



The 65th ASH Annual Meeting Abstracts

POSTER ABSTRACTS

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

Quality of Care Among Emerging Adults with Sickle Cell Disease Using the Ascq-ME Qoc Measure: Baseline ST3P-up Study Data Results

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ASCQ-Me[®] (**Adult Sickle Cell Quality of Life Measurement Information System**) is a disease specific patient-reported outcome measurement system to evaluate and track the physical, mental, and social well-being of adults living with sickle cell disease (SCD). It includes a mixed format ASCQ-Me Quality of Care (QOC) measure which aims to quantitatively, and qualitatively, understand the way adults living with SCD experience healthcare. The ASCQ-Me QOC measure follows the Donabedian's model that evaluates health services research around structure, process, and outcomes of healthcare system interactions.¹ Prior and ongoing research report that adults with SCD avoid going to the emergency department (ED) for acute symptoms.^{2,3} Poor provider knowledge and understanding of SCD feeds a misperception as drug seeking and heightens the structural inequities and racial stigma of living with the disease.⁴ This is further compounded by poor adherence to acute triage guidelines, disbelief in patient reports of pain and of their usual care plan, severe delays in receiving acute care, poor provider patient communication and distrust. The Sickle Cell Trevor Thompson Transition Project (ST3P-UP), a multicenter, comparative effectiveness study of a structured education-based transition program +/- peer mentoring to improve acute care utilization for SCD ages 16–26y was conducted at 14 SCD clinical sites.⁵ Each site was required to engage a community-based organization (CBO) and had established community advisory boards (CABs) focused on collaborative partnerships to improve access to and experience of care. The study captured baseline and longitudinal reports of patients' experiences with health care using the ASCQ-Me QOC measure on all enrolled participants with annual rescoring as part of routine care.

ST3P-UP study demographics: N=291, mean age 18.8y (SD1.5); 52% F; 96% Black; 3.6 acute care visits/yr. at baseline (range 0–31, SD4.9). Over 84% of participants reported being *usually* or *always* satisfied with the QOC when care was needed right away. Overall health care was rated between 7–10 (10 = best care possible) by 83%; 73% reported they *usually* or *always* were able to access care right away when needed while 78% *usually* or *always* waited <2h to receive treatment for their acute pain. These reports were equivalent to that reported when SCD experts care for SCD patients.

QOC scores for ED care were higher than previously published and also better than anecdotal reports. Specifically, patients reported that they felt the doctors (84% of the time) and nurses (83% of the time) *usually* or *always* seemed to really care about them and that when they needed care right away, they were treated with courtesy and respect by clerks and receptionists *usually* or *always* 87% of the time. Only 11% of participants reported that providers were able to only help their pain "a little or not at all" and that providers "did not" or "only slightly" believed their report of pain, respectively. Participants were *usually* or *always* satisfied with the care received in the ED 94.1% of the time. However, a bad experience continues to drive

the decision to avoid going to the ED for care in 63% of participants. A previous report by Kanter et al cited only 51% of adults with SCD were *usually or always* satisfied with the ED care received and 52% indicated a bad experience in the ED led them to decide to avoid seeking care.⁶

These results demonstrate a surprisingly higher satisfaction with the quality, process and outcomes of ED care delivered and less discrepancy between ambulatory vs. ED care than expected compared to published and anecdotal reports. This could reflect the bias of ST3P-UP study enrollment and a younger patient population with ~25% having <1 baseline acute visits /yr. ST3P-UP sites had existing strong partnerships with providers, a local CBO and established CABs thus care may not be generalizable to the broader SCD care ecosystem. While longitudinal survey results will be important as comparison, our data highlights the value of objectively quantifying ambulatory and ED experiences soon after a visit to gain quantitative insights into these experiences. Our results do not obviate the need for subjective reports on specific experiences however both types of data can guide local and systemic improvement efforts with attention on identifying subpopulations differently affected and interventions that lower the risk for poor QOC experiences.

Disclosures Osunkwo: *Forma Therapeutics:* Consultancy, Ended employment in the past 24 months, Honoraria; *Novartis:* Consultancy, Honoraria; *Takeda:* Consultancy; *Cheisi:* Consultancy; *Emmas:* Consultancy, Speakers Bureau; *Acceleron:* Consultancy; *Agios:* Consultancy; *Global Blood Therapeutics:* Consultancy, Speakers Bureau; *Novo Nordisk:* Consultancy, Current Employment, Current equity holder in publicly-traded company, Honoraria. **Desai:** *US Food & Drug Administration:* Research Funding; *University of Tennessee:* Research Funding; *University of Pittsburgh:* Research Funding; *PCORI:* Research Funding; *NIH:* Research Funding; *Novartis:* Research Funding, Speakers Bureau; *POC Detection of Hemoglobin Sickling via Magnetic Fractionation:* Patents & Royalties: (Pending); *Forma Therapeutics:* Consultancy; *Chiesi:* Consultancy; *Vertex:* Consultancy. **Symanowski:** *Astellas:* Consultancy, Other: DSMB; *Immatics:* Consultancy, Other: DSMB; *CARsgen:* Consultancy, Other: DSMB; *Eli Lilly:* Consultancy, Other: DSMB; *PCORI:* Research Funding. **Bryant:** *Novo Nordisk Rare Disease:* Consultancy, Speakers Bureau; *GLOVAL consulting LLC:* Other: Medical Writer; *Novant Health Pediatric Hematology:* Ended employment in the past 24 months. **Smith:** *Agios:* Consultancy, Research Funding. **Lawrence:** *Novo Nordisk Rare Disease:* Consultancy; *Forma Therapeutics:* Consultancy.

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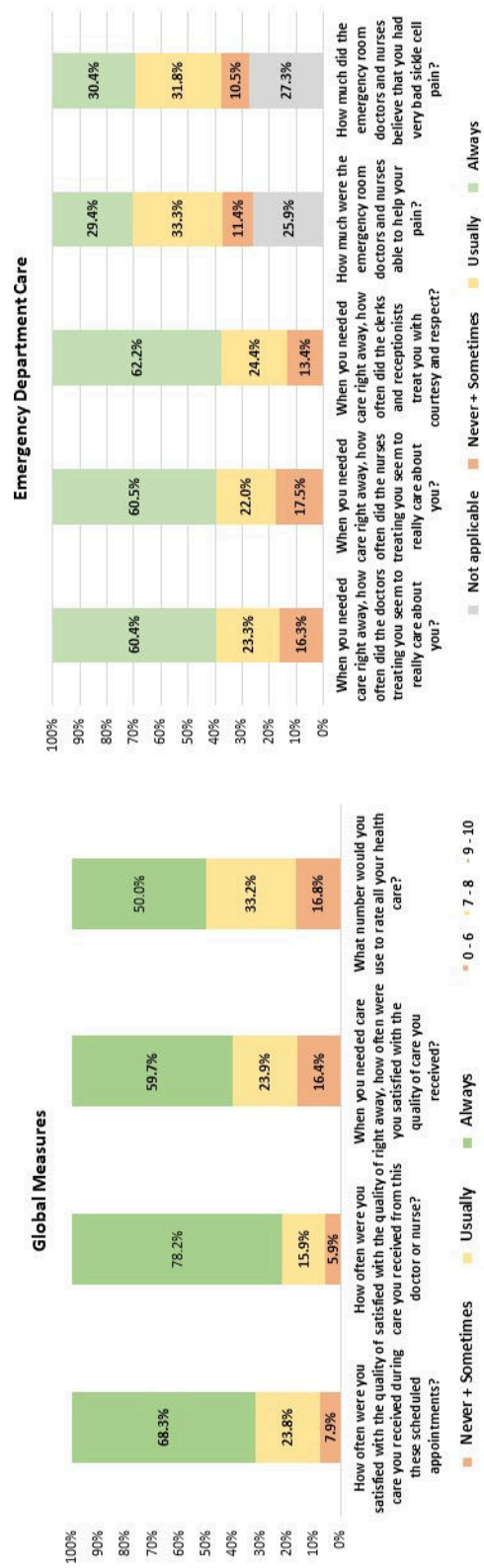


Figure 1