

Gaps in Care

Category	Gap	Prenatal	Interstage	Childhood	Adolescence	Adulthood
Communication	When termination is presented repeatedly, families feel hopeless	●				
	Health care providers sometimes communicate in ways that are perceived as lacking compassion and empathy	●	●	●	●	●
	Messaging across providers is inconsistent	●	●	●	●	●
	Communication deficiencies between different health care providers disrupt continuity of care	●	●	●	●	●
Transitions Across Life Stages	Initial transition from hospital to home presents a myriad of physical and emotional challenges that warrant better preparation and support		●	●		
	Transition to school age brings new responsibilities and stressors that are rarely discussed or addressed by the medical community			●		
	There is a paucity of anticipatory guidance about the transition to adolescence, which presents numerous challenges				●	
	Many patients do not receive a comprehensive transition and formal transfer to adult CHD care				●	●
	Many adult patients and parents are reluctant and feel uncomfortable transitioning to adult CHD care				●	●
Patient and Family Support	Patients and parents lack a sense of partnership in decision-making with their provider		●	●	●	●
	Comprehensive and supportive family planning advice for patients with SV CHD and current information about the risks related to having children are scarce			●	●	●
	Adult patients struggle to come to terms with the unknowns of their condition including prognosis and other long-term comorbidities					●
	Adult patients and parents often feel unprepared to navigate conversations about the condition with other people, such as romantic partners, family, friends, teachers, coaches, etc.					●
	Many families do not have insider knowledge of navigating resources, such as parking, childcare, and meals, to make their hospital stay less burdensome	●	●	●	●	●
	Many parents and patients lack connection to peers or mentors affected by SV CHD	●	●	●	●	●
	Parents and patients rarely receive specialized psychosocial and mental health care	●	●	●	●	●

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Structural Deficiencies in Care	Parents experience long wait times to see a CHD expert	●				
	Access to affordable health insurance is a major barrier for many patients and families	●	●	●	●	●
	Parents and patients often struggle with financial burden due to the condition	●	●	●	●	●
	Rescheduling of surgeries is emotionally draining and logistically challenging for parents	●	●	●	●	●
	Providers in other medical specialties frequently have limited CHD knowledge	●	●	●	●	●
	Parents are the ones responsible for synthesizing and communicating critical medical information for themselves and to their providers	●	●	●	●	●
	There are relatively few providers who specialize in adult CHD care				●	●
Education	Many parents do not receive comprehensive, relevant, and accurate CHD information when the diagnosis is first suspected	●				
	Parents are uncomfortable with non-medical providers (e.g. babysitters and extended family) caring for their child due to limited SV CHD knowledge	●	●			
	Many patients do not realize they need to find an adult CHD specialist				●	●
	Preparation and education for young adults to independently manage their condition is inadequate				●	●