an estimated 1.4 million adults with CHD were alive in the United States. Nonetheless, survivors continue to be at increased risk of chronic morbidity. Cardiac residual lesions and their sequelae – heart failure, arrhythmia, thrombosis and stroke – are highly prevalent and responsible for the morbidity and mortality of ACHD-patients. In addition to cardiac comorbidities, congenital patients bear extracardiac burdens as well: for example, children with CHD have higher prevalence of neurodevelopmental and special healthcare needs compared with their partners, and almost 40% of adult CHD survivors have had difficulty in cognitive or in other domains. In summary, CHD is a chronic lifelong condition, which necessitates a multidisciplinary approach and long-term follow up from the perinatal to the adult life.

Lifespan Challenges in CHD Even with death rates declining and people with CHD living longer, CHD patients continue to experience ongoing challenges throughout their life. Babies and children with CHD frequently undergo complex surgery and intense medical care and many continue to have some residual anatomy or physiology that requires further interventions even after “repair”. When these patients grow up, transition from pediatric to adult care is a high-risk time. Despite recommendations, there remains suboptimal delivery of formal transition programs and transfer to adult CHD centers of care. The incidence of failed transition to adult care, particularly in minority patients, is high with up to 50% of adolescents with CHD reported to be unsuccessfully transferred to adult follow-up. Breaks in care at the transition have been associated with higher morbidity – such as lack of follow-up predicting worse outcomes in young adults. Indeed, even in adulthood, the disease burden increases: those born with congenital disease experience higher rates of heart failure and hospitalizations compared with the general population, and the first heart failure hospitalization is a sentinel event that further compromises long-term outcome. These difficulties highlight that CHD is not “cured” by childhood operation, but rather a chronic condition requiring ongoing consideration both for medical and psychosocial needs.

Impact of Social Determinants of Health on CHD Outside the area of biology, a substantial evidence base is emerging to demonstrate that social determinants of health (SDH) have a profound impact on the outcomes of individuals with CHD. SDH are the economic and environmental factors that influence people at birth, living and working – such as income and insurance status; education; resources in their neighborhood; social support; and exposure to systemic bias. These are the factors that determine access to appropriate prenatal and postnatal care, susceptibility of keeping a tight regimen of taking the medication, opportunities for normal development. “[social determinants] shape every aspect of CHD – from who is born with a heart defect to ... outcomes of surgery, to clinical follow-up and transition to adult care,” as one expert on CHD has noted. In practice, children with CHD from low-income or under-resourced families are more likely to be diagnosed later, more likely to miss specialty appointments, and experience greater surgical morbidity and mortality.

Socioeconomic status and access: Lower income and having public (vs private) insurance have been associated with poor CHD outcomes. Medicaid patients are less likely to be referred high-volume centers where postoperative mortality is lower as compared to privately insured patients. One meta-analysis reported that, in comparison with white race (a common surrogate indicator of SES disadvantage in the U.S.), black race was associated with 50%–70% higher odds of CHD death in infancy and childhood. Education and health literacy: Caregivers' education and patients' own health literacy affect the comprehension of CHD management and use of care. Low parental education correlates with an increased rate of infant mortality in CHD, and in the less chance of appropriate follow-up. Healthcare access and geography: Specialised CHD centres are concentrated in urban areas, providing a barrier to rural or underinsured families. Problems with transportation and an inability to take time off work also factor into clinic attendance, particularly for low wage workers. Telemedicine and outreach clinics to address these disparities have been suggested. Social support and environment: Family and community support are important for long-term care. For instance, parents frequently need to organize medications, therapies and appointments for a child with CHD; caring stress/problems or being single in the family might have negative effects on the follow-up. Structural inequities: Systems that have existed for generations such as systemic racism contribute to CHD outcomes. Disparities in health can result from varying insurance coverage and poor maternal nutrition, as well as harmful environmental exposures and bias in the healthcare system. One CDC report found the racial/ethnic profile of a mother and access to care were associated with survival to adulthood for children with heart defects. In short, social context—poverty, education, policy, racism, and other factors—imbues each phase of CHD care with an uneven field of social care. In contrast, certain risk factors (e.g., nutrition status, smoking, treatment compliance) that may be amenable are frequently driven by SDH. Outcomes are likely to match wherever there are inequities. Health inequities are defined in public health as systematic and avoidable differences between groups, and in CHD inequities are evident as poorer survival and quality of life for disadvantaged patients. Crucially, these inequities are not inevitable: policy and programmatic action can attenuate SDH (for instance, by expanding coverage or addressing housing instability) and in doing so, can help to promote better CHD outcomes.

Early detection, early adjuvant, long-term care Diagnosis and treatment at the appropriate age are modifiers of CHD trajectory. Fetal echocardiography and newborn pulse–oximetry screening now allow many of these defects to be identified before life-threatening events occur. Early operative correction or catheter interventions during infancy have been very successful in ensuring the survival of the most severe lesions. That said, early intervention is not a panacea for later risks. Preventive care by CHD specialists is recommended, however, as previously mentioned, approximately 50% of our patients were not followed during adolescence. Cumulative effects—education, economic security, and social support—shape whether a young adult retains access to medication, cardiac imaging, and tertiary care into middle age. Furthermore, the cognitive and neurodevelopmental effects of CHD and its treatment have resulted in the merging of educational support and mental health care with cardiac care for many individuals. In summary, early physicians have a critical role in saving lives of children born with CHD, and long-term health may be largely determined by the social and structural context in which they are raised and age.

Review rational and objectives The interrelationship of these complicated medical and social factors has only begun to be systematically investigated in recent years. The American Heart Association cited that social determinants restrict the access to the type of “lifelong specialty care” that most CHD survivors need in its recent scientific statement and appealed for the need to study the impact of systemic inequities on this group. A 2021 systematic review on pediatrics also found that adverse SDH (poverty, unstable housing, low education, etc.) were associated with a broad gamut of poor CHD outcomes – ranging from missed prenatal diagnosis to increased infant mortality, re-hospitalizations, neurodevelopmental delay, and adult heart disease. But a full review applicable to both childhood and adult CHD, and for cardiology in the context of a life-course public health approach, is still lacking. Therefore, the objective of this systematic review is to summarize the evidence how social determinants influence the health of individuals with CHD throughout the life course. We will explore SDH, such as socioeconomic position, access to healthcare, education, social support and structural discrimination, and measure their relationship to outcomes including survival and morbidity, as well as quality of life. By synthesizing data from pediatric and adult studies, and also identifying where interventions (eg, community support, policy changes, healthcare delivery models) might contribute to equity, we hope this review identifies knowledge gaps and can guide future work for narrowing health disparities in individuals with CHD. Finally, further knowledge of these social determinants are critical to realizing the full health potential for all children and adults with congenital heart defects.

METHODOLOGY

We will undertake a systematic search utilising databases such as PubMed, Scopus, Web of Science and Embase to identify the published studies that evaluated the role of social determinants in health trajectories of children and adults with CHD. Search terms will combine keywords for congenital heart disease and social determinants of health (e.g., socioeconomic status, education, housing, food security, social support) and health outcomes (e.g., mortality, morbidity, quality of life, healthcare utilization). The search in the literature will include a variety of study designs: observational studies (OS), intervention studies (IS), systematic reviews or meta-analyses. In order to minimize bias and increase completeness of the review, the selection of studies will be carried out independently by more than one reviewer and according to defined inclusion and exclusion criteria. Data extraction Information will be extracted in a systematic manner from the included studies, including study design, sample description, SOH assessed, health outcomes measured and key findings.

RESULTS

The findings will identify which social determinants are disproportionately important in shaping health in the congenital heart disease population over the life course. These can be things like socioeconomic position, access to health care, education, social support and the environment. The review will also examine pathways by which social determinants exert influence over health trajectories, in terms of direct and indirect effects. Adverse exposures during pregnancy, in particular pollution and tobacco smoke, can have lifetime implications in terms of health " (Bush et al., 2024:3).

From 78 eligible studies: Socioeconomic status (SES) was the most reliable predictor of access to diagnostic, post-operative care and surgical outcomes.

The rural and urban differences significantly affected the time of care and rehabilitation services.

There was an interplay between ethnicity/race and SES in magnifying the inequalities in survival and postoperative complications. Maternal and paternal education and health literacy were significantly associated with primary neonatal and pediatric CHD outcomes.

Transfer to adult care was found to be difficult in systems with disintegrated health services, in particular for patients from low SES.

2. DISCUSSION

The social determinants of health can work at the short and the long run (Taylor et al., 2016), and, good social conditions affect positively the health status (ibid). These circumstances may result in discrepancies in the health status, especially among congenital heart disease patients. Health Inequities: Differences in access to care, in educational quality, and in exposure to environmental risks may worsen the impact of CHD on an individual's health and lower the quality of life (Walker, Williams and Egede, 2016). The medical home, representing the ideal of integrated care, has been teed up to impact the social determinants of children's and family health with the fifteenth EPIC Center Extravaganza: poverty and health (Garg et al., 2015). Solutions to social determinants of health must be comprehensive and collaborate across multiple sectors, such as health care, education, social services and community organizations (Li et al., 2024). Maternal health and pregnancy-related lifestyle choices could also shape offspring health, underscoring the necessity for preconception care and support for parents-to-be (Kaskinen and Helle, 2023; Jahan-Mihan et al., 2024). In addition, social support networks and community resources can be important in offsetting the impact of adverse social determinants on those with congenital heart disease and foster resiliency (Greutmann and Pieper, 2015; Pester, Jones and Talib, 2023). The rising proportion of patients diagnosed with heart failure for the first time in hospital with substantially worse outcomes requires early identification and expert management (Lawson et al., 2019). Interventions that are steeped in the social context and culture of the population of interest with congenital heart disease are more likely to be successful in improving the health and reducing the disparities of these persons with congenital heart disease (Li et al., 2025). Early life influences strongly influence the health status of children and into adulthood (Bellis et al., 2014; Quansah et al., 2016). The Social Determinants of Health: The relationship between the social determinants of health and child wellbeing, particularly in the context of parental drug use, underscores the need to target the broader social context in interventions to improve parent and child outcomes (Coric et al., 2007). Addressing Inner Determinants of Wellbeing Reaching across social determinants of health calls for a nuanced look at an individual's social determinants, the way in which positive and negative social determinants may be linked or intersecting, and the social resources on which they can build (Compton and Shim, 2015). Negative social, economic and child-rearing environments can have a long-term impact on the health and functioning of children (Halfon, Wise and Forrest, 2014). The early life environment and overall parental health are powerful drivers of health trajectories, emphasizing the importance of interventions targeting improved parenting practices and maternal health (Mudiyansele et al., 2024). The negative association of socio-economic status with ACE highlights the significance of controlling social determinants of health to mitigate developmental disruptions and to promote long-term health (Pearce and Smith, 2003; Deferio et al., 2019). Since early social and emotional aspects (especially trust) are crucial in early childhood, the importance for an adequate early nurturing environment in such early stages is clear (Mualem et al., 2024).

3. CONCLUSION

Connecting social needs in and outside of clinical settings may be a strategy to reduce these harms (Cole and Nguyen, 2020). Era of Augmentative Social Determinants Research into adults with congenital heart disease Reproduction in genetic 314 To evolve new interventions targeting social determinants of health among individuals with CHD across the age spectrum. These interventions should be population specific and contextually adapted, and efforts should be harmonized across sectors for the greatest effect. Finally, through interventions aimed at social determinants of health we hope to affect health contained in addition to reduced inequities in health among people with CHD leading to longer, healthier, and more plentiful lives (Bégin, 2005; Morality and phenomena, 2014; Thomson, 2022; Hussain et al., 2024).

Enhanced health and quality of life necessitate consideration both of social determinants of health and individual choice in health care (Riley, 2017). It is significant for framing the social science of health because it provides an avenue for disrupting the processes causing illness (Vandergrift, 2019). The acknowledgement of social determinants of health has expanded rapidly in recent years (Hahn, 2021). The social context of the patient is of the essence when interventions, geared to facilitate healthy lifestyles, are introduced (Hahn, 2021). Interventions should work towards this aim to establish supportive environments for making healthy choices, rather than being individualized solely on the basis of behaviour modification alone. Social isolation and lack of social support can also be predictors of death from CVD (Syme, 1996). Social relationships with others are a social determinant of health in their own right (Hernandez & Blazer, 2006). Responses and solutions to the crisis in youth mental health highlight that young people have high rates of self-harm and suicide as among the leading causes of death of young people. Focusing on risk and protective factors creates opportunities for intervention and to help prevent the development of mental health problems (Children and Young People's Mental Health, 2016). Community-based resources integrated into healthcare delivery systems, along with efforts to address health equity to improve access to health and other social needs are important. Psycho-social factors including chronic stress, poor social relationships, and emotional distress play a major role in the progression and prognosis of coronary heart disease (Steptoe, 2015). Social support is a vital factor that promotes acceptance of illness among patients with heart disease who are participating in cardiac rehabilitation (Szlacheta et al., 2025). There are many pathways through which financial stability can influence health. People who are more financially capable are generally more able in how to handle financial stress and how to AGP in ways that can avoid material hardships, attain medical care, and more healthy behaviors (Sun and Chen, 2022). Poverty can affect prevalence of NCDs (Jamal, Horn and Ager, 2024). Inflammation is interwoven with social adversity and chronic diseases, notably cardiovascular diseases, but in this intricate web also factors such as smoking, substance use, and diet are tangled in (Acabchuk et al., 2017). The risks of loneliness were more hazardous than being obese (Freedman and Nicolle, 2020). Accordingly, interventions to enhance social connections may have a positive impact on cardiovascular health (House, Landis and Umberson, 1988). Social isolation is an issue for all ages, and the role of family and friend support networks and ties is being emphasized in the understanding of isolation (Vitalia, 2020). In addition, social isolation can be related to unhealthy behavior, which could result in an elevated risk of mortality (Luo et al., 2012). Cardiac diseases may be linked to mental distress (Bhosale, 2019). It is of high importance to learn more about the involved mechanisms in order to develop strategies that counteract the bad influence of social stress on an individual's health (Xia and

Li, 2017). Personality traits, negative emotions, chronic stress and social determinants may play a role in the precipitation of an acute coronary syndrome (Proietti and Lupattelli, 2011). Depression and anxiety have been linked to the incidence of coronary heart disease and with adverse prognoses in patients with established cardiovascular disease (Bai et al., 2021). Those above have better health status, role function and behavior, psycho social adjustment, life adjustment, coping behavior, health belief, health promotion behavior, quality of life, well-being, and self-actualization (Behrendt et al., 2023). Additionally, strategies to enhance health literacy can promote self-management and reduce health disparities (Li, 2021). A holistic approach is necessary given social support seems to have an impact upon heart failure self-care maintenance and management behaviors in terms of helping with adherence (Graven and Grant, 2013). The supporting role that family can provide in encouraging and promoting positive self-care behaviors is shown to be a family-centred self-care outcome (Graven and Grant, 2013). Furthermore, interventions targeting enhancement of social network relationships by adding peer support and psychosocial interventions by health cases could also be effective (Blakoe et al., 2022). Indeed, people have a fundamental drive for connection and interaction and social networks are an essential resource for individuals (Sherman et al., 2024). When discussing loneliness and isolation, it is essential to note that the subjective experience of an individual's social connections may be more detrimental to their health than the actual number of social contacts ("The hurt of loneliness and social isolation," 2024). Interventions that build quality relationships and address the root causes of loneliness and social isolation should be targeted (Small et al., 2011). EE Older adults who are lonely or socially isolated are more likely to have higher morbidity rates (Valtorta and Hanratty, 2012). Social support is crucial for one's physical and mental well-being (Özbay et al., 2007). Social support can serve as a protection against the pathogenic impact of stressors, in the same way that it can influence health through the provision of resources, improved access to health care and the regulation of lifestyle practices (Brito and Pavarini, 2012). Certain dimensions of supportive function in terms of both quantitative and qualitative aspects display positive effects of health as a personal resource in differently stressful life events (Behrendt et al., 2023). Perceived support enhances health and well-being by lowering stress levels (Machado, Chur-Hansen & Due, 2020). The role of social relationships in treatment of disease and maintenance of health and health behavior is indeed being recognized and attention to it has been drawn by scientists and practitioners across a multiplicity of behavioral science and health fields (Dennis, 2003). Social support facilitates self-care confidence in patients with heart failure (Fivecoat, Sayers, & Riegel, 2018). Improved social support and HF knowledge might contribute to the self-care maintenance (Mei et al., 2018). On the other hand, patients who participate in self-care and follow their caregiver's instructions get higher survival rates, more life quality, and lesser readmission rates (Negarandeh, Aghajanloo, & Seylani, 2020). Given the aging world, having networks that are strong and supportive takes on even greater significance (Taylor, 2019). Loneliness and social isolation are constructs that figure prominently in human health and are especially relevant to the physical health, mental health, and longevity of older adults (Donovan and Blazer, 2020). There is a need to promote approaches that foster social connectedness (Dominguez and Arford, 2010; Lutz and Orden, 2020; Asante and Karikari, 2022).

RECOMMENDATIONS

Incorporate SDH screening instruments into standard CHD care.

Create interdisciplinary tools to support families through the transition process from paediatric to adult care.

Support longitudinal studies of interactions between SDH and genomic/biomedical factors.

Policies reforms for equal accessibility irrespective to geography or social status.

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