Commentary: Moving beyond survival: The long-term psychosocial impact of congenital heart disease

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Outcomes that shape the health of an individual and family with congenital heart disease.

Central Message

Deep understanding of psychosocial, behavioral, neurodevelopmental, medical, and other factors is necessary to improve the overall health of patients with congenital heart disease and their families.

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What is health, and how should we measure it? These seemingly innocuous questions have significant implications for the direction of our field. Health implies more than perioperative survival or even long-term optimization of cardiac care. Health is a multifactorial and multidimensional construct that is related to the holistic well-being of an individual. “Medical” health only represents a portion of the overall well-being of an individual, with the health of the family being closely interrelated with the personal health of the individual (Figure 1). Survival for patients with congenital heart disease (CHD) has dramatically improved during the last few decades,¹ so it is time for our field to focus on outcomes that go beyond measuring the traditional medical outcomes after surgery and focus instead on the long-term well-being of the patient with CHD and that patient's family.

In this issue of the *Journal*, Jegatheeswaran and colleagues² measured health-related quality of life (HRQOL) in long-term survivors after neonatal surgical treatment of interrupted aortic arch.² This study is a welcome addition to our limited understanding of the long-term psychosocial implications of living with CHD. Jegatheeswaran and colleagues² found HRQOL in patients was similar for most domains compared with published norms; was better for several domains related to mental health, freedom from bodily pain, and vitality; and was worse only for physical functioning among older patients. The results may indicate a tendency for patients with CHD to “learn” how to live with their disease and adapt accordingly. It is important to note in the study, however, that patients who were unable to complete the questionnaires by themselves, and obviously those who did not survive, were excluded. It is likely that these patients could have had worse HRQOL than the patients ultimately included in the study, therefore possibly biasing the results.

FIGURE 1. Measurable outcomes that contribute to the health of an individual with congenital heart disease and that individual's family. To gain a full understanding of overall health, it is important to account for outcomes that go beyond the traditionally measured medical outcomes. Health-related quality of life measures are broader than medical outcomes, but they still do not measure the entirety of the health of the individual and family. ©2018 University of Texas Dell Medical School (reprinted with permission).

An important, although not surprising, finding of the study was that mental health issues and socioeconomic factors were significantly associated with worse HRQOL. Health is the result of multiple factors, some modifiable and some not. Medical care determines only 11% of an individual's overall health outcomes.³ This means that 89% of what determines the health of an individual is a combination of individual behavior, social circumstances, environmental factors, genetics, and biology. This is quite important, because evidence suggests a bidirectional relationship between the disease process and family functioning, with CHD affecting family and caregiver functioning (eg, parenting style, stress, and maternal mental health),⁴ which in turn affects behavioral and neuropsychologic outcomes.⁵

It is imperative for our field to start focusing on studying the implications of CHD for the long-term holistic health of the patient and the patient's family (including siblings), the complex interactions between the health of the family and the health of the patient, and the

identification of psychosocial risk factors and protective factors in this patient population. Only by gaining a deep understanding of all these factors will we fulfill our mission of improving the overall health of patients and families with CHD.

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