



The 65th ASH Annual Meeting Abstracts

POSTER ABSTRACTS

114. SICKLE CELL DISEASE, SICKLE CELL TRAIT AND OTHER HEMOGLOBINOPATHIES, EXCLUDING THALASSEMIA: CLINICAL AND EPIDEMIOLOGICAL**Engagement with Incharge App - a Mobile Health Intervention to Improve Adherence to Hydroxyurea Among Individuals with Sickle Cell Disease**

Christina M Abrams, MD¹, Natalia Davila², Cathy Melvin, PhD MPH³, Sherif M. Badawy, MD MBA, MS⁴, Michael B Potter, MD⁵, Robert Gibson, PhD MS⁶, Allison A King, MD MPH, PhD^{7,8}, Victor R. Gordeuk, MD⁹, Chinonyelum Nwosu, MPH¹⁰, Jerlym S. Porter, PhD MPH¹¹, Sophie Li¹², Jeffrey A. Glassberg, MD¹³, Richard Lottenberg, MD¹⁴, Lisa Klesges, PhD MS¹⁵, Nirmish Shah, MD¹⁶, Jane S Hankins, MD MS^{17,18}

¹Department of Pediatrics, Division of Hematology/Oncology, Medical University of South Carolina, Charleston, SC

²College of Nursing, Medical University of South Carolina, Charleston

³Department of Public Health Sciences, Division of Health Behavior and Health Promotion, Medical University of South Carolina, Charleston, SC

⁴Ann & Robert H. Lurie Children's Hospital of Chicago, Northwestern University, Chicago, IL

⁵University of California San Francisco School of Medicine, San Francisco, CA

⁶Department of Emergency Medicine, Medical College of Georgia-Augusta University, Augusta, GA

⁷Department of Pediatrics, Washington University in St. Louis, Saint Louis, MO

⁸Division of Public Health Services, Department of Surgery, Washington University School of Medicine in St. Louis, Saint Louis, MO

⁹Sickle Cell Center, University of Illinois at Chicago, Chicago, IL

¹⁰Department of Hematology, St. Jude Children's Research Hospital, Memphis, TN

¹¹Department of Psychology and Biobehavioral Sciences, St. Jude Children's Research Hospital, Memphis, TN

¹²RTI International, Research Triangle Park, NC

¹³Department of Emergency Medicine, Icahn School of Medicine at Mount Sinai, New York, NY

¹⁴Department of Medicine, University of Florida, Gainesville, FL

¹⁵Department of Public Health Sciences, Department of Surgery, Washington University School of Medicine in St. Louis, St Louis, MO

¹⁶Division of Hematology-Duke Sickle Cell Comprehensive Care Unit, Duke University Medical Center, Durham, NC

¹⁷Departments of Hematology and Global Pediatric Medicine, St. Jude Children's Research Hospital, Memphis, TN

¹⁸Center for Sickle Cell Disease, University of Tennessee Health Science Center, Memphis, TN

Introduction: Sickle cell disease (SCD) affects around 100,000 people in the United States, causing acute vaso-occlusive events and chronic end-organ damage. Hydroxyurea (HU) is a proven treatment for SCD that reduces acute and chronic complications. Despite extensive evidence and guideline recommendations, many people with SCD do not receive optimal HU therapy. Our group has shown that using the InCharge Health app, a SCD-specific app co-developed with patients (Alberts et al, JMIR mHealth uHealth, 2020), for at least 24 weeks, increases adherence to HU up to 29%, but engagement with the app varied among users. This study reports user's perceptions of the app relative to their degree of app utilization, thus informing future app adaptations to optimize app engagement and potentiate its effect.

Methods: The InCharge Health app features included daily reminders, adherence and pain progress tracking, communication with providers and other patients, hospital mode deactivation, educational resources, and an accountability partner. Participants used the InCharge Health app and completed the validated Mobile Application Rating Scale (MARS, Stoyanov SR, JMIR mHealth uHealth, 2015) after 24 weeks of app use. The MARS evaluates the quality of mobile health apps by eliciting users' perceptions of engagement, functionality, aesthetics, and information quality. App utilization data (% of the study days) were obtained from the backend of the app and defined as low (<25%), medium low (25-50%), medium high (50-75%), and high (>75%). HU percentage of days covered (PDC), the percentage of days covered by filled HU prescriptions during the study period, was used as a proxy for medication adherence. Baseline pain frequency 12 months before study enrollment

was obtained using the Adult Sickle Cell Quality of Life Measurement Information System. After 24 weeks, the ease of use, importance, and helpfulness of app features were evaluated and stratified based on the level of app usage.

Results: A total of 208 participants enrolled, median age 26.3 years (range, 15 to 45), 52% (108/208) females, 87% (181/208) with HbSS/S β ⁰-thalassemia. Fifty-eight percent (121/208) of participants were low app utilizers, 19.2% (40/208) medium low, 15.9% (33/208) medium high, and 6.7% (14/208) high app utilizers (Table 1). As app usage increased, users reported lower pain frequency and pain severity. After 24 weeks, all groups increased PDC, which sustained post-study, and the magnitude of an increase was proportional to the amount of app use (Table 1). The mean (SD) daily use was 2.3 (4.8) minutes/day, and daily duration of app use increased with the total app use. Conversely, the interval between app usage decreased with total app use (Table 2). The most used app features included pain tracking (56.2%, 117/208) and weekly progress report (20.7%, 43/117). The least used features were connecting to educational resources (7.2%, 15/208) and communicating with treating providers (6.3%, 13/208, Table 2).

Overall, 57.7% (120/208) rated the app moderately or very interesting, 63.0% (131/208) reported using it daily to 2 to 3 days/week, 83.2% (173/208) found the app easy to learn, simple, or intuitive. Low users found the app less interesting and had more concerns of the time and effort it took to use the app (Table 2).

Across all groups, daily reminders were considered the most important and useful feature. Fewer high users considered daily reminders the most important feature, however high users more often deemed other features as most important. HU information was found to be the most important by high users, but this varied between the other user levels. High users also found adherence tracking most important with more users valuing it as app usage increased. Adherence and pain progress tracking were found helpful in all groups except the medium-high users. Importantly, more than 50% of all groups intended to continue using the app beyond the study period.

Conclusions: The InCharge Health app promoted increased HU adherence proportional to its engagement. All users considered daily reminders the most beneficial and crucial feature, while pain tracking was widely utilized. Distinct app consumption and preference patterns were observed according to app usage level. Plans are underway to improve the app functionality and interface to allow real-time customization to boost app engagement and further adherence enhancement among individuals with SCD.

Disclosures Badawy: Editas Medicine: Consultancy; GBT/Pfizer: Consultancy; Bristol-Myers Squibb: Consultancy; Forma Therapeutics/Novo Nordisk: Consultancy; Vertex Pharmaceuticals Inc: Consultancy; Bluebird bio, INC: Consultancy; Chiesi, Inc: Consultancy. **King:** GBT: Research Funding; NIH: Research Funding; HRSA: Research Funding; ASH: Research Funding. **Gordeuk:** Modus Therapeutics: Consultancy; Emmaus: Consultancy, Research Funding; Incyte: Research Funding; Forma: Consultancy, Research Funding; Novartis: Research Funding; GBT/Pfizer: Consultancy, Research Funding; CSL-Behring: Consultancy; Takeda: Consultancy. **Shah:** Alexion Pharmaceuticals: Speakers Bureau; Agios Pharmaceuticals: Consultancy; Global Blood Therapeutics/Pfizer: Consultancy, Research Funding, Speakers Bureau; Bluebird bio: Consultancy; Vertex: Consultancy; Forma: Consultancy.

Table 1: Demographics of patient participants.

	Low N=121	Medium Low N=40	Medium High N=33	High N=14	All N=208
Gender (n, %)					
Male	58 (48%)	21 (53%)	16 (48%)	5 (36%)	100 (48%)
Female	63 (52%)	19 (48%)	17 (55%)	9 (64%)	108 (52%)
Age (years)					
Median	24.8	25.5	30	30.6	26.3
Range	15.1 - 44.7	16.0 - 43.9	17.6 - 45.5	21.1 - 45.2	15.1 - 45.5
Sickle Cell Genotype (n, %)					
HbSS/S β ⁰ -thalassemia	98 (81%)	39 (98%)	31 (94%)	13 (93%)	181 (87%)
HbSC/S β ⁰ -thalassemia/other	23 (19%)	1 (3%)	2 (6%)	1 (7%)	27 (13%)
Race (n, %)					
Black	117 (97%)	38 (95%)	32 (97%)	14 (100%)	201 (97%)
Other	2 (2%)	2 (5%)	1 (3%)	0 (0%)	5 (2%)
Ethnicity (n, %)					
Hispanic	5 (4%)	1 (3%)	0 (0%)	0 (0%)	6 (3%)
Non-Hispanic	115 (95%)	39 (98%)	33 (100%)	14 (100%)	201 (97%)
Not reported	1 (1%)	1 (2.5%)	0 (0%)	0 (0%)	2 (1%)
Hydroxyurea PDC Adherence (Mean %, \pm STD)					
Baseline PDC	38.0 (26.9)	33.6 (24.5)	42.8 (31.2)	36.0 (29.2)	38.0 (27.3)
24 week PDC	52.7 (31.0)	61.4 (27.4)	65.8 (26.5)	81.1 (24.3)	58.4 (30.1)
36 week PDC	49.4 (29.6)	58.0 (29.1)	59.3 (27.6)	72.2 (26.5)	54.1 (29.5)
Pain frequency in the past 12 months (n, %)					
1	15 (12%)	2 (5%)	5 (15%)	5 (36%)	27 (13%)
2	23 (19%)	9 (23%)	4 (12%)	0 (0%)	36 (17%)
3	14 (12%)	2 (5%)	6 (18%)	3 (21%)	25 (12%)
4 or more	49 (40%)	23 (58%)	12 (36%)	4 (29%)	88 (42%)
I did not have a pain attack in the past 12 months	18 (15%)	4 (10%)	6 (18%)	2 (14%)	30 (14%)
Pain severity (how often did you have severe pain?) (n, %)					
Never	24 (20%)	10 (25%)	4 (12%)	4 (29%)	42 (20%)
Rarely	35 (29%)	5 (13%)	12 (36%)	4 (29%)	56 (27%)
Sometimes	34 (28%)	15 (38%)	13 (39%)	5 (36%)	67 (32%)
Often	23 (19%)	9 (23%)	3 (9%)	1 (7%)	36 (17%)
Always	4 (3%)	1 (3%)	1 (3%)	0 (0%)	6 (3%)

Notes: Low <25% of the days in the study period, Medium-low 25-50% of the days in the study period, medium-high 51-75% of the days in the study period, High >75% of the days in the study period

Table 2: Description of app utilization and ease of use experienced by patient participants.

	Low N=121	Medium Low N=40	Medium High N=33	High N=14	All N=208
App utilization					
Usage Per Day (mean minutes, \pm STD)	4.4, 7.6	1.4, 2.4	1.5, 3.9	2.3, 3.3	2.3, 4.8
Days Between Accessing App (mean, \pm STD)	5.6, 12.3	2.1, 2.7	1.5, 1.2	1.2, 0.8	2.2, 5.3
Feature utilization (n, %)					
Support Contacts	15 (12%)	6 (15%)	2 (6%)	2 (14%)	25 (12%)
Weekly Progress Report	16 (13%)	8 (20%)	11 (33%)	8 (57%)	43 (21%)
Pain Score Documentation	61 (50%)	24 (60%)	24 (73%)	8 (57%)	117 (56%)
Hospital Mode Use	9 (7%)	5 (13%)	8 (24%)	1 (7%)	23 (11%)
One SCD Voice Use	5 (4%)	2 (5%)	5 (15%)	3 (21%)	15 (7%)
Doctor Call Use	8 (7%)	2 (5%)	2 (6%)	1 (7%)	13 (6%)
InCharge Health Utility (n, %)					
Not interesting at all	15 (12%)	1 (3%)	1 (3%)	0 (0%)	17 (8%)
Mostly uninteresting	8 (7%)	0 (0%)	4 (13%)	0 (0%)	12 (6%)
OK, neither interesting nor uninteresting	35 (29%)	12 (30%)	6 (19%)	4 (29%)	57 (27%)
Moderately interesting	29 (24%)	16 (40%)	11 (34%)	5 (36%)	61 (29%)
Very interesting	33 (28%)	11 (28%)	10 (31%)	5 (36%)	59 (28%)
InCharge Health frequency of use (n, %)					
Every day	34 (28.3%)	22 (55%)	24 (75%)	11 (79%)	91 (44%)
Two to three times per week	24 (20%)	10 (25%)	4 (13%)	2 (14%)	40 (19%)
Once a week	18 (15%)	3 (8%)	2 (6%)	1 (7%)	24 (12%)
Once a month	21 (18%)	2 (5%)	2 (6%)	0 (0%)	25 (12%)
Did not use at all	23 (19%)	3 (8%)	0 (0%)	0 (0%)	26 (13%)
InCharge Health ease of use (n, %)					
No. Limited instructions, menu labels/icons are confusing, complicated	7 (6%)	2 (5%)	0 (0%)	0 (0%)	9 (4%)
Useable after a lot of time and effort	6 (5%)	1 (3%)	0 (0%)	0 (0%)	7 (3%)
Useable after some time and effort	7 (6%)	1 (3%)	5 (16%)	0 (0%)	13 (6%)
Easy to learn how to use the app	62 (53%)	18 (45%)	11 (34%)	6 (46%)	97 (47%)
Able to use app immediately, intuitive, simple	35 (30%)	18 (45%)	16 (50%)	7 (54%)	76 (37%)

Notes: Low <25% of the days in the study period, Medium-low 25-50% of the days in the study period, medium-high 51-75% of the days in the study period, High >75% of the days in the study period

Figure 1

<https://doi.org/10.1182/blood-2023-179272>