The Positive Impact of Journaling on Adolescents with Cystic Fibrosis

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June 7, 2023

Abstract

Background Individuals with cystic fibrosis (CF) often have psychological difficulties on top of their medically complex care, such as anxiety, depression, and medical mistrust. These have been shown to be associated with worse adherence, pulmonary function test results, and other health outcomes. In this pilot trial, we implemented a journaling program based on narrative therapy methodology to improve mental and physical health outcomes for individuals with CF. Methods Eight adolescents aged 12-17 with a confirmed diagnosis of CF followed in a single center cystic fibrosis clinic were emailed weekly journaling prompts that explored topics like: treatment adherence, feeling different with CF, anxiety, depression, and interpersonal relationships. Subjects were emailed surveys about their experience with the writing assignment, and baseline health data was collected from the electronic medical records. Results The average score for the Pediatric Symptom Checklist (PSC-17) decreased by 5.5 points, and the post-study average (mean 23.5, SD 12.2) fell to less than 28, which is the cutoff for screening positive for behavioral or emotional problems. Participants reported the study was enjoyable and had improvement in feelings of anxiety/depression. 100% of participants responded "Strongly Agree" to the statement "I recommend other people with CF to write about the topics from this study". Conclusions The journaling intervention for individuals with CF was feasible and well received. Initial results show improvement in PSC-17 and other wellbeing measures. Further studies are needed to evaluate the impact of journaling on mental health and disease outcomes.

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This work was supported by the Cystic Fibrosis Foundation [grant CMHCO14-15].

keywords: cystic fibrosis, pediatric, adolescent, narrative therapy, journaling

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Methods

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Conclusions

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Background

Individuals with cystic fibrosis often face many psychological stresses on top of their medically complex care.[1] These can include depression, anxiety, feelings of isolation, risk-taking behavior, and difficulty navigating relationships.[2] In one international study, adolescents with cystic fibrosis had depression rates from 5-19%, and anxiety rate of 22%.[3]Adolescents with cystic fibrosis also are saddled with medically and emotionally taxing management plans. This can put them at risk for issues regarding medication adherence, treatment compliance, time management, and poor relationships with their medical team.[4-6] These psychological and mental health issues in patients with cystic fibrosis have been shown to be associated with worse adherence, worse pulmonary function, increased hospitalization and healthcare costs, and decreased health related quality of life.[3]

A potential avenue to help address some of these issues is through narrative medicine therapy. Narrative therapy is a journaling practice that encourages objectification of the problem, making it possible to experience an identity that is separate from the problem.[7] Journaling and writing to explore psychologically distressing issues have been shown to increase understanding of self-awareness and understanding as well as provide the foundations for potential positive cognitive change.[8] Expressive writing also has the potential benefits of promoting cognitive processing, creating adaptive internal schemas, and reducing physiological stress resulting from inhibition of negative emotions.[9] There has been prior research done in adult populations regarding expressive writing and chronic disease management that have shown positive results in mental health, daily functioning, baseline disease control, and other health measures .[10-13] Specifically, there have been narrative medicine and expressive writing interventions in patients with breast cancer and coronary artery disease that have shown improvements in physical and psychological health.[14-16] Notably, data regarding this intervention is not as well studied in pediatric population, and even less so in those with chronic illnesses. Therefore, we developed a feasibility trial that applied theories from narrative therapy to

structure a journaling therapy for adolescents with cystic fibrosis with the goal of improving their mental and physical health outcomes.

Methods and Procedures

The IRB approved study was divided into three phases – the screening phase, intervention phase, and follow up phase. [Figure 1] In the screening phase, a maximum of eight participants were recruited using verbal and written means of communication. Inclusion criteria included participants who have diagnosed cystic fibrosis, participants who were followed at the research institutions' CF Center, age 12-17 at the start of the screening phase, participants are able to read and write in English at an age appropriate level, participants have the ability to receive and send assignments electronically, including but not limited to access to the internet and access to compatible devices (computer, smart phone, etc.), and ability to have follow up for the duration of the study intervention phase. Exclusion criteria included age < 12 or > 17 years at start of screening phase, inability to read or write English proficiently to allow participation in the writing intervention, and lack of means to receive and send assignments electronically. Participants all received their care at a Children's Hospital Los Angeles, a quaternary free standing children's hospital with a Cystic Fibrosis Center. We selected a maximum of eight participants because the study was a trial to assess the feasibility of the intervention and the qualitative feedback from participants. The social worker of the CF clinic was responsible for screening, identifying, and recruiting participants, including the consent and assent process. Guardians filled out paper consents and minors filled out paper assents. Information regarding the study was sent to participants and their guardians electronically. The screening phase concluded once eight participants were enrolled or at the end of two months since the start of the screening phase.

The intervention phase started one week after the conclusion of the screening phase. Baseline health data was collected from the participants via the electronic medical record (EMR) as well the CF data registry PortCF. Baseline information included gender and ethnicity/race, age, weight, height, BMI, FEV1 % of predicted, number of hospitalizations, number of respiratory infections in the last year, and previous positive sputum culture species. Study data were collected and managed using REDCap electronic data capture tools hosted at Children's Hospital Los Angeles. REDCap (Research Electronic Data Capture) is a secure, web-based software platform designed to support data capture for research studies, providing 1) an intuitive interface for validated data capture; 2) audit trails for tracking data manipulation and export procedures; 3) automated export procedures for seamless data downloads to common statistical packages; and 4) procedures for data integration and interoperability with external sources. [17,18]

Every week, a survey from REDCap was automatically distributed via email to all participants. All surveys and data were stored in REDCap under password, and only investigators had access to the data. These surveys included a pre-study survey, eight weekly prompts, and a post-study survey. The pre-study survey was created by the research team and included questions regarding familiarity with narrative therapy, health related quality of life, and the Pediatric Symptom Checklist. The Pediatric Symptom Checklist is a validated psychosocial screen used to evaluate and recognize cognitive, emotional, and behavioral problems.[19] Weekly prompts covered topics that included: introduction to narrative therapy, living with cystic fibrosis, treatment adherence, feeling different with cystic fibrosis, anxiety, limitations, depression, and interpersonal relationships. To encourage participation, if the participant did not want to answer the topic, they were able to state that, offer an explanation why, and had space to write about whatever they wanted instead of the topic sent to them. Recurring questions were provided at the end of weekly surveys regarding how much time was spent writing that week's topic, how well the participants liked that week's topic, and how well the participants felt they managed their CF that week. Post-study survey included the same questions as the pre-study survey as well as questions regarding how well the participants liked the study and other feedback.

As some topics could be foreseen to trigger negative emotions, responses were reviewed weekly by the investigators for any content that could indicate that the participants were in immediate danger from psychological distress, such as suicidal or homicidal ideation. We created a standard of procedures (SOP) for this in conjunction with the cystic fibrosis social worker. If such content was found, the investigators would contact

participants through the CF clinic social worker during normal business hours, the on-call social worker on off hours, or national/local authorities. The surveys also had information regarding who to contact if negative feelings were induced by participating. We also let participants know what day of the week the results would be reviewed. Upon completion of one survey, the subsequent survey was distributed automatically at the start of the next week. If a participant did not turn on the survey by the one week deadline, automated reminders were sent, and participants did not receive additional surveys until the previous week's survey was completed. The intervention phase concluded once all participants had attended a routine quarterly clinic visit after completion of all eight weekly assignments or at the conclusion of six months, whichever came earlier. Participants were given compensation for participation from residual funds from the CF Foundation (CFF) Mental Health Coordinator Grant [grant CMHCO14-15]. Participants were offered their choice of an incentive item (meditation board, mindfulness journal) at the completion of the fourth weekly prompt, and a choice of gift card ($25 to Footlocker or iTunes) at the completion of all eight weekly prompts.

The follow up phase lasted up to three months from the end of the intervention phase. Additional health data was collected to compare to the baseline health data collected at the beginning of the intervention phase. These data included weight, height, BMI, FEV1 % of predicted, number of hospitalizations and infections in the last three months, and previous positive sputum culture species. We also obtained written feedback on the participants' experiences in the study.

Analysis

Data analysis was done via Microsoft Excel. Due to this being a pilot study for feasibility, data analysis for statistical power or significance was not pursued. Qualitative analysis was not pursued for this pilot study. Sample size calculation was done for an independent t-test using data from our initial study results in order to gain insight into future numbers needed for statistical significance.[20]

Results

A total of eight participants were recruited for the study. Our patient population included participants with varying degrees of mental health history and disease control. [Table 1] Three participants were actively receiving mental health services, two had a history using mental health services but were not currently. One participant was healthy enough to have every other quarterly visit be telehealth and only required PFT monitoring twice a year per the CF clinic policies. One participant frequently had inpatient admission for CF exacerbations. All but one participant had a history of multiple positive sputum cultures. Not exclusively, six participants had positive sputum cultures for MSSA, one with MRSA, six with pseudomonas, two with aspergillus, one with mycobacteria, and one with achromobacter.

In response to the question "Are you limited in any way in any activities because of any impairment or health problem?", before completion of the study, two of the four participants who completed the study responded "Yes", one responded "Don't Know/Not Sure" and one responded "No". After completion of the study, two of the four same participants responded "No", and two responded "Don't Know/Not Sure". When asked "What other topics do you wish you were able to write about?", participants responded, "What our relationships or friendships are like with CF" and "More positive things about my CF about how you can have a healthy outlook on it or how there may be some things that CF patients have an advantage in". When asked "What things did you not like, or would you change about the study?", participants responded that they felt a time pressure to complete the prompts within one week and two participants (50%) specifically mentioned wanting to write about more positive topics during the study. When asked "What things did you like, or would you keep the same about the study?", participants responded "the week we have to turn it in", the topics and their variety, and the different options of prompts within each prompt. 75% of participants responded "Yes" when asked if they would like their writings to be shared with other people with CF. 75% of participants responded "Yes" when asked if they would like to read about writings from other people with CF.

Additional participant feedback included: "I enjoyed participating in this study because I felt as though I had a safe space to talk about my troubles and obstacles I faced with my CF [along] with my accomplishments

and any positive things that have happened with my CF", "I liked participating in the journaling study since it helped me to think about my CF in a different light. Usually, I avoid thinking and talking about my CF or thinking of the things that make me different from everyone else. This study helped me to realize that I am not the only one with CF who may have those experiences," and "I liked it because it helped me explore and understand."

Notably, we saw improvement in almost all areas in mental health questions from the pre and post survey. There was a decrease in the number of days participants self-reported their physical and mental health as poor and days that this interfered with their daily activities. There was also a decrease in the reported days participants felt pain, sad, anxious, not getting enough sleep. [Table 2, Table 3] Pediatric Symptom Checklist scores also decreased from a mean of 29 to 23.5. There was a decrease in BMI percentile and FEV1 percent of predicted for all study participants, regardless of completion of study [Table 4]. However, it must be noted that the study was not powered to analyze these data for statistical significance.

Discussion

Our study was initially designed as a feasibility pilot study for initiating journaling therapy in individuals with cystic fibrosis. In designing the study, the investigators had previous experience with journaling and narrative therapy and wanted to apply this knowledge to individuals with cystic fibrosis. After discussing the study design with social workers and psychiatrists who were knowledgeable about narrative therapy, as well as the CF clinic social worker and providers, we were able to design a pilot study to assess feasibility of such an intervention. Based on the CF clinic social worker's experience and the baseline GAD7 and PHQ9 scores that are routinely collected in the clinic, the social worker also recognized that this population would benefit from and be amenable to this intervention. Therefore, we wanted to include journaling topics that targeted major issues that face individuals with cystic fibrosis, including those recognized by the staff in the CF clinic as well as those reviewed in literature. Overall, we wanted to highlight the importance of the multidisciplinary collaboration necessary to design a study that benefits and aligns with the goals of our specific population with cystic fibrosis. Unfortunately, no individual with cystic fibrosis were directly involved in the study design. Due to this fact, we included specific survey questions and a section for open feedback and comments to elicit participants' opinions about the study design.

We were very pleased with the level of participation in our study. We limited the maximum participants to eight, but there was at least one other individual who met inclusion criteria who expressed interest in the study after we had completed recruitment. Two participants did not complete any weekly prompts after the initial pre-study survey. One participant completed up to the 3rd weekly prompt, and one participant completed up to the 4th weekly prompt. Three participants stopped writing upon starting the school year due to concerns of the world load of completing the study on top of regular schoolwork. One participant who only completed up to the fourth weekly prompt was hospitalized during the study for a prolonged period. Participation in the study was promising and above our expectations since the other four participants (50%) completed the entirety of the study.

When comparing pre-study and post-study data for those four participants who completed the entire study, we found improvement in many areas. The average score for the Pediatric Symptom Checklist decreased by 5.5 points, and more importantly the post-study average fell to less than 28, which is the cutoff for children ages 6-16 for screening positive for significant behavioral or emotional problems. There was a decrease in averages for items related to internalizing problems, indicative of the success of narrative medicine theory. Interestingly, the average Pediatric Symptom Checklist score for all participants is lower than that for participants who completed the study, suggestive that healthier individuals chose not to continue the study.

The study also helped with participant exposure to narrative therapy and journaling. There were improvements in average scores for Table 2 items 1 and 2, which ask about the participants familiarity and comfort with narrative therapy. These results show we achieved our goal of increasing familiarity and comfort level of our patient population towards using journaling/narrative therapy to process emotions. There was a decrease in responses for item 4 indicating a lower desire to plan to journal/write, which is inverse to what

we would expect after participating in our study. Perhaps the question was worded poorly to assess participants' current action of writing versus their planning to write more. Conversely, this may also indicate that participation in our study was associated with a decreased desire to plan to write more, pointing out that our study was either too time consuming, causes participant distress, or had other reasons to dissuade them to continue writing.

Participant feedback was important for this pilot study. 100% of participants reported "I recommend other people with CF to write about the topics from this study" and "this study helped me express my feelings". 75% of respondents replied "Strongly Agree" with Table 3 items 1, 4, 6, and 7, which shows that the study not only was enjoyable and likely feasible to expand beyond the pilot study, but also provided subjective improvement in participants' feelings of anxiety/depression and perception that providers understood their patients more though these writings.

In terms of health benefits from the study, we only collected BMI percentile and FEV1 as surrogate objective markers for health. Although the sample size was small and analysis was confounded by missing FEV1 data for two participants, we did find that FEV1 percent of predicted decreased less for those who completed the study compared to those who did not. BMI percentile change was more negative for those who completed the study as well. Of note, those who completed the study started at a higher BMI percentile, averaging $>$ 85, and so increased negative change could indicate improvement from overweight status as well. A properly powered study would be helpful to elucidate these changes in health measures. It is important to note that although participants did write about negative emotions, the SOP never needed to be activated and no mental health intervention was necessitated, indicating that our intervention for this group of participants was able to explore sensitive topics without increasing risk for suicidal/homicidal ideation or other reportable events.

Participants also provided feedback regarding their experience at the end of the study. In designing the study, the prompts being too negative was one of the team's focuses. We had wanted to phrase the topics in a way to discuss resiliency in the face of adversity. However, these responses indicate that we were not successful in our efforts. In future endeavors, we hope to focus more on the phrasing of the topics, as well as introducing topics focused solely on positive strength without comparing to hardship. One participant liked the weekly deadline, and another participant did not and felt like the deadline caused too much pressure instead of allowing "my own time" to write. Based on the completion rate of our pilot study and mixed feedback about the timing, we felt that a weekly deadline was appropriate for this type of intervention. This intervention was also completed during the start of a new school year, and so it is likely a weekly deadline is not too burdensome for our patient population. 75% of participants who finished the study indicated they would like their writings to be shared with other people with CF, and they would like to read about writings from other people with CF as well. We were glad to see these results, since we had specifically wanted these interventions to be written so that they can be recorded in the hopes of providing valuable material to be shared with other individuals with CF. Although the writings of the participants from this pilot study will not be shared, future interventions can have publishing of results as an option, in hopes that sharing and reading other relatable stories can help individuals with CF and other complex medical problems. We hope that our study can be an example and gateway to more journaling and dissemination of writings to help patients with medical complexity address the topics included in our study, such as isolation, depression, anxiety, and interpersonal relationships.

One limitation of our study is that our participants may not be the most representative of all individuals with CF, since the average FEV1 percent of predicted was 92.1, with low average hospitalizations in a year, and also majority being non-white Hispanic or Latino and female. However, these demographics may indicate a subpopulation that is more open to journaling or would be more receptive to other interventions focused on mental health. In the future, timing of the study initiation can be optimized to increase participation, such as adjusting for the school year and timing of exams or holiday breaks, and to expand participant numbers for sufficient statistical power. We hope that this study design can be utilized and tailored to other patient populations that suffer from chronic conditions that can be emotionally taxing (i.e., type 1 diabetes mellitus,

sickle cell disease, and oncologic conditions). Using the Pediatric Symptom Checklist data, we calculated that a properly powered study will require 128 participants in each study group, assuming a 50% attrition rate. We hope future properly powered studies will be able to gather more statistically significant data regarding this intervention.

Conclusion

This feasibility pilot study to implement a journaling intervention for individuals with CF was successful. Our expected level of participation and completion of the study was exceeded. Additionally, initial results are promising for improvement of general wellness as measured by the Pediatric Symptom Checklist, as well as participant subjective reports of benefit from the study. Overall, we hope this study design can be expanded to more participants in a formal study, as well as be adapted to include other populations with medical complexity who can benefit from journaling and improvement in wellness. Our study was specific to our patient population, and required a multidisciplinary approach towards designing, screening and recruiting, and choosing of journaling prompts. Adaptation to other populations would require equal specificity for the benefits of journaling and narrative therapy theories to be realized.

Acknowledgements

The Cystic Fibrosis Foundation

Sarah Voyer, Social Worker

Truc Nguyen, IMPACT Program Coordinator

Amanda Daigle, IMPACT Program Coordinator

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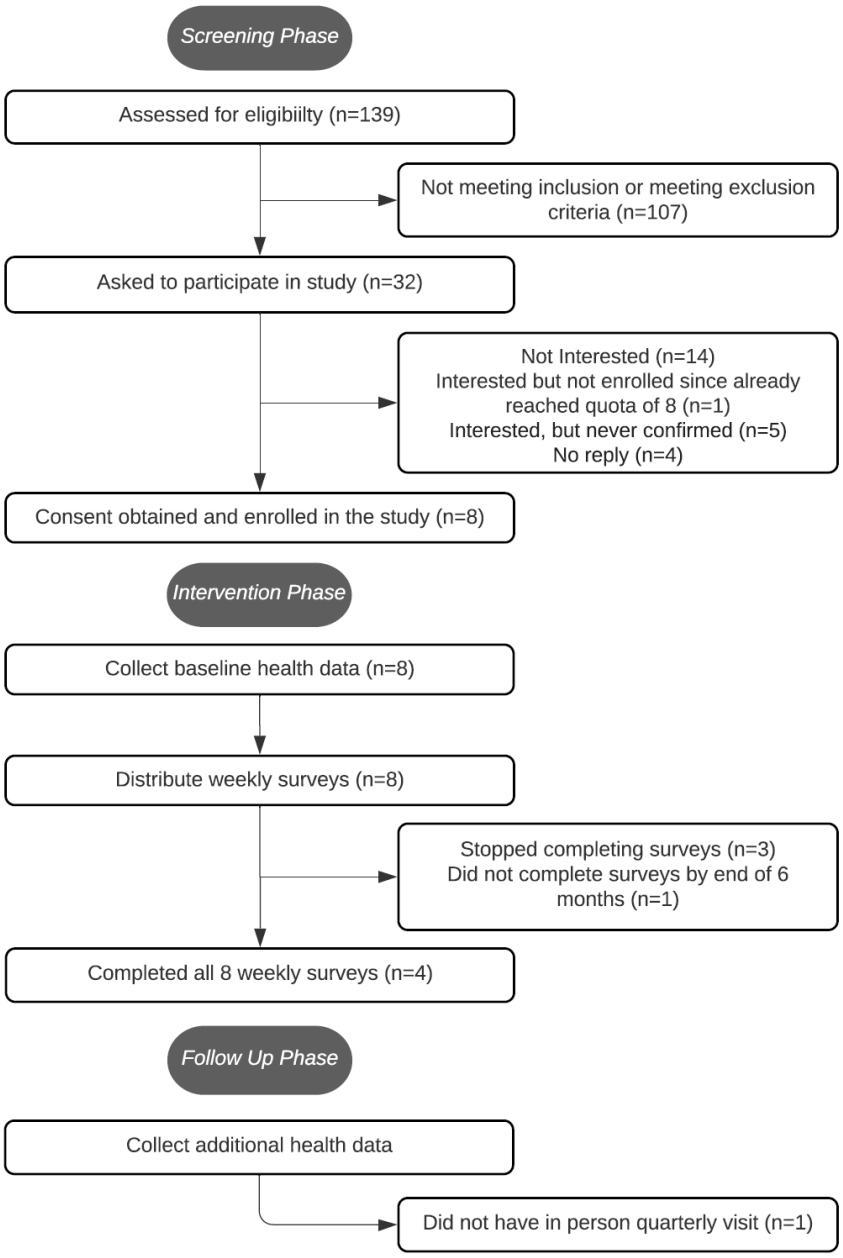

Figure 1. Study design and participant recruitment flowchart

Sample Characteristic	Result
Average Age in Years	15.5 ± 2.2
Percentage Female (count)	87.5% (7)
Percentage Male (count)	12.5% (1)
Race	
Percentage White	25%
Percentage Unknown / Not Reported / Prefer Not To Answer	75%
Ethnicity	
Percentage Hispanic or Latino	62.50%
Percentage Not Hispanic or Latino	12.5%
Percentage Unknown / Not Reported / Prefer Not To Answer	25%
Average BMI Percentile	67.1 ± 30.2
Average FEV1 Percent of Predicted	92.1 ± 24.9
Average Number of Hospitalizations in Last Year	1.4 ± 2.6
Average Number of Infections in Last Year	2.1 ± 2.4

Table 1. Participant demographic data. Race, and ethnicity data were obtained from participant responses. Age, BMI percentile, and FEV1 percent of predicted were obtained from CF clinic data that was also registered into the PORT database. Hospitalizations in the last year were collected with chart review through EMR review. Number of infections in last year was collected via chart review based on CF clinic documentation and previously ordered prescriptions for antibiotic courses.

Item	Text
1	I am familiar with narrative therapy and/or journaling.
2	I am comfortable with expressing myself through writing.
3	I plan to journal/write (i.e. writing in a diary).
4	Writing helps me express my feelings.
5	Now thinking about your physical health, which includes physical illness and injury, for how many days during the p
6	Now thinking about your mental health, which includes stress, depression, and problems with emotions, for how mar
7	During the past 30 days, for about how many days did poor physical or mental health keep you from doing your usu
8	During the past 30 days, for about how many days did PAIN make it hard for you to do your usual activities, such a
9	During the past 30 days, for about how many days have you felt SAD, BLUE, or DEPRESSED?
10	During the past 30 days, for about how many days have you felt WORRIED, TENSE, or ANXIOUS?
11	During the past 30 days, for about how many days have you felt you did NOT get ENOUGH REST or SLEEP?
12	During the past 30 days, for about how many days have you felt VERY HEALTHY AND FULL OF ENERGY?
13	Pediatric Symptoms Checklist Score

Table 2. Results from Pre-Study and Post-Study Surveys. For items 1-4, participants responded based on a Likert Scale of 1-5 (Strongly Disagree, Disagree, Unsure, Agree, and Strongly Agree). For items 5-12, participants were asked to respond with a number between 0 and 30 or "Don't Know/Not Sure". For item 13, participants completed the Pediatric Symptoms Checklist.

Item	Text	Percent Particip
1	I enjoyed participating in the study.	75%
2	I recommend other people with CF to write about the topics from this study.	100%
3	This study helped me express my feelings.	100%
4	My writings helped my providers get to know me better.	75%

5	This study helped me manage my CF better.	25%
6	This study helped me with issues related to feeling worried/anxious when thinking about my CF.	75%
7	This study helped me with issues related to feeling sad/depressed when thinking about my CF.	75%

Table 3. Results from Post-Study Survey. Participants were asked to respond to each statement on a Likert Scale 1-5 (Strongly Disagree, Disagree, Unsure, Agree, and Strongly Agree).

	Participants Who Did Not Complete the Study	Participants Who Did Not Complete the St
Measure	Before study	After Study
BMI Percentile	45.5 ± 29.0	44.0 ± 29.3
FEV1 Percent of Predicted	83.0 ± 24.5	80.3 ± 34.2

Table 4. Health Measures Changes. BMI percentile and FEV1 percent of predicted were collected via chart review at the most recent quarterly in person visit for each participant, both before the study and after completion of all eight weekly prompts. Timing of these visits were thus variable depending on the schedules of each participant. Among all the participants, one participant had BMI < 3 percentile and one participant had BMI >97 percentile, so the values of 3 and 97 were used respectively for calculation. Among participants who completed the study, one participant was healthy enough to skip their FEV1 measurement, so the value was repeated for the after study calculation, and one participant was unable to obtain their FEV1 at the visit so that value was omitted from the calculation.

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