SARCOIDOSIS VASCULITIS AND DIFFUSE LUNG DISEASES 2023; 40 (1); e2023010 DOI: 10.36141/svdld.v40i1.12395

Activity tracking devices in sarcoidosis

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Abstract. *Introduction:* Activity tracker device usage can help analyze the impact of disease state and therapy on patients in clinical practice. Factors such as age, race, and gender may contribute to difficulties with using such technology. *Objective:* We evaluated the effect of age, race, and gender on the usability of the Fitbit One™ activity tracking device in sarcoidosis patients and the impact of device on sarcoidosis patients' activity. *Method:* Patients participated in a six-month prospective study where were asked to wear a Fitbit One™ activity tracker daily. Device usage education was provided at study enrollment. Weekly data download and submission reports to participating centers was required. Patients were asked to complete a post-study questionnaire reviewing the motivation of the activity tracker on daily activity. *Results:* At three centers, 91 patients completed all study visits and the post study questionnaire with a mean age of 55 and 75% were female and 34% African American. Accurate downloads occurred >75% of the time, regardless of age, race, or sex. Results of the post-study questionnaire did not show a correlation between the likelihood of wearing the device and motivation to increase activity. *Conclusion:* Using an activity tracking device to evaluate and/or correlated with quality of life (QOL) instruments may prove beneficial for gathering more data on patients. Age, race, and gender did not contribute to differences in usability among sarcoidosis patients.

Key words: sarcoidosis, activity tracker, patient compliance, quality of life

Introduction

Sarcoidosis patients face a multitude of symptoms related to the organs affected. Regardless of organ involvement, the most commonly reported symptoms include fatigue, dyspnea, and exercise intolerance (1,2). To assess quality of life (QOL), physicians have relied on patient reported QOL instruments to assess treatment effectiveness and activity level in this population (3). The drawback to this method is the reliance on the patient's accuracy in reporting experiences over a fixed interval. The QOL assessment forms also rely on symptoms at the time of completion and recall of events over a prior period (such as past two weeks). Activity trackers have been proposed to assist with the assessment of patient activity level continuously throughout treatment. The reliability and effect of the activity tracker on patients remains unclear from the studies published to date (4,5). The Food and Drug Administration (FDA) has approved some commercially available activity tracking devices for use in research (6). Utilizing an activity tracker in the sarcoidosis population allows activity data to be captured over an extended period. Instead of relying on an individual's

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memory, the activity tracker helps quantify objective data in real time for a more accurate assessment of activity and potentially its impact on QOL (7). Other studies identify correlations between changes in activity level captured by the device and changes in QOL instrument reporting (8). Some patients may find the technology of the activity tracker to be useful for motivation, while others may have difficulty navigating the device and associated software, suggesting that such technology could have positive or negative impacts on QOL.

Activity trackers require the use of mobile devices or computers. This technology may not be available to all patients, especially those at high risk for sarcoidosis. The sarcoidosis population in the United States has a high proportion of African American females over the age of 55 (9,10) and tends to experience lower income (9). Internet and mobile usage in the United States is shown to be most accessible to white males, under 65 years of age (11). Low income and low education level have been identified as factors contributing to mobile technology ownership disparities (12). Though we did not collect this data, we recognize that this could provide non-uniform access to patients, as well as contribute to difficulty with use of the activity tracking devices. A previous study utilizing activity trackers found that patients who drop out of the study report technical issues as one of the main reasons for not completing the study, with women dropping out more frequently than men (13). Assistance with device set-up and review of the device with the patient may prove beneficial to patient compliance with device usage, as patients may not reach out to clinical staff for technical assistance (13).

Sarcoidosis and other patients who are comfortable with activity tracker technology may choose to use the device as a motivational tool (14). Multiple studies have shown positive effects of activity trackers on physical activity levels in patients (15,16). Patients have reported the devices may incentivize, motivate, and increase confidence (13) in activities, with greatest increases in activity following interventions and/or coaching (15). On the other hand, some patients feel negatively challenged by having a device monitoring them, and in contrast may find ways to cheat the device (17).

The aim of this study was to understand the utilization of an activity tracker in the sarcoidosis population. Furthermore, we evaluated the impact of the activity tracker itself, without coaching, on the level of activity in the sarcoidosis patient over a six-month period.

Methods

Patients participated in a six-month prospective study on the impact of sarcoidosis on (QOL). This larger study tracked patients' QOL over a six-month period and was conducted across six sarcoidosis centers in the United States (University of Cincinnati, Albany Medical Center, National Jewish Health, University of Illinois – Chicago, Cleveland Clinic, John Hopkins Medical Center). Patients diagnosed with sarcoidosis using ATS criteria (18) were eligible for inclusion. Non-ambulatory patients were excluded from the study. All patients voluntarily signed informed consents approved by each center's Institutional Review Board. Some of the results of the overall study have been previously reported (19). This sub-study was performed at three of the sarcoidosis centers (University of Cincinnati, Albany Medical Center, and National Jewish Health). In the sub-study, patients were asked to complete a post-study questionnaire evaluating the impact of the Fitbit on the patient's activity level during the study (Supplement S-1). The sub-study analyzed how consistently patients at these centers were able to successfully download their Fitbit device data as directed. We also analyzed if race, age, and gender affected the ability to properly use the device, and if possession of the device motivated an increase in activity level of the patient over the six-month study. The clinical trials registry number for this study is NCT04342403.

Participants of the sub study were given a Fitbit One™ activity tracker (Fitbit™, San Francisco, CA, USA) to electronically monitor daily walking distance. Study personnel instructed patients to download the Fitbit™ app onto their personal electronic devices prior to the initial visit. During the initial visit, research coordinators assisted patients with setting-up the Fitbit activity tracker on mobile devices or laptop computers, and creating an account, to ensure capturing of downloaded data. Patients were educated on how to download data, instructed to do so at least once weekly, and provided take-home instructions for clarification and to assist with setup on home computers. Patients were instructed to email individual weekly activity reports provided by Fitbit to study coordinators for capturing activity data.

Patients who failed to provide weekly downloaded data received emails and/or phone calls as reminders.

Downloads of the patient data were captured, and results entered in an electronic database (Assessment Center, Evanston, IL). The results of the downloads at weeks 1, 2, 4, 8, 12, 16, 20, and 24 were then analyzed for each patient who had completed accurate download of activity data. We analyzed the steps per week per download. A download was considered complete if recorded steps per week were at a minimum of 2000 steps and less than 100,000 steps. For patients who either did not download, or had less than 2000 steps or greater than 100,000 steps per week, the download was not used for that time point as these downloads were considered inaccurate. For each week, the number of patients who downloaded correctly was determined. In addition, the number of times a patient correctly downloaded for the 8 time points was determined. The completed number of downloads were divided by the total number of requested downloads to establish percentage of complete downloads per patient.

Patients who did not complete all visits and the post study Fitbit™ questionnaire (See Supplement Figure S-1) were not analyzed.

Patients were seen for a six-month follow-up where the same information was captured as the initial visit. In addition, a questionnaire was administered to assess the impact of the Fitbit™ on an individual's activity level. Some patients reported taking part in activity challenges offered by the Fitbit™ app (https://www.fitbit.com/us/motivation/challenges). This was not encouraged or discouraged by study personnel.

Statistics

Statistics were calculated using MedCalc (MedCalc Software Ltd, Ostend, Belgium).

Comparisons between groups were performed using Chi square analysis to calculate response rate. A p value of less than 0.05 was considered significant.

Results

From January 2017 through May 2019, a total of 35 patients were enrolled into the overall study. At the three centers who agreed to participate in this sub-study there was a total of 209 patients enrolled during this time. The sub study was performed from August 2017 through March 2019. Of the 143 patients seen at the three centers during the that time, 91 patients completed all study visits and the post study Fitbit™ questionnaire (See Supplement Figure S-1). We did not analyze the data for the 52 patients that did not complete all visits and the subsequent questionnaire. The clinical features of the sub study patients compared to the patients in the main study are summarized in Table 1.

Figure 1 shows a histogram with the number of steps per week for each of the download points. Of the 728 possible download points to analyze, there were 87 instances where the downloads captured less than 2000 steps during the week with 83 of these events capturing no steps per week. There were 12 outliers with more than 100,000 steps counted in a one-week period. For those downloads ≥100,000 steps per week, the individual downloads were reviewed, and most were found to be artifactual or a misrepresentation of the sample population. These events included capturing the vibrations of a bus that the subject drove at work, a marathon runner, and a hospital dietary employee who was on their feet for over ten hours per day. Therefore, those downloads of

Table 1. Demographics of patients in sub-study

	Sub-study	Total
Total number	91	325
Age (median, range)	55 (23-76)	57 (20-77)
Female: Male	68:23:00	204:110 *
African American: Caucasian: Unknown	31:58:02	89:208:15:12 *

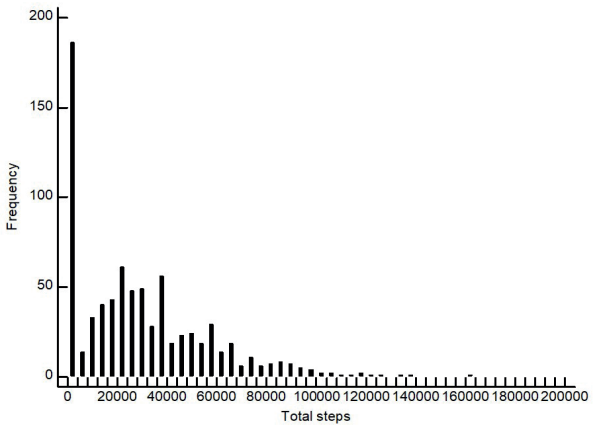

Figure 1. Histogram showing the number of steps per week at each of the download points.

≥ 100,000 steps per week were not further analyzed due to the likelihood of inaccurate or misrepresented data. Table 2 outlines the clinical features of these patients. There was no significant difference in the rate of inaccurate downloads based on race or gender.

The ratio of accurate downloads versus the total number of downloads at weeks 1, 2, 4, 8, 12, 16, 20, and 24 are shown in Figure 2. The accurate download rate was lowest at week 2 (74%), highest at week 12 (87%), and fell by week 24 (77%). There was a significant difference in the proportion of accurate downloads at week 2 versus week 12 (Chi square=4.769, p=0.029), but no other interval.

Figure 3 shows the proportion of patients with complete data versus other rates of downloading. Forty-four percent of patients were able to download their data accurately 100% of the time, and 37% completed downloads with 80-90% accuracy. Six percent of patients downloaded less than 20% of the time. Twenty three percent of patients lost their Fitbit device at least once, with 23% of those patients losing multiple devices. Technology issues related

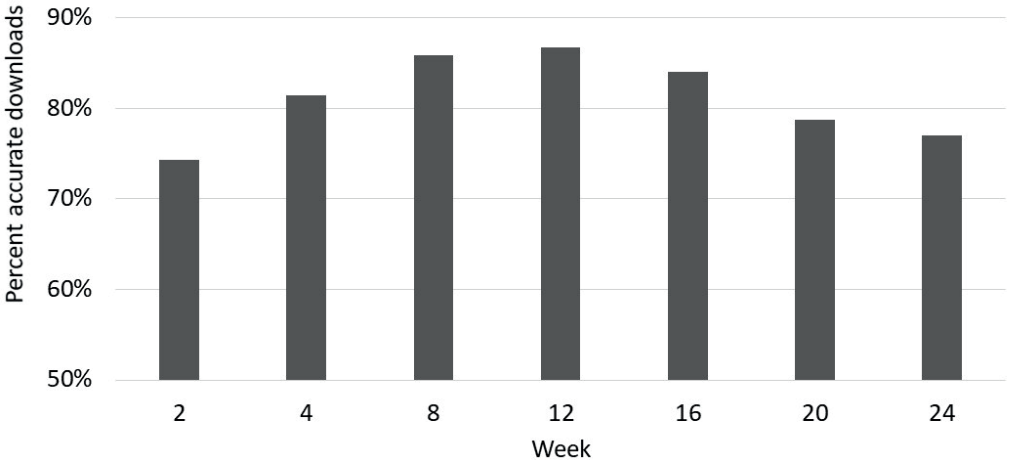

Figure 2. Percent of accurate downloads versus week of download. The percentage rose between Week 2 and Week 12 and then fell back by Week 24.

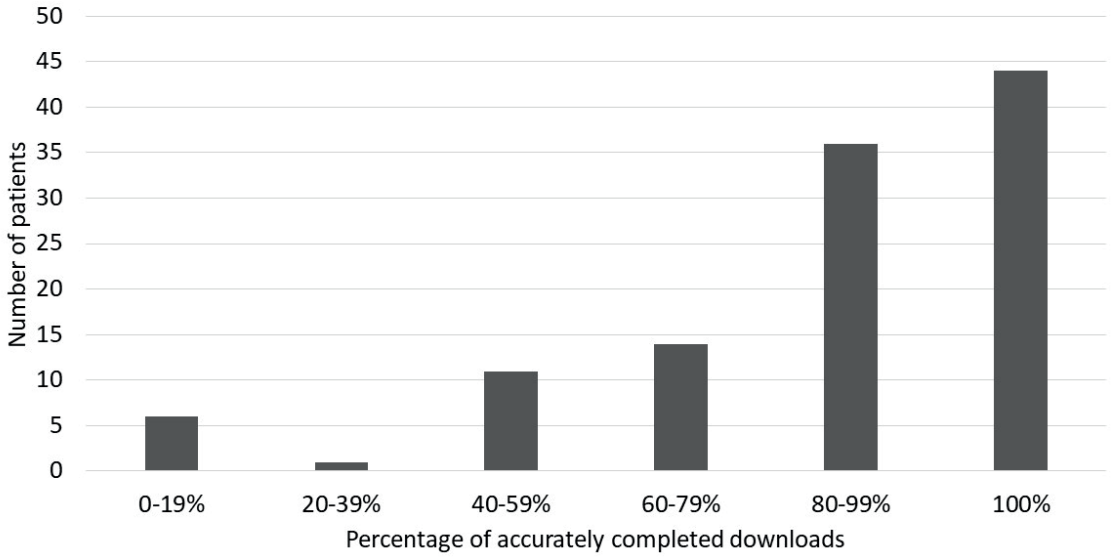

Figure 3. The proportion of patients versus the percentage of time an individual patient accurately downloaded is shown. Eighty-one percent downloaded accurately more than 80% of the time.

to missing transmission of weekly data reports from Fitbit to individuals and user errors accounted for 2% of the missing data. Devices ceasing to work with no explanation of malfunction occurred with 4 patients. We compared the rate of downloads versus race, age, and gender. There was no difference in rate of accurate downloading based on race, age, or gender (Table 2).

The results of the post-study questionnaire are summarized in Figure 4. There was significant correlation between the individual questions, as patients who gave a higher score (more likely to agree) to one question were highly likely to give a higher score to another question. There was no correlation between the change in the number of steps per week between week 2 and week 24 and how likely the patient was to agree with any of the questions. Eighty-three percent of those completing the questionnaire were somewhat to very more aware of their daily activity levels, and 77% were somewhat or much more motivated to increase their daily activity levels. However only 67% of those completing the questionnaire felt that they were somewhat or much more active while using the FitBit. Only seven patients were aware of the FitBit challenges. All seven were somewhat or much more motivated to increase their daily activity levels, and six of these felt that they were somewhat or much more active while using the FitBit.

The number of steps per week captured at weeks 4, 8, 12, 16, 20, and 24 were compared to week 2. The change in the number of steps per week for each patient is shown in Figure 5. There was no significant change in the number of steps per week over the six-month span. We did not collect further information related to step counts for any given week, so we do not know if changes in steps were random or influenced by other factors.

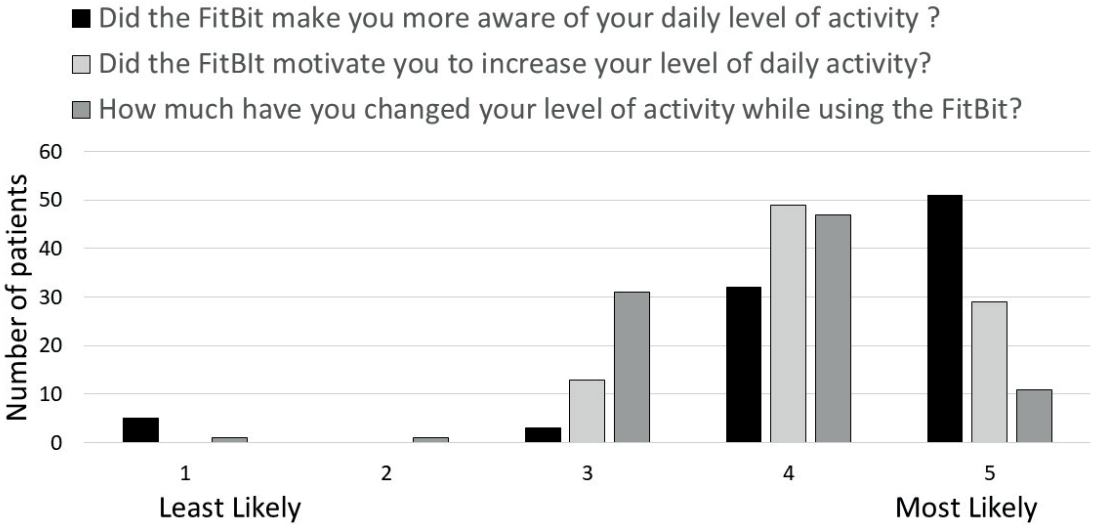

Figure 4. The response to each of the three questions regarding the use of the FitBit device from least likely (1) to most likely (5).

Table 2. Clinical Features of Accurate versus Inaccurate Downloads

Demographic	# Patients	Total # Downloads	Any inaccurate download N (%)	Inaccurate download <2000 steps per week*	Inaccurate downloads ≥100,000 steps per week*
Male	23	184	15 (8.2%)	14 (7.6%) †	1 (0.5%)
Female	68	544	47 (8.7%)	43 (7.9%)	4 (0.7%)
Black	31	248	23 (9.3%)	19 (7.7%)	4 (1.6%)
White	58	464	39 (8.4%)	38 (8.2%)	1 (0.2%)
Other	2	16	0	0	0

*Patients could have more than one inaccurate download; †Number (percent of downloads)

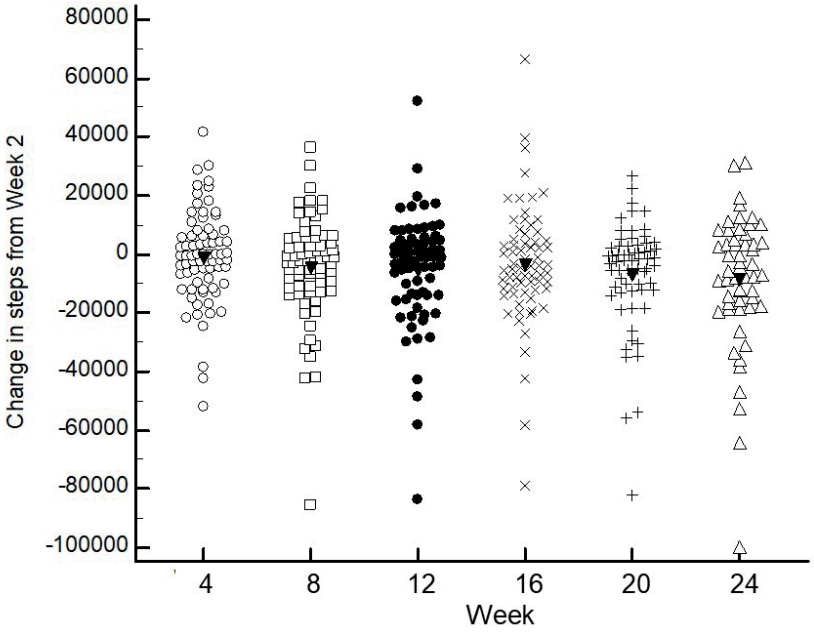

Figure 5. Change for step count from Week 2 for each patient at each time point. There was no significant difference in number of steps per week walked for each patient.

Discussion

This observational study assessed the usability of the Fitbit One™ activity tracker as a research tool in a multicenter American sarcoidosis population and evaluated the impact of the device on individual activity levels. Overall, the activity tracker was correctly used by more than three quarters of patients over the six months of the study. Age, race, and gender did not show any significant difference in ability to use the activity tracking device. Identifying educational needs and potential motivators of the device should be considered in future trials. Potential studies should also prepare for predicted technological issues to ensure higher accuracy of data collected.

Out of 91 sarcoidosis patients who completed this sub-study, we found there to be no significant relationship between age, race, or gender in percentage of accurate downloads. While previous studies have shown age to be a significant factor regarding inaccurate usage of technology [1], as time goes on this seems to no longer be an issue regarding the activity tracker. Examples of specific reasons for inaccurate downloads include loss of Fitbit™ device (21 patients, with some losing devices multiple times), inaccurate wearing of device (5 patients wore on wrist when device was calibrated to be worn on torso/hip), malfunction of computer/smartphone/tablet (16 patients), errors on behalf of Fitbit™ company releasing weekly reports (4 patients). For the purposes of this study, we considered any download with more than 100,000 steps per week as an inaccurate download. However, there were two participants who accurately accumulated over 100,000 steps per week multiple times (a marathon runner and a hospital dietary employee) and it is possible that these patients did have that many steps per week. Since we could not verify this was the cause of the high number of steps, these downloads were not included in the analysis. Investigating individual downloads and understanding the obstacles to device usage may be useful in creating educational guidelines to ensure precise data collection.

There were no significant changes in the percentage of patients accurately downloading the Fitbit™ dat between the beginning and end of the study (Figure 2). The accuracy of downloads increased between weeks 2 and 12, possibly due to novelty of the new device and motivation to use the benefits offered by possession of an activity tracker. The frequency of accurate downloads fell from week 12 until the end of the study. Device fatigue may have played a role in this decrease. Similar trends have been observed in prior studies (6;13;15). We also ran into difficulty with the Fitbit™ Company not sending weekly reports due to technical issues on their part. The patients were only required to visit

the clinic at enrollment and end of study. Had we seen the patients more often during the study, technical issues and lack of understanding of use of device may have been addressed in a timelier fashion. Previous studies have shown that technical difficulties experienced while utilizing activity trackers was a common reason for patients withdrawing from the study (13). Although we did not experience many patients withdrawing from the study, about 1% did stop downloading data within the last 3 analysis timepoints (8-week timespan). We did not query the reasons for the lack of downloading, though these patients did experience previous timepoints in which data was not downloaded.

Activity trackers have been reported a part of home monitoring for sarcoidosis (20) and for comparing to healthy controls (21;22). One of these studies relied on self-reporting of noncompliance of device and noted that one subject did not use the device correctly (22); another study noted that one of ten subjects did not download the device information correctly (20); while there is no comment on compliance in the final study.

A prior study found that possession of smartphones increased likelihood of participation in studies utilizing activity trackers (13). The patients enrolled in this study all owned smartphones or computers and had at least minimal experience with technology. Level of education data was not collected on patients for this study. The teaching provided by the study team during enrollment aided with activity tracker set-up on individual electronic devices. Time in the clinic was given to participants to practice using the device and ask questions. However, there was no standardized educational information used across all participating centers. Throughout the course of the study, researchers learned common difficulties experienced and were able to adjust the set-up education as needed. Given the rising implementation of electronic resources for both research and clinical management, a formal assessment of digital health literacy in sarcoidosis patients would be valuable to gain insight to improve the value and adaptation of these tools (23) and help identify disparities and other barriers to their adoption by our patients (24).

There was a question as to whether possession of an activity tracker would provide motivation to be more active. For this study, we wanted to assess the Fitbit™ activity tracker data versus QOL assessments, and we were not trying to motivate participants. Previous studies have shown that coaching participants does correlate with an increase in activity (4;5;14), and short study duration seems more likely to capture activity level increases (8;15). This study was not evaluating any therapeutic intervention to improve level of activity and we found no significant change in the number of steps per week taken by an individual patient over the course of the study.

About a third of the patients initially included in the study were not analyzed due to various factors, mostly related to difficulties with the use of the activity tracker device and downloading. Throughout the course of the study, we were able to determine limitations of the utilization of an activity tracker to help assess QOL. Technological issues were the greatest limitation. We did not query any issues that may have contributed to lack of any weekly download points, but some patients were willing to contact us on their own to discuss technical difficulties. Many patients reported issues with downloading data and not receiving weekly reports, or issues with device set-up in the case of a new smartphone purchase. Depending on where the patient wore the Fitbit™, step counts were miscounted as the Fitbit One™ device is calibrated to be worn within the torso region. This is key information that we were unaware of until step reports returned significantly higher than average numbers. Previous studies have also discovered that certain body movements and location of where the tracker is worn can affect the overall step count numbers either positively or negatively (7;15). The study did not include an active intervention, only used one type of device, and excluded patients who did not already possess a smartphone or computer. A more diverse population with varying experience utilizing technology would be beneficial to assess usability of the tracker for activity and QOL assessments. We only saw the patients twice, once at the beginning and once at the end of the study. Seeing the patients more often would allow for assessment of usage accuracy and data download.

There are several limitations of the study. We did note a drop in number of downloads from 12 weeks to end of study. However, we did not specifically investigate the reason for the reduction in downloads over time. Most of the patients who reported that the FitBit™ was somewhat or much more motivating to increase their daily activity levels also reported that they were somewhat or much more active while using the FitBit. However, ten percent of the those who felt the FitBit was a positive motivator did not feel they increased their activity. The current study was not designed to determine those subjects did

not report increased activity. As noted above, we did not analyze whether the changes in step numbers were affected by changes in treatment or evidence of changes in the disease activity. Overall, three quarters of the patients did complete the downloads correctly. We did not analyze whether data from those who did versus those who did not download correctly affected other aspects of the study.

In conclusion, from the zero to twelve-week period, there was a general improvement in accuracy of downloads believed to be resulting from familiarization and motivation of device ownership. The frequency of acceptable downloads began to drop after week 12. There was no correlation between age, race, or gender and these findings. Device fatigue may have played a role in this drop, as well as loss of device and technology issues that were not reported. Future studies may investigate standardization of educational guidelines regarding activity tracker usage, a more diverse population, and improved quality control mechanisms.

Statement: The datasets generated during and/or analysed during the current study are available from the corresponding author on reasonable request

Conflict of interest: The authors declare that there are no competing interests.

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Appendix

Supplementary file

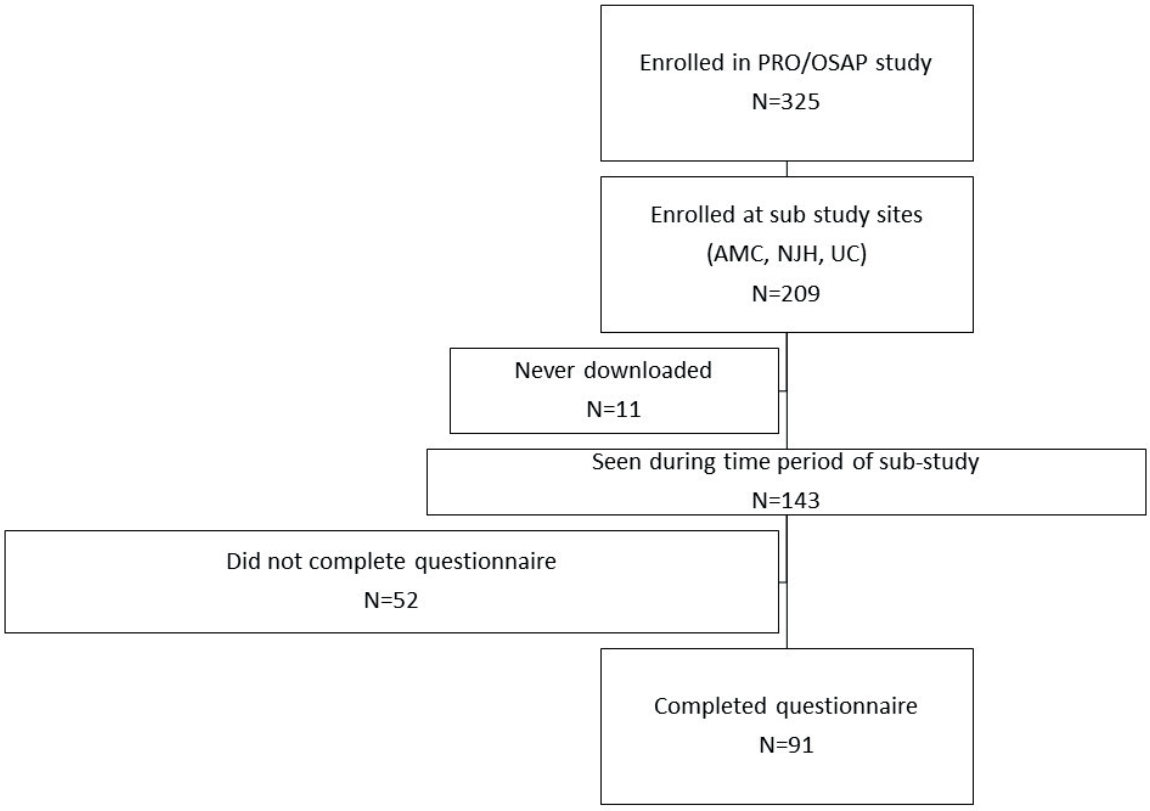

Figure S-1. The CONSORT flow sheet of patients in the study