Feasibility of Digital Monitoring of Physical Activity via App Questionnaires in Patients with Bleeding Disorders

Lara M[1], Acharya S[2], Stanco J[2], Janbain M[3], Rafique A[3], Kellum A[3], Sidonio R[4], Young G[5], Callaghan M[6], and Chitlur M[6]

1. MicroHealth, Inc. 2. Northwell Health 3. Tulane University School of Medicine 4. Children's Healthcare of Atlanta 5. Children's Hospital of Los Angeles 6. Children's Hospital of Michigan.

BACKGROUND

The number of new therapeutic options for hemophilia patients is on the rise: from factor clotting concentrates with extended half-lives, to non-factor therapies and soon, gene therapy. While these therapies are promising, the optimal prophylaxis dose/schedule to prevent bleeding based on a key risk factor, level of physical activity (PA), remains unclear.

In hemophilia, patients are increasingly using digital health tools to manage treatment. However, there is currently no quick, cost-effective, PA monitoring system that can be scaled nationwide to personalize treatment and minimize bleeds. Activity monitoring devices, while useful in controlled studies, have several limitations, including: cost, battery life, syncing, consistent use, standardization, and multiple users sharing the wearable/smartphone.

OBJECTIVE

To assess feasibility of a digital health monitoring method to collect PA data for patients with bleeding disorders. In particular, we aimed to determine the

(a) response rate over time to bi-monthly PA questionnaires;
(b) distribution of patients by exercise intensity and time;
(c) types of activities reported.

METHODS

Eligible patients were affiliated with one of three participating hemophilia treatment centers (Tulane, Northwell Health, Children's Hospital of Michigan) and were using the MicroHealth App along with their healthcare professional to monitor their bleeding disorder.

Patients received an initial message on the app explaining that brief monthly surveys would be sent via a push notification to screen PA levels. Responses were visible to healthcare providers using their professional dashboard. Patients were free to ignore the survey or voluntarily participate. No additional training or education was provided.

The bi-monthly questionnaire contained 4 questions:

1. How many days did you exercise last week? Focus on the most intense exercise.

Range: 0-7. (If zero, the questionnaire is finished.)

2. How intense is your exercise?

Maximum (e.g. racing)
Medium (e.g. jogging)
Low (e.g. walking).

3. Approximately, how many minutes per week did you exercise?

30 minutes
60 minutes
90+ minutes

4. Please type any physical activity you did last week.

(running, boxing, etc.)

RESULTS

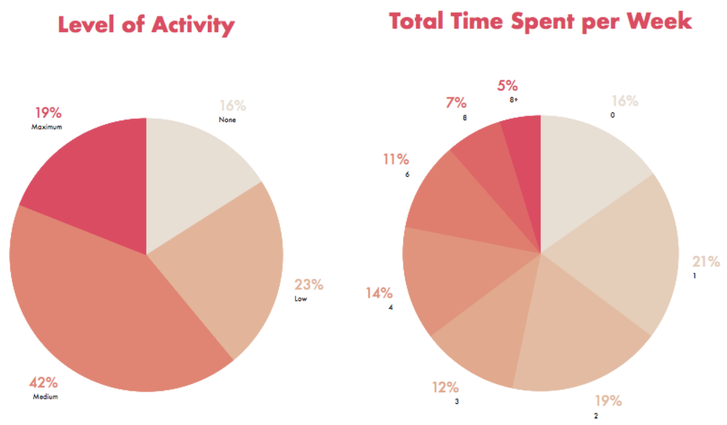
Two surveys were sent via the app on August 15 and October 15, 2019 to 136 active users (i.e. logged an infusion/bleed in each of the 2-month periods). A total of 249 observation months were collected. The median reported patient age was 17 years (n=104) and the range 3-66. The most common reported bleeding disorder was hemophilia A or B (88%, n=120).

A. Response rates for active users.

48% response rate for active users

119/249 observation months

B. Levels of physical activity and total time spent per week (n=119).



C. Summary of key Physical Activity data, as reported in patients' words.

31 total activities reported

most common: running walking basketball weightlifting soccer

most intense: running soccer basketball weightlifting swimming

CONCLUSIONS

This study demonstrates the feasibility of obtaining efficient and meaningful PA data directly from the bleeding disorder patient without compensation or significant training. This methodology engages patients, collects clear data on physical activity levels to make treatment decisions, and can be scaled to query patients on relevant research topics. Further research in this field, such as cross-validating physical activity responses with wearables, or optimizing patient response, is encouraged.