



The 65th ASH Annual Meeting Abstracts

POSTER ABSTRACTS

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

Title: The Impact of Recent Vaso-Occlusive Crisis on Health-Related Quality of Life in Adults with Sickle Cell Disease

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Introduction: Sickle cell disease (SCD) is characterized by vaso-occlusive crises (VOCs) and a progressive clinical course, often leading to end organ damage and mortality. Individuals living with SCD with recurrent VOCs experience daily life disruptions due to recurrent pain crises, debilitating chronic pain and fatigue, which substantially impair health-related quality of life (HRQoL). The impact of a recent VOC on HRQoL has not been quantified. We investigated HRQoL impacts in adults with SCD who experienced a recent VOC (< 1 week) in comparison to overall adults with SCD with recurrent VOCs.

Methods: A mixed-methods study was conducted to quantify the HRQoL, work impacts, and perceived health inequalities of individuals with SCD with recurrent VOCs. The study consisted of qualitative interviews and an online longitudinal survey administered at 3 timepoints (month 0, 3, and 6) in the US, UK, France, Germany, and Italy. Patient advocacy groups used multi-channel outreach to invite participants, who were required to meet the eligibility criteria and provide consent. Key eligibility criteria included recurrent VOCs defined as ≥ 2 VOCs/year in each of the 2 years prior to enrollment requiring a medical facility interaction and administration of pain medication or red blood cell transfusion. The survey included multiple patient-reported outcome (PROs) measures: the Functional Assessment of Cancer Therapy - Bone Marrow Transplant (FACT-BMT) inclusive of the FACT-General (FACT-G), EuroQol- 5 Dimension 5-Level (EQ-5D-5L), 11-point pain numerical rating scale (NRS), Adult Sickle Cell Quality of Life Measurement Information System (ASCQ-Me), and the Work Productivity and Activity Impairment (WPAI) questionnaire. In this post-hoc analysis study participants with a current or recent VOC (< 1 week ago) were identified based on ASCQ-Me responses (herein referred to as recent VOC). The HRQoL impact of a recent VOC was assessed by descriptively comparing PRO scores between those with a recent VOC and the overall population of adults with SCD with recurrent VOCs (herein referred to as overall population).

Results: The survey was completed by 142 participants with SCD (≥ 18 years) with 139 providing time since last VOC living in the US (n=82) and UK, Germany, France, and Italy (n=57). Fifty-six (40.3%) reported a recent VOC and had a similar mean age (35.7 vs. 35.3 years) and hydroxyurea use in the past month (58.9% vs. 61.9%) compared with the overall population. A higher proportion of those with a recent VOC were unemployed or unable to work due to SCD (76.8% vs. 64.7%).

The mean EQ-5D VAS (0-100 scale, 100=best health) among those with a recent VOC was 49.2 (SD: 14.2), which was 16.2% and 38.8% lower relative to the overall study population (58.7 [SD: 19.4]) and the US general population (80.4 [SD: 15.6]), respectively. The overall mean EQ-5D health utility US index score (0.59 [SD: 0.27]) was much lower than the US general population (0.85 [SD: 0.21]) and further reduced among those with a recent VOC by 0.11 (0.48 [SD: 0.25]).

The FACT-G total mean score was 53.6 (SD: 14.3) (0-108 scale, 108=best HRQoL) among those with a recent VOC representing a clinically meaningful reduction compared with the overall population (62.5 [SD:18.1]); with all FACT-G domain scores negatively impacted by a recent VOC. Based on the WPAI, those employed with a recent VOC (n=15) reported a mean of 35.4% (SD: 35.8%) absenteeism and 62.5% (SD: 21.8%) presenteeism, which were higher than the overall study population (24.7% [SD: 27.1%] and 42.0% [SD: 27.8%]), respectively).

In the past 12 months, those with a recent VOC had a greater mean number of emergency room visits (9.6 [SD: 12.6] vs 6.2 [SD: 8.8]), hospitalizations with overnight stays (6.0 [SD: 5.7] vs. 4.0 [SD: 4.5]), and days overnight in the hospital (21.8 days [SD: 32.9] vs. 14.7 [SD: 24.7]) compared to the overall population.

Conclusions: Despite current treatments, nearly 40% of adults with SCD in the surveyed population experienced a recent VOC (< 1 week), which has significant negative impacts on HRQoL and functional status, including the ability to work. These results demonstrate the substantial humanistic burden of those living with SCD with recurrent VOCs and the additional impairment of a recent VOC. Novel treatments that reduce or eliminate VOCs may provide an opportunity to improve health inequalities, HRQoL, and address unmet needs in this patient population.

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