EDITORIAL COMMENT

Patient-Reported Outcomes and Resilience in Patients With Congenital Heart Disease*

Pak-Cheong Chow, MBBS, MPH, MSSAPSY, LLM(MEL)

Striving for good outcomes is the prime target in treating patients in medicine, this is unexceptional in managing congenital heart disease (CHD) patients. Other than mortality and morbidity, there is increasing emphasis on assessing and improving psychosocial outcomes in CHD patients.[1,2] Interventions to improve these outcomes are also increasingly discussed and being sought. Building psychological resilience represents an area of interest and research in improving the psychosocial outcomes of adult congenital heart disease (ACHD) patients.[3]

In this issue of *JACC: Advances*, Steiner et al[4] studied psychological resilience, health-related quality of life (QOL), health status, perceived self-competence, anxiety and depression symptoms, and psychological distress in 138 ACHD patients with moderate or great complexity. They found that resilience was higher among patients with higher education and patients with moderate complexity. They showed that resilience and psychological outcome measures were relatively stable after 3 months, except that anxiety symptoms were less. They further found that baseline psychological resilience was associated with health-related QOL measured by the EuroQol-5 Dimensions-3 Level (EQ-5D-3L) Scores and linear analog scale after 3 months. This study is 1 of the few to study psychosocial measures in ACHD patients using prospective observational design. The stability of these measures over 3 months provides support that improvement in these outcome measures after 3 months of any interventions in future study could be considered as genuine rather than intrinsic temporal fluctuation of the measures themselves. Also, their study supported the well-known association between greater resilience and better psychological outcome.

That said, several points related to this study warrant discussion. First, the rationale of studying the association of baseline resilience and the outcome measures 3 months later was not fully understood. Obviously, the psychological outcomes such as QOL, anxiety, depression, and distress are important measures, and resilience had been reported to be associated with these outcome measures such that resilience building may be an actionable way to improve those outcomes measures. Therefore, studying resilience 3 months ago to correlate current QOL may not be of utmost importance; instead, studying the relationship of concurrent change in resilience and the psychological outcome may demonstrate the effect of resilience. Furthermore, while the authors prospectively studied the patients for 3 months, this would be important to provide information about any clinical events or interventions occurred during this 3-month period, and whether these events might influence resilience or other outcome measures.

Second, the reason of recruiting only ACHD patients with moderate or great complexity and physiological class B, C, or D was that the authors[4] considered patients with simple lesions and class A physiology are less affected by their underlying heart lesions. However, there has been studies showing QOL being not only influenced by CHD complexity.[5]

Moreover, sense of coherence, another psychological construct reflecting the ability of coping better with the stressors in life, such as living with a chronic condition, was found to be lower in simple CHD compared to complex CHD in an intercontinental study.[6] Therefore, including simple ACHD and physiological class A would provide full spectrum of the outcome measures in ACHD population.

Third, the authors evaluated health-related QOL in their study,[4] in a way similar to other studies. QOL is a broad concept encompassing different domains other than health;[7] however, detailed discussion is beyond the scope of this paper. Nevertheless, literature on conceptualization did raise the criticism that health-related QOL is a confusing term and may overlap with the health status.[8] Being widely studied, EQ-5D and linear analog scale were used in their study to capture the health-related QOL, but they do not capture the full spectrum of QOL or patients' valuation of health, instead, these measures reflects more on self-perceived health status.[9] In contrast, increasing consideration of the patient-reported outcomes (PROs) has been demonstrated by the landmark project, the "Assessment of Patterns of Patient-Reported Outcomes in Adults with Congenital Heart disease-International Study,"[10] and it is apparent that future study should focus on PROs, rather than QOL alone, in congenital heart population in order to evaluate the outcome of various interventions in this population.

Fourth, regarding the relationship of psychological resilience with various outcome measures and health status, the authors hypothesized that patients with more severe ACHD would have higher resilience.[4] This hypothesis needs further exploration. Although studies in United States and Korea showed that CHD patients had higher resilience than general population,[11,12] but the relationship between CHD severity and resilience could be influenced by the functional class.[11] Therefore, the hypothesis posited by the authors may be more complex than it appeared. Further, they found that resilience was greater in moderate ACHD patients than complex ACHD, it would be imperative to assess any factors explaining such difference. One factor may be education level because higher education level was found to be associated with greater resilience in their study[4] as well as in early study.[13] This would be reasonable to consider the question: is this possible that complex ACHD patients attain lower education due to their cardiac condition and have less resources to build resilience?

Finally, when this comes to relationship of resilience with health status and psychological measures, they reported that resilience remained significantly associated with EQ-5D and linear analog scale after adjustment for demographic variables and baseline psychosocial measures. This needs further scrutiny on 2 aspects. As mentioned previously, education level is associated with resilience, it would be more optimal if education level was also adjusted in the analysis. Moreover, the reason why the association between baseline resilience and other outcome measures at 3 months became insignificant after adjusted for the baseline deserved exploration. The authors[4] questioned whether they might not use the appropriate outcome measures, however, these measures are well-validated and used in other studies. Perhaps, it would be interesting to understand whether the sample size was large enough to detect the association after adjustment. Furthermore, the rationale of adjusting for baseline outcome measure in assessing the relationship between baseline resilience and the outcome measures 3 months later in this observational study may be not necessary, as point out by some researchers[14] that adjustment for baseline variable in observational studies may cause bias.

There is no doubt that PROs measurement is important to help decide the effectiveness of intervention in ACHD patients, but more importantly, there is great potential in determining the best strategy to build resilience to improve the PROs. The study by Steiner et al[4] could provide information to help guide the PROs measurement and resilience building interventions. Further studies of the impact of demographic, disease-specific, social, and contextual factors together with the resilience-building interventions on the PROs would bring more insight on how to apply these interventions in improving patient's outcomes.

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ADDRESS FOR CORRESPONDENCE: Dr Pak-Cheong Chow, Cardiology Centre, Department of Paediatrics & Adolescent Medicine, Hong Kong Children's Hospital, 1 Shing Cheong Road, Kowloon Bay, Hong Kong SAR. E-mail: chowpc@ha.org.hk.

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