Exploring Patterns of Treatment Utilization and PROMIS Scores in a Home-Reported Outcomes Study for Individuals with Sickle Cell Disease (SCD)

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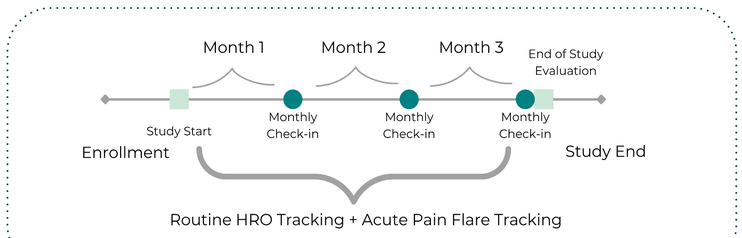
OBJECTIVE

To investigate the relationship between baseline PROMIS Global Health Scale scores and patient-reported treatment utilization among individuals with SCD.

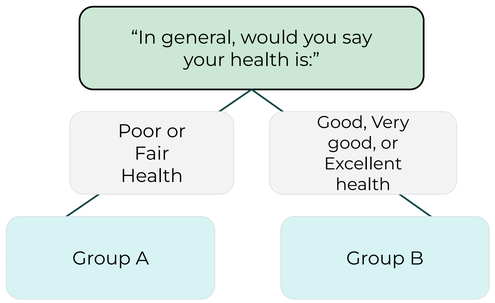
METHODS

Study Design



- Remote, prospective, observational study with 82 participants diagnosed with SCD
- Home-reported outcomes (HROs) collected via a mobile-based platform over a 3-month period
- Baseline survey included the PROMIS Global Health v1.2 questionnaire (also collected monthly)

Subgroup Analysis:



- The average GPH and GMH were calculated after converting raw scores of baseline results into T-scores for group A and B.
- Summary statistics of treatment utilization analyzed by total number of responses for each unique treatment track per participant.
- Treatments categorized by pharmaceutical classification using the National Drug Code database.

RESULTS

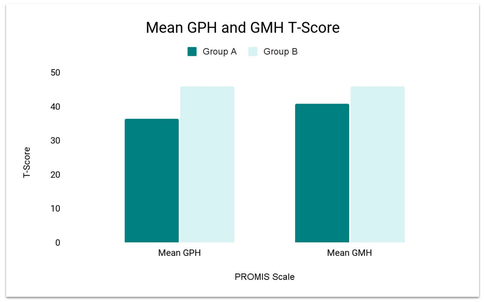


Figure A. Overall Mean GPH and GMH T-score for Group A and B

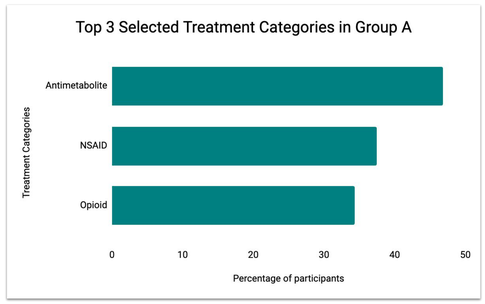


Figure B. Top 3 Tracked Treatment Categories in Group A

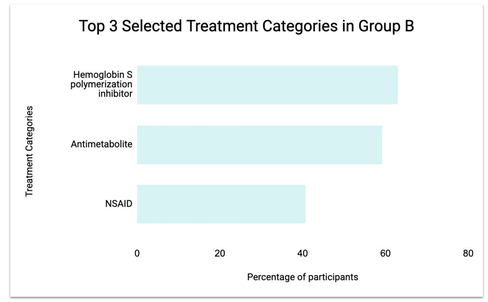


Figure C. Top 3 Tracked Treatment Categories in Group B

Figure A. Overall Mean GPH and GMH T-score for Group A and B

- 59 of the 82 enrollees (71.9%) completed the PROMIS questionnaire at baseline.
- For Group A (n= 32), the mean GPH score is 36.3 (STD: 6.0) and the mean GMH is 40.7 (STD: 7.2).
- For Group B (n=27), the mean GPH score is 45.8 (STD: 7.4) and the mean GMH is 45.9 (STD: 8.5).

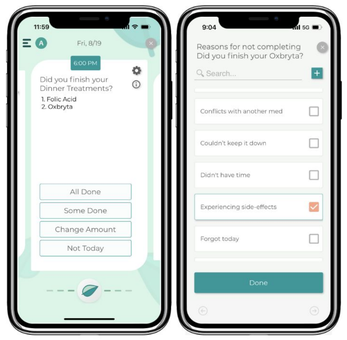
Figure B. Top 3 Tracked Treatment Categories in Group A

- The top treatment categories tracked in Group A included opioids, antimetabolites, and NSAIDs.
- 29 participants (90.6%) of participants in Group A skipped at least one treatment.
- The top 3 reasons for skipping treatments for Group A: 'Wasn't needed' (10.3%), 'Need to refill or pickup' (6.9%), and 'Used alternative treatment' (3.4%)

Figure C. Top 3 Tracked Treatment Categories in Group B

- The top treatment categories tracked in Group B included a Hemoglobin S polymerization inhibitor, antimetabolites, and NSAIDs.
- All 27 participants in Group B tracked skipping a treatment at least once.
- The top 3 reasons for skipping treatments: 'Forgot today' (25.9%), 'Wasn't Needed' (22.2%), and 'Didn't have time' (11.1%). .

"Why Not" Reasons Collected for Treatment Non-Use



- When participants indicate not completing a treatment, they have the opportunity to answer additional questions regarding why.
- Participants are able to multi-select any number of reasons for a skipping a treatment.

CONCLUSION

Patient-reported outcome measures such as PROMIS can provide a point-in-time overview on the state of health for individuals. The utilization of HROs can further contextualize disease burden for individuals with SCD and other complex and rare conditions.

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