Editorial

Quality of life: an underutilized patient-reported outcome for adults with congenital heart disease

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Quality of life (QOL) is defined as "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" (1). It is the general wellbeing of individuals and should not be confused with the concept of "standard of living" which is based on income. QOL includes everything from physical health, family, education, employment, wealth, finance and the environment (2).

A variety of surveys are being used by healthcare providers to measure patients' health-related QOL to help determine therapeutic options based on previous experiences from other patients. This helps to formulate a treatment plan for the patient and to come up with the best treatment option that would improve healthcare.

Enormous growth in the number of adults with congenital heart disease (CHD) has occurred worldwide over the last two decades. Approximately 80% of neonates and infants with CHD can expect to reach adulthood, and this percentage is likely to increase further due to continued improvements in surgical techniques and perioperative care. It is estimated that there are approximately three million US citizens with CHD, with at least half of them having complex defects (3). Knowing the QOL in children and adults with CHD will complete our knowledge with clinical data that will help in the decision-making process for healthcare providers (4).

QOL as a concept has emerged in the recent era as an important measure of outcome in CHD. Since the feedback comes directly from the patient as they describe how they feel or function is what makes it valuable. However, this outcome measure remains underutilized. Several studies have been published from several countries to address QOL in patients with CHD; however, these studies share several limitations that include the use of poor-quality methods and the results have been inconsistent.

In their large study "Quality of life of adults with congenital heart disease in 15 countries", Apers and Colleagues (5) used a linear analog scale (LAS) and Satisfaction with Life Scale (SWLS) to explore QOL in an international sample of adults with CHD. The authors found that overall QOL in adults with CHD was "good." The variation noted was related to patient characteristics and not country-specific characteristics. The data in their study were collected from more than 4,000 patients from 15 countries and five continents through a questionnaire package. The authors included patients 18 years of age or older with CHD in whom the diagnosis was established prior to adolescence. All were followed at a CHD center or included in a national/regional registry. Patients with prior heart transplantation or primary pulmonary hypertension were excluded. The use of LAS and SWLS as instruments to measure QOL in that study adds strength to it through the use of a more robust score in comparison to other instruments used in several other studies that address QOL measure. These surveys were used in other countries and were associated with higher scores (6).

This is a large-scale international study with few missing

variables of interest, which will help identify patients at risk for a worse QOL by using uniform criteria. This will also help to design interventions, which can improve QOL. It may be expected that QOL scores among patients with CHD are higher in countries known to have higher QOL in the general population; however, this has never been proven.

Several interesting points from this study deserve comment:

(I) In general, the countries chosen for the study are all from the developed world. Consequently, they are more likely to have access for continued medical and surgical care. This could result in a selection bias towards patients having more favorable QOL since they are in a more favorable medical environment;

(II) It is still not clear what the impact of complexity of the CHD is on the QOL since the majority of patients had defects of simple to moderate degrees of complexity (26% and 49%, respectively). The literature has documented many patients with more complex defects having the need for repeated procedures over the course of a life time. This results in intermittent periods of favorable versus unfavorable QOL because of the ongoing potential need for repeated intervention(s) (7,8);

(III) There may be some selection bias involved in the study as the majority of the patients are white/Caucasian with a college or university degree (51%), part-time or full-time work (64%), and married or living with partners (51%) with NYHA class I/II (89%). All of this will reflect a good or reasonable QOL. Patients with CHD who made it to adulthood may have self-selected themselves and reflect a reasonable QOL irrespective of their anatomic or pathologic diagnosis;

(IV) The authors identified unemployment, older age, higher NYHA classes to be associated with worse QOL, but whether or not this is a reflection of more complex CHD is not clear;

(V) The study included 15 countries, but the data were collected from only one center in each country. It is likely that the single center from each country has a more comprehensive CHD program providing good long-term medical care. This may also bias the analysis towards more favorable QOL and may not be reflective of QOL issues for other patients with CHD elsewhere in that country;

(VI) Major variations in health care exist between different countries and sometimes between different geographical areas within the same country. The transition of care between pediatrics and adulthood can be well-organized or poorly organized from program to program and country to country. This will also impact QOL issues;

(VII) Interestingly, the pediatric CHD literature demonstrates lower QOL compared to other children without CHD (9) and also is correlated with complexity of CHD (10);

(VIII) The study did not elaborate on the psychological issues that not infrequently encountered in adults with CHD. This may have a great impact on their QOL as well. Almost 1/3 of adults with CHD have mood or anxiety disorders which go untreated very frequently (11) and the guidelines have recommended targeting the psychological issues related to adults with CHD (12) to improve their QOL and decrease their stress.

In summary, the overall QOL for adults with CHD in the current era is good due to the overall improvement in surgical techniques and perioperative care with improved late survival even in the presence of complex anatomical lesions that require reoperation(s) over a lifetime. It remains critical to identify those patients with poor QOL and focus interventions on the shortcomings in the care of those defects in order to improve their QOL. Future studies are needed to identify the differences between CHD practices and QOL in patients and controls from different cultures around the world.

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Footnote

Conflicts of Interest: The authors have no conflicts of interest to declare.

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