

Psychosocial Functioning and Quality of Life in Adults with Congenital Heart Disease and Heart Failure

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KEYWORDS

• Adult • Heart defects • Congenital • Quality of life • Psychosocial • Heart failure

KEY POINTS

- North American adults with congenital heart disease (CHD) are at increased risk of psychosocial difficulties, including depression and anxiety. This finding has been less consistently shown in European studies.
- Data regarding the quality of life (QOL) of adults with CHD are inconsistent, likely because of differences in study methodology.
- Adults with heart failure associated with acquired heart disease are likely to experience impaired psychosocial functioning and QOL.
- Although research is limited, it is reasonable to predict that adults with CHD who develop heart failure are vulnerable to psychosocial and QOL impairment.
- An interdisciplinary approach to clinical care and research is recommended in order to attend to the broader psychosocial and QOL implications of living with CHD and heart failure.

INTRODUCTION

Adults with congenital heart disease (CHD) represent a growing population of cardiac patients. Because patients with CHD of moderate to great complexity are not cured, CHD is considered to be a chronic medical condition to which patients are expected to adapt throughout their lives. One common adult-onset development is heart failure,¹ and approximately 1 in 4 adults with CHD die of heart failure.^{2,3} An exclusive focus on medical symptoms and treatment neglects the broader

psychosocial and quality-of-life (QOL) implications of living with CHD and heart failure. The 3 aims of this article are (1) to summarize what is currently known about the psychosocial functioning and QOL of adults with CHD, (2) to summarize what is known about the psychosocial functioning and QOL of adults with heart failure associated with acquired heart disease, and (3) to generate a discussion regarding the psychosocial and QOL implications of managing heart failure associated with CHD.

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Psychosocial functioning and QOL are interrelated, both in CHD and heart failure,⁴⁻⁷ although they are distinct entities. Psychosocial functioning is an umbrella term that includes both psychological and social factors, as well as their interplay. Psychological factors include mood, anxiety, and cognitive functioning, and examples of social factors include social support and social role fulfillment (eg, employment). Psychosocial factors have been shown to affect QOL among adults with CHD.^{8,9} QOL is also sometimes used as an umbrella term, in that it encompasses psychosocial functioning as well as other factors such as health symptoms and functional status, lifestyle, and life conditions.¹⁰ It is this broadness that has hampered a solid understanding of the concept of QOL, because it has led to multiple conceptualizations and definitions, each of which is a subject for debate.⁸ However, concept analyses, concept clarifications, and structural equation modeling have shown that it is most appropriate to define QOL in terms of life satisfaction.^{8,11-14} As a reflection of this conceptual foundation, the following definition for QOL has been proposed: “the degree of overall life satisfaction that is positively or negatively influenced by individuals’ perception of certain aspects of life important to them, including matters both related and unrelated to health.”¹⁵ Life satisfaction is being increasingly used in QOL studies of CHD, whereas heart failure studies have typically defined QOL from a functional or health status perspective. Nonetheless, health status and QOL are related, albeit distinct, concepts, and therefore should not be used interchangeably.¹⁶

ADULTS WITH CHD: PSYCHOSOCIAL AND QOL CONSIDERATIONS

Psychosocial Functioning of Adults with CHD

International guidelines for the care of adults with CHD underscore the importance of attending to patient psychosocial needs.¹⁷⁻¹⁹ Approximately 1 in 3 North American adults with CHD experience difficulties with depression and/or anxiety,²⁰⁻²³ and this includes patients considered to be well-adjusted by their cardiologists.²¹ However, European data regarding psychological outcomes are less consistent. In a series of Dutch studies, the emotional functioning of adults with CHD was observed to be similar, and occasionally superior, to reference norms.^{24,25} A recent Italian study similarly concluded that patient psychological well-being was comparable with reference norms.²⁶ German patients have been shown to be similar to reference norms in trait anxiety, although their rates of state anxiety were increased.²⁷ However, Portuguese adolescents and adults with CHD

have been shown to be at increased risk of psychopathology.²⁸

Regardless of the presence or absence of formal psychiatric diagnoses, many adults with CHD of moderate to great complexity face typical adult stressors, such as managing careers, relationships, and finances, in addition to a unique set of stressors related to living with a chronic medical condition. It has been noted that, “psychosocial challenges are part of the everyday lives of adults with CHD, yet they are rarely addressed as part of routine medical care.”²⁹ Intrapersonal concerns include dealing with uncertainty, balancing goals with limits, and people accepting a health condition without letting it define them; CHD has been described as the “worst part time job.”²⁹ Interpersonal concerns include feeling different from peers, body image concerns, social isolation, overprotection from parents and teachers, and ongoing medical surveillance and interventions that disrupt lives. Although it is important to avoid generalizations because there are many high-achieving adults with CHD, as a group, they seem less likely to pursue higher education or secure employment.^{25,30,31}

The impact of CHD complexity on psychosocial outcomes remains unclear. Some researchers have observed that psychosocial functioning is poorer among patients with more complex CHD,^{21,28,32} whereas others have not detected this relationship.^{20,23,33,34} Most likely, there are multiple factors that interact to contribute to higher or lower psychosocial functioning. The following is a list of correlates of poorer psychological functioning in adults with CHD:

- Female sex^{28,32}
- Lower exercise capacity^{32,35,36}
- Restrictions placed by physicians³²
- Body image/patient perceptions of scarring^{32,37}
- Perceived health status or disease severity^{23,26,38}
- Poor social support/loneliness/social anxiety/poor social problem solving^{23,28,39}
- Poorer academic performance²⁸
- Perceived financial strain⁴⁰

Most adults with CHD with significant depression or anxiety do not receive appropriate mental health treatment.^{22,23,33} There are also no empirically evaluated psychosocial interventions for adults with CHD.⁴¹ This is in contrast with the existence of dozens of psychological intervention trials for adults with acquired heart disease.⁴² A survey of adults with CHD revealed that half report high interest in at least one area of psychological

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