

Patient Perspectives on Living with Congenital Heart Disease in Adulthood

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Introduction

Congenital Heart Disease (CHD) is one of the most prevalent birth defects, affecting approximately 1 in 100 live births. Advances in medical technology and surgical techniques have significantly improved survival rates for individuals born with CHD, allowing many to live well into adulthood. However, despite these advancements, adults with congenital heart disease face a unique set of challenges that can impact their physical health, emotional well-being, and quality of life. As a result, understanding the patient perspective on living with CHD in adulthood is crucial for healthcare providers, policymakers, and support organizations aiming to improve care and support for this population. Adults with CHD often navigate a complex healthcare landscape, requiring ongoing medical care, monitoring, and potential interventions throughout their lives.

Their experiences can vary widely based on the severity of their condition, the types of interventions they have undergone, and their individual circumstances. Furthermore, they may encounter a range of psychosocial issues, including anxiety, depression, and social isolation, which can arise from the long-term effects of their condition. This study aims to explore the lived experiences of adults with congenital heart disease, focusing on their perspectives regarding health management, emotional challenges, social relationships, and the overall impact of CHD on their lives. By capturing these patient perspectives, we aim to shed light on the multifaceted nature of living with CHD and identify areas for improvement in care and support [1,2].

Description

This study employed a qualitative research design to gain in-depth insights into the experiences of adults living with congenital heart disease. Participants were recruited through cardiac clinics, support groups, and online forums dedicated to CHD. The sample consisted of individuals aged 18 and older who had been diagnosed with CHD at birth or during childhood. Data were collected through semi-structured interviews, allowing participants to share their personal narratives and reflections on living with their condition. Interviews were conducted in a supportive and empathetic environment, encouraging participants to discuss their health management practices, emotional experiences, and the social implications of their condition. Thematic analysis was employed to identify key themes and patterns in the data, providing a comprehensive understanding of the diverse experiences of adults with CHD.

The findings of the study revealed several key themes that encapsulated the patient perspectives on living with congenital heart disease in adulthood. One of the most prominent themes was the necessity of ongoing health management. Participants described the importance of regular medical follow-ups, including

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cardiac evaluations, echocardiograms, and consultations with specialized healthcare providers. Many expressed gratitude for the advancements in treatment that had allowed them to lead relatively normal lives. However, they also acknowledged the burden of frequent medical appointments, ongoing monitoring, and potential interventions, which often created feelings of anxiety and uncertainty about their future health. Several participants emphasized the need for a comprehensive care approach that addressed not only their physical health but also their emotional and psychological well-being [3]. They expressed a desire for healthcare providers to adopt a holistic perspective that considers their overall quality of life, rather than focusing solely on cardiac outcomes. The emotional toll of living with congenital heart disease emerged as another significant theme. Many participants reported feelings of anxiety and depression, often stemming from the unpredictability of their health and the fear of complications. Some individuals spoke of feeling like they were constantly "waiting for the next shoe to drop," a sentiment that contributed to heightened stress levels and emotional distress. Moreover, participants highlighted the impact of CHD on their self-image and identity.

Living with a visible scar or physical limitation often led to feelings of inadequacy or alienation, especially in social situations. The desire for acceptance and understanding from peers and family members was a recurrent theme, with many adults expressing the importance of finding supportive communities where they could share their experiences with others who understood their challenges. The study also explored the role of social relationships in the lives of adults with CHD. Many participants reported that their condition influenced their relationships with family, friends, and romantic partners. While some described strong support systems, others noted feelings of isolation and misunderstanding from those around them. For example, individuals with CHD often felt that their friends and family could not fully grasp the complexities of living with a chronic health condition, leading to frustration and a sense of being misunderstood [4].

Support groups emerged as a valuable resource for many participants, providing a space where they could connect with others who shared similar experiences. These groups offered emotional support, practical advice, and a sense of community that was vital for coping with the challenges associated with CHD. Participants emphasized the importance of creating awareness about CHD within broader communities to foster understanding and reduce stigma. A critical phase in the lives of individuals with congenital heart disease is the transition from pediatric to adult healthcare services. Participants shared their experiences of this transition, which could be both daunting and disorienting. Many expressed concerns about finding appropriate adult care providers who understood their specific needs and could provide continuity of care. Some described feeling lost in the healthcare system during this transition, leading to gaps in care and increased anxiety about their health [5].

The study highlighted the importance of structured transition programs that facilitate this process, ensuring that young adults with CHD receive the necessary support and resources as they move into adult healthcare settings. Participants advocated for more comprehensive education and guidance during this critical time to empower them to take an active role in their healthcare. The findings of this study underscore the need for healthcare providers to adopt a patient-centered approach when caring for adults with congenital heart disease. Understanding the complexities of their experiences can inform more effective communication strategies, foster trust, and enhance the overall quality of care. By actively listening to patients' concerns, providers can better address their emotional and psychological needs, creating a more

holistic approach to healthcare. Moreover, integrating mental health support into the care of adults with CHD is essential. Healthcare systems should prioritize access to mental health resources, including counseling and support services, to help patients cope with the emotional challenges associated with their condition. By addressing both physical and mental health, providers can significantly improve the quality of life for individuals living with congenital heart disease.

Conclusion

This study sheds light on the multifaceted experiences of adults living with congenital heart disease, emphasizing the importance of understanding their perspectives in shaping healthcare practices. The ongoing health management, emotional challenges, social relationships, and the transition to adult care are critical themes that underscore the complexities of living with CHD. As healthcare providers and policymakers strive to enhance care for this population, it is imperative to prioritize a patient-centered approach that considers the unique needs and experiences of adults with congenital heart disease.

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