The Most Important Opinion Is the Patient's: It Doesn't Really Matter What Anyone Else Thinks!

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The ultimate goal of congenital heart surgery is to provide patients with a long, productive, and fulfilling life similar to that which can be achieved by children without congenital heart disease (CHD). The use of quality of life (QOL) questionnaires in the field of congenital cardiac surgery is relatively new due to our initial and longstanding focus on operative morbidity and mortality. That said, as the risks of CHD surgeries have declined, QOL instruments have continued to gain importance.

In this issue of *Seminars in Thoracic and Cardiovascular Surgery*, Pragt et al examined QOL in adult CHD (ACHD) patients who have had previous valve replacement, compared this with QOL in the general population, and determined the features associated with QOL scores. They evaluated 324 patients from the PROSTheses in Adult congenital heart Valve disease (PROSTAVA) cohort, with a mean age of 40.6 years (range 19–70), who completed the generic (non-disease specific) Dutch version of the RAND-36 (similar to the SF-36). The primary findings from this study included that ACHD patients with a prosthetic valve scored lower than the general population on the domains of General Health, Vitality, and Social Functioning. While those findings from the study may be predictable, unexpectedly patients were found to score higher than the general population on the domain of Bodily Pain (indicating less pain); however, they felt no worse than their peers in several domains including Physical Functioning, and Physical Role Performance (patients scored similarly in Emotional Functioning, and Mental Health). The primary feature found to be associated with lower domain scores in this study was poorer NYHA scores (in all domains). Age was also associated with lower scores in all but 2 domains. Employment (although loosely defined to include volunteer work) was found to be associated with higher scores in all domains, similar to percentage predicted exercise capacity (in all domains except Mental Health). Of note, presence of an AVR was generally found to be associated with lower scores, as was the presence of a mechanical valve, while presence of a PVR was associated with higher domain scores.

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Central Message

Quality of life studies must diminish group heterogeneity and ensure that the dataset has a wide range of potential associated factors for optimal evaluation.

While this study does have several merits, there are several limitations that bear mention. One of the primary limitations is the significant group heterogeneity. This study not only includes patients with a wide variety of diagnoses ranging from aortic stenosis to Marfan Syndrome (which can have numerous extracardiac manifestations that potentially affect QOL), it also includes a wide range of ages, and patients who have had either biological or mechanical valves in any position. With respect to age, although the reference population used for comparison also has a broad age range, it is likely that both the youngest and oldest ends of the spectrum (of both the study and reference populations) have very different expectations pertaining to their QOL, which further confuses matters. As the authors chose to evaluate all patients as a single group, not surprisingly diagnosis, age, type of valve, and valve position were often the factors which significantly affected domain scores. As with several studies that have evaluated the factors associated with

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domain scores, Pragt et al were also limited by their ability to consistently explain the variation seen, with adjusted R^2 values ranging from 0.18 to 0.57.[1–3] It remains that we do not seem to have the data to determine the nuanced factors affecting QOL. Finally, the authors chose to compare those patients with aortic valve replacement to those with pulmonary valve replacement, although perhaps this is not the most relevant comparison because the primary diseases within each group are likely very different. More useful would have been a comparison between those patients with biological valves and those with mechanical valves. Such a comparison could have informed valve selection by both patients and surgeons.

Clinicians who wish to use QOL questionnaires should be aware of the following considerations prior to applying these tools to their own research. First, numerous questionnaires exist and thus tool selection must be carefully considered. Not only should the questions within each be reviewed to determine whether they convey what one is truly hoping to determine, each has a specific age range to which it applies. This is significant if a study population has a diverse age range which includes pediatric patients, as some tools have versions tailored to different age groups. Second is the use of generic questionnaires in comparison to those who have a disease-specific component. If an investigator plans to compare patients to a normal population, a generic questionnaire must be chosen; however, this precludes determining the disease-specific features which may further elucidate patient QOL. Of course, multiple questionnaires may be administered, but one must avoid overburdening patients which may lead to lack of completion.

I congratulate Pragt et al for their study evaluating QOL in these ACHD patients, and look forward to their further contributions in this field. As we continue to improve patient care and operative mortality decreases, the importance of subsequent QOL must remain a priority. Future work must tackle the outstanding gaps in our knowledge related to how patients perceive their own well-being, primarily as a means to narrow any remaining deficits these patients face as we diminish the effect of perioperative morbidity and mortality. Further delineation of the explanatory variables associated with scores, including data from exercise testing, education, employment, socioeconomic status, and demographic features such as marriage require consideration. However, our inability to explain scores through these associated variables doesn't diminish that the most important thing is a patients' perception of their own well-being. In the end, it doesn't really matter what anyone else thinks!

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