Transition Readiness Assessment in Adolescents and Young Adults With Heart Disease: Can We Improve the Outcome?

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Objective: Transition is defined as “the process by which adolescents and young adults with chronic childhood illnesses are prepared to take charge of their lives and their health in adulthood”. We previously reported common knowledge deficits and lack of transition readiness (TR) in 13-25 year olds with congenital or acquired heart disease. The aims of this study were to reevaluate TR in these patients at follow-up (F/U) and to examine the relationship between changes in TR and quality of life (QOL).

Methods: Patients (n=106) completed the TR Assessment and Pediatric Quality of Life Inventory (PedsQL) utilizing an e-tablet,web-based format at a routine F/U clinic visit. Changes from initial to F/U scores were evaluated.

Results: Median patient age was 18.7 yrs at a median F/U time of 1.02 yrs. Average perceived knowledge deficit score (% of items with no knowledge) at F/U was 18.0 ± 15.2%, decreased from 24.7 ± 16.5%, p<.0001. On a 100-point scale, the mean score for self-efficacy increased from 71.4 ± 17.0 to 76.7 ± 18.2 (p=.004) and for self-management increased from 47.9 ± 18.4 to 52.0 ± 20.7 (p=.0004). While physical QOL did not change, the mean psychosocial QOL score increased significantly from 80.2 ± 13.3 to 82.5 ± 12.0, p=.02. A decrease in knowledge deficit score at F/U was significantly associated with an increased psychosocial QOL score, p=.03. An increase in self-efficacy score was associated with an increase in psychosocial QOL score (p=.04), especially social QOL (p=.02). Among patients who reported receiving specific information after initial TR assessment, knowledge deficits decreased related to medication (p=.002), symptoms to call for (p=.02), how to contact heart doctor (p=.02), and health insurance (p=.10). Self-efficacy scores improved in patients reporting receipt of information regarding how to contact the heart doctor (p=.06) and how to communicate with healthcare team (p=.05).

Conclusion: While deficits in knowledge and self-management skills persist, TR assessment and recognition of deficits can improve transition readiness with improved psychosocial QOL. Routine TR assessment is important to identify transition needs. Further studies are needed to examine the relationship between TR and outcomes in young adults with heart disease.