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# 5071 Comparison of Sickle Cell Disease Patient Experiences in Developed and Developing Countries: Insights from UK and India Patient Cohorts

Program: Oral and Poster Abstracts
Session: 904. Outcomes Research: Hemoglobinopathies: Poster III
Hematology Disease Topics & Pathways:
Sickle Cell Disease, Hemoglobinopathies, Diseases

Monday, December 9, 2024, 6:00 PM-8:00 PM

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*Background*

Sickle cell disease (SCD) is the most common genetic blood disorder, affecting millions globally with 300,000 new cases annually. ~14,000 people live with SCD in the UK, while the number exceeds 20 million in India. Differences in patient population size, disparities in healthcare access, socio-economic and environmental factors may lead to varied care experiences. Geographic and cultural distinctions between these populations can influence disease management strategies, particularly in preventing vaso-occlusive crises (VOCs), a key predictor of mortality. Understanding these patient experience variations is essential for developing targeted interventions to improve global patient outcomes.

*Aims*

To understand real-world patient experiences and compare trends in physiological measures and patient-reported outcomes (PROs) across 2 geographically distinct patient cohorts.

*Methods*

A total of 200 participants, with 100 each from the UK and India, were selected based on key demographic characteristics (age, gender) to ensure comparability. Data was collected from December 2023 to July 2024 using a wearable smartwatch paired with a specialized mobile app. After giving informed consent, participants accessed the app to enter PROs daily, including EQ-5D-5L, pain levels, mood, fatigue and self-reported VOCs. The smartwatch automatically recorded data on physical activity, sleep quality, and heart rate. Cohort comparisons were conducted using the U-Mann-Whitney test.

*Results*

HbSS was the predominant genotype in both cohorts. The UK cohort (50% female, 50% male; median age 33, range 17-57) comprised 81% HbSS and 14% HbSC patients, whereas the India cohort (44% female, 56% male; median age 23 years, range 12-58) had a lower proportion of HbSS patients (47%).

Statistically significant differences ($P<0.05$) were observed across several PRO metrics. The UK cohort reported higher mean scores for EQ-5D Health State (70.6 vs 65.1), Tiredness (4.86 vs 3.13), Pain (2.86 vs 2.67) and Fatigue (6.22 vs 2.80), while the India cohort reported higher Psychological (7.61 vs 6.83) score.

EQ-5D-5L domain severity scores (1-5) revealed key variations, including higher mean scores in the UK than in the India cohort regarding anxiety/depression (1.75 vs. 1.49), pain/discomfort (1.96 vs. 1.62), usual activities (1.80 vs. 1.57), mobility (1.72 vs. 1.54) and self-care (1.61 vs. 1.56) All domains showed statistically significant differences ($P<0.05$).

Despite a similar overall proportion of patients experiencing at least 1 VOC within the extracted period, some differences in VOC rate were observed between the cohorts. 29 (29%) UK patients reported VOCs, with those affected having a mean of 6.1 VOCs per patient. Similarly, 31 (31%) Indian patients reported VOCs, however, those affected reported a significantly lower mean of 2.0 VOCs per patient ($P<0.05$).

Regarding wearable data, the UK cohort recorded higher overall activity levels than the India cohort, including a higher mean daily step count (3,361 vs. 3,283), and total daily calorie expenditure (1,447 vs. 1,251 kcal). However, the mean heart rate was lower in the UK cohort (68 bpm vs. 85 bpm). All differences were statistically significant ($P<0.05$).

*Summary/Conclusions*

This study reveals significant differences in PRO and physiological measures between the 2 cohorts. The UK cohort generally reported higher levels of symptom severity, including increased tiredness, pain and fatigue, with higher EQ-5D-5L domain severity scores compared to the India cohort. This may have been linked to a higher % of patients with HbSS genotype and more frequent VOCs in the UK cohort. The difference in wearable data may be attributed to varying lifestyle habits and environmental influences, as early research indicates that factors like temperature, altitude and pollution have an impact on heart rate. However, it should be noted that 2 different wearable devices were used in the 2 cohorts.

In conclusion, the observed differences between the 2 cohorts underscore the need for region-specific care approaches and

In conclusion, the observed differences between the 2 cohorts underscore the need for region-specific care approaches and key biometric baseline considerations when developing models for patient health tracking and prediction. Further research is needed to explore the underlying causes of these variations, including age, genotype, environment, healthcare systems and cultural perspectives on health to improve patient outcomes.

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