



## The 65th ASH Annual Meeting Abstracts

## ORAL ABSTRACTS

## 901. HEALTH SERVICES AND QUALITY IMPROVEMENT - NON-MALIGNANT CONDITIONS

**Implementing a Structured Health Care Transition (HCT) Process for Sickle Cell Disease Using Quality Improvement: Results from the Sickle Cell Trevor Thompson Transition Project HCT Learning Collaborative**

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Ensuring consistent healthcare during transition is challenging for sickle cell disease (SCD). Emerging adults with SCD (EASCD) experience triple the mortality rates and double the acute care utilization rates compared to younger and older ages. The transition period is also plagued by reduced quality of life (QOL) with increased missed school days per year and worse standardized test scores.

The Sickle Cell Trevor Thompson Transition (ST3P-UP) study aimed to improve acute care utilization and QOL for EASCD by standardizing the transition process while engaging the community as an equal partner. A prior regional stakeholder needs assessment identified care standardization, establishing individual emergency care plans (ECPs), and community engagement as critical success factors for improved access to and engagement in care during transition.

The ST3P-UP SCD health care transition (HCT) learning collaborative engaged 14 pediatric and adult paired sites that included a partner community-based organization (CBO) using the concept of a site "Triad" as the critical framework of each sites transition team. The collaborative aim statement established at a kickoff meeting was **" to improve the health of EASCD by implementing an education-based transition program in pediatric and adult SCD clinics to be accomplished by 24 months, using the Model for Improvement and the Got Transition Six Core Elements of Transition (6CE) model. "**

Using the 6CE framework established by Got Transition® and the Model for Improvement QI methodology, we established a SCD HCT Process Measurement Tool (PMT) and 2 outcome measures for the transition learning collaborative namely: transition readiness assessment (RA), and an individualized emergency care plan (ECP).

Monthly virtual meetings provided coaching on HCT recommendations, use of Plan-Do-Study-Act cycles, and practical guidance on implementing the 6CE. Sites were given a change package that included provider and patient education materials, resources to establish and strengthen a QI team, transition billing and coding resources etc.) to improve their transition processes.

Implementation of 6CE was measured across 14 clinical sites, each comprised of both pediatric and adult clinics, who cared for 1625 EASCD aged 16-25. Clinical programs varied: 12 urban, 2 rural; 12 academic, 2 non-academic; 6 small, 8 large. The HCT-PMT assessed 6CE implementation adherence using iterative QI strategies at baseline (2018) and every six months thereafter for 54mo (2022). Pre-post results were compared for the overall group and by practice size.

All 14 sites made substantial progress towards implementing a structured HCT process within 24 months. Overall HCT-PMT scores improved by 402% by the end of the 54mo collaborative ( $19.4 \pm 14.1$  to  $97.4 \pm 5.2$ ). PMT scores improved significantly by

312% (24 to 99) for pediatrics and 539% (15 to 96 for adult sites. Pediatric PMT scores were higher at each assessment interval vs. adult scores, however adult sites achieved a higher degree of improvement. Smaller sites achieved a higher degree of improvement vs. large sites. Large site PMT scores improved 362% (21 to 97); small site PMT scores improved 444% (18 to 98). Additionally, sites demonstrated substantial improvements with having current ECPs for EASCD annually (completed and reviewed within the past year). At baseline, only 20% of pediatric and 3% of adult EASCD had a current ECP; only 38% of pediatric and 20% of adult EASCD had a current RA. Run charts demonstrated significant improvement with implementing the ECP measure. Pediatric sites had significant and sustained improvement in adherence to the ECP measure for >6mo. Adult sites started with a lower baseline score. Although they met their goal of showing process capability, they have not yet demonstrated sustained improvement.

By Dec. 2022, site adherence with current ECP improved to 84% and 70% for pediatric and adult sites respectively. Adherence with current RA also improved to 76% and 70% for pediatric and adult sites respectively.

All 14 sites showed significant improvement with implementing a structured HCT process aligned with the 6CE using QI confirming its feasibility in establishing a standardized and measurable transition process that can be applied to various chronic conditions.

**Disclosures Osunkwo:** Agios: Consultancy; Emmaus: Consultancy, Speakers Bureau; Cheisi: Consultancy; Takeda: Consultancy; Novo Nordisk: Consultancy, Current Employment, Current equity holder in publicly-traded company, Honoraria; Global Blood Therapeutics: Consultancy, Speakers Bureau; Forma Therapeutics: Consultancy, Ended employment in the past 24 months, Honoraria; Acceleron: Consultancy; Novartis: Consultancy, Honoraria. **Desai:** US Food & Drug Administration: Research Funding; University of Tennessee: Research Funding; University of Pittsburgh: Research Funding; Novartis: Research Funding, Speakers Bureau; NIH: Research Funding; PCORI: Research Funding; POC Detection of Hemoglobin Sickling via Magnetic Fractionation: Patents & Royalties: (Pending); Vertex: Consultancy; Chiesi: Consultancy; Forma Therapeutics: Consultancy. **Lawrence:** Forma Therapeutics: Consultancy; Novo Nordisk Rare Disease: Consultancy.

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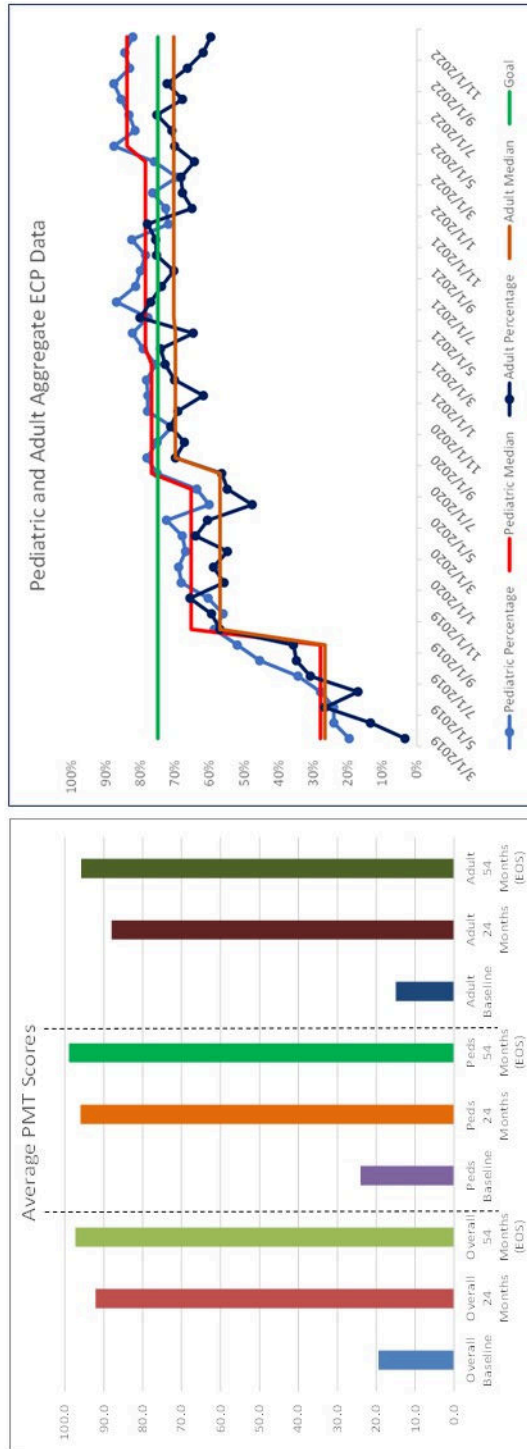


Figure 1  
 Percent pediatric and adult patients (aged 16-25y) across all 14 sites seen in clinic monthly across the 14 sites, who received or reviewed a current Emergency Care Plan (ECP) within the last year. The medians show the periods of change in the data in pediatrics and adults over time. The goal for both groups was 75%.

The mean collaborative baseline PMT score was 19 and this increased by 80% after 54 months to 97. Pediatric clinic PMT scores increased 76% (24 to 99) while adult clinic PMT scores increased 84% (15 to 96).