

Standardized Quality of Life Assessment During Routine Follow-Up for Tetralogy of Fallot Increases Referrals for Rehabilitation Services

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Background: The Herma Heart Center (HHC) at Children's Hospital of Wisconsin implemented a quality improvement initiative to identify tetralogy of Fallot (TOF) patients with functional deficits during routine cardiology follow-up and refer them to appropriate rehabilitation resources. The aim of this project was to compare referral rates before and after protocol implementation.

Methods: Between May – July 2017, TOF patients (5-18yrs) and/or their families were asked to complete a validated health-related quality of life assessment. The Pediatric Quality of Life Inventory (PedsQL™) was administered via EPIC MyChart portal during routine HHC Clinic visits. Providers were encouraged to refer patients with abnormal PedsQL™ scores to appropriate resources. Referral rates to cardiac rehabilitation, psychology, neurodevelopmental clinic, and school intervention were assessed. Baseline referral rates to these services were determined by chart review of all TOF patients 5-18 yo seen in clinic from November 2016 - April 2017 (n=27). The two groups were mutually exclusive. Chi square analysis was used to assess differences between groups.

Results: Thirteen patients completed the PedsQL™ (54% of eligible patients). Groups were similar in age and gender (p=1.0, p=0.752, respectively). At least one abnormal score was reported in 6/13 (46%) of patients [31% (n=4) Physical Health, 23% (n=3) Emotional Functioning, 31% (n=4) Social Functioning and 15% (n=2) School Functioning]. Identification of challenges led to an increase in referrals (p<0.001 for all, Figure 1). While 10/16 (62%) referrals were for abnormal PedsQL™ scores, 6/16 (38%) were based on clinical judgment regardless of PedsQL™ scores.

Conclusions: Significant functional challenges are common in patients with TOF and may go unaddressed during cardiology clinic visits. Administering PedsQL™ identifies patients with physical, emotional, social and school challenges resulting in increased referrals for intervention. Future endeavors will address barriers that prevent completion of the PedsQL™ and assessing whether referrals impact quality of life.

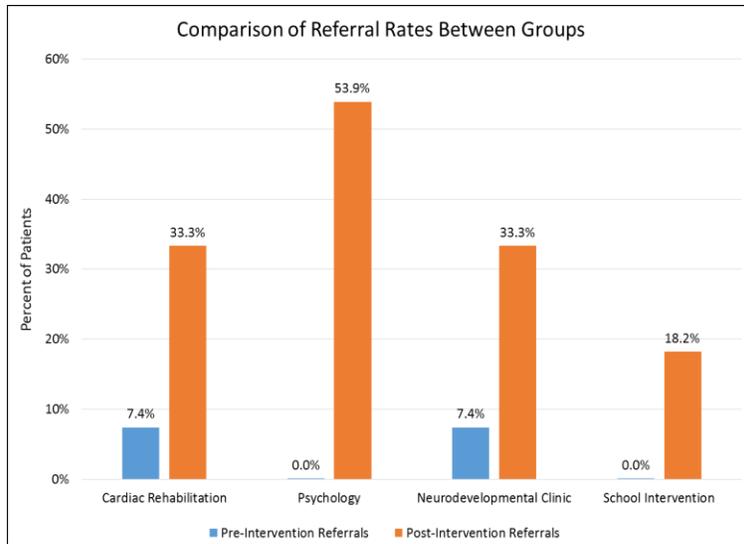


Figure 1.