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Changes in Parent/Guardian and Youth Patient Reported Outcomes (PROs) After T1D Diagnosis for Families in the 4T Study 1

Author Block: SELMA A. ALAMARIE, ERICA PANG, ANA L. CORTES-NAVARRO, NORA ARRIZON-RUIZ, ILENIA BALISTRERI, ALONDRA LOYOLA, AIKA SCHNEIDER-UTAKA, VICTOR RITTER, BLAKE SHAW, FRANZiska K. BISHOP, DESSI P. ZAHARIEVA, PRIYA PRAHALAD, MANISHA DESAI, DAVID M. MAAHS, KOREY K. HOOD, ANANTA ADDALA, Palo Alto, CA, Stanford, CA

Abstract:

The 4T Study 1 is a clinical pragmatic research trial that starts continuous glucose monitoring (CGM) within 30 days of T1D diagnosis and monitors PROs. We report the longitudinal relationship of PROs between newly diagnosed youth and parents/guardians (PG). PROs surveys were administered to youth and PG at baseline, 3, and 6 months. PG PROs included the 20-item parent Diabetes Distress Scale (DDS-P) and youth PROs were the 2-item Diabetes Distress Scale (DDS-2) and the 7-item PROMIS Pediatric Global Health Scale (PGH-7). Pearson correlations evaluated the relationship between scores on the PG and youth PROs. Youth (n=60 who were aged \geq 11 years) with new onset T1D and their PG (n=125) were eligible to complete PROs, yet response rates varied (at baseline, 3-, 6-months: Youth 59%, 53%, and 50% vs PG 74%, 70%, and 66%). Correlations showed that PG diabetes distress was positively correlated with child diabetes distress at baseline ($r=0.48$, $p=0.003$) and at 3 months ($r=0.35$, $p=0.058$). However, by 6 months, this association decreased in strength and significance ($r=0.16$, $p=0.42$). Youth global health was inversely correlated with PG diabetes distress at baseline ($r=-0.36$, $p=0.029$) and 3 months ($r=-0.53$, $p=0.002$) and this correlation was not significant at 6 months ($r=-0.049$, $p=0.81$). These data suggest that the relationship between PG diabetes distress and youth psychosocial states are dynamic. PG and youth psychosocial states are strongly associated after diagnosis and decrease over time. Utilization of CGM, age, T1D duration, response rate, and changes in the PG-youth relationship (such as decreased adult involvement or increased independence of youth) may contribute to our findings. Further investigation of longitudinal relationships between PG and youth PROs may provide additional insight into PG and youth psychosocial states and diabetes outcomes and indicate optimal timing for assessment and treatment referral.

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2451 Crystal Drive, Suite 900
Arlington, VA 22202

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