



Special Edition: Advancing Adherence Through Technology



In this Issue...

One of the few valid truisms in medicine is that “the medicine won’t work if the patient doesn’t take it.” In chronic diseases like cystic fibrosis, adherence to therapy is an especially critical factor in maintaining patient health.

The 2017 North American Cystic Fibrosis Conference in November saw the premiere of the Ahead-of-the-Curve (AOTC) Adherence Lab. This interactive learning experience allowed clinicians to familiarize themselves with some of the new technologies or platforms available (or in development) to help improve adherence to therapy in patients with CF. Some are geared toward improving communication between the care team and the person with CF; others are designed to enable and motivate those with CF to become more engaged and involved in managing their disease, and others transmit adherence data directly to clinicians. Regardless of the user or the mechanism, the goal of all the devices, technologies, and platforms that were introduced at the AOTC Adherence Lab is to improve medical outcomes for patients with CF by moving the adherence needle in the right direction.

Chris Landon, MD, a pediatric pulmonologist and a pioneer of technology and interventions that improve health outcomes, was stationed at the Adherence Lab during NACFC. Dr. Landon spoke of the importance of treatment adherence and introduced those who attended to some of the devices and programs displayed. Dr. Landon has been involved in devices and medication intervention in pediatric pulmonary disease for 40 years, including the LifeShirt as a cough frequency tracking measure in PTC-124,¹ the Breathe Technology portable ventilator, development of the PARieTracker, and the placement of Bluetooth tracking in the Hill-Rom VEST. As a chairperson at the Intelligent Health Pavilion at HIMSS and at Health Achieve in Canada, Dr. Landon is exposed to medical technologies in all stages of development, always with an eye to their application in the cure and control of cystic fibrosis. Here, Dr. Landon reflects on his experience as "Ambassador of Adherence."

Special Edition

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Length of Activity

- 1.0 hour Physicians
- 1.0 hour Nurses

Launch Date

February 28, 2018

Expiration Date

February 27, 2020

LEARNING OBJECTIVES

- Discuss the importance of medication adherence and potential groups at higher risk for nonadherence.
- Identify ways to support optimal treatment regimens to improve adherence.
- Recognize novel technologies’ application and how they improve adherence measurement.

GUEST AUTHOR OF THE MONTH

Commentary & Reviews

Guest Faculty Disclosure

Dr. Landon has disclosed that he has served as a Principal Investigator for Gilead Sciences, Inc. and Abbott Laboratories.

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Christopher Landon, MD

Clinical Assistant Professor of Family Practice and Pediatrics, Clinical Associate Professor of Pediatrics University of Southern California University of California Los Angeles, CA

Unlabeled/Unapproved uses

Dr. Landon has indicated that there will be no references to the unlabeled/unapproved uses of any drugs or products in today's discussion.

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Program Directors

Peter J. Mogayzel, Jr., MD, PhD

Director, Cystic Fibrosis Center
Professor of Pediatrics
The Johns Hopkins University
Baltimore, Maryland

Suzanne Sullivan, RN, BSN

Senior Clinical Nurse
Johns Hopkins Hospital
Baltimore, Maryland

COMMENTARY

Forty years ago, Michael, a rebellious 16-year-old boy with CF, became my first patient on the first day of my pediatric rotation. The attending physician had instructed me that Michael was to take a vitamin pill, and I was expected to make certain that he did. After some negotiating, Michael agreed to take a vitamin pill, but only if it were purple. In those days before the Internet, I searched the hefty Physicians' Desk Reference (large paper-bound compendium of drugs with photographs) for a suitable vitamin.

Through my conversations with Michael over the next few weeks, I learned about the burden of disease on this young boy. Together, we cleared a path to adherence to health and fitness goals.² Since then, I wake every day thinking about what I may be able to do to cure and control CF, as I know many others do.

Treatments for CF have evolved considerably since Michael's CF was diagnosed when he was 11. But even for patients prescribed a pill that taken twice a day halts disease in its tracks, adherence remains an obstacle, with rates that hover around 60%.³ Real-world adherence to inhaled and oral therapies for CF patients remain discouragingly low, ranging from 31% to 53% for inhaled antibiotics and from 41% to 72% for hypertonic saline.⁴ A diary-based study of children ages 6 to 13 found that only 51% of recommended airway clearance treatments were completed, while adherence to nebulized medications and digestive enzymes was below 50%.⁵ Adherence for adults with CF is similar to those in other chronic illnesses, with higher adherence for antibiotics.⁶ Another study found that adherence to pancreatic enzymes and nebulized medications is moderate (65% to 80%), while adherence to dietary and exercise recommendations is low (40% to 55%).⁷

Patients with CF are not solely responsible for poor adherence. When clinicians at cystic fibrosis centers were surveyed, 64% discussed the importance of adherence with their patients at every clinic visit but only 8% used an objective assessment of adherence. Most centers reported frequent use of strategies to increase knowledge; behavioral and support strategies were used less regularly. Several barriers to adherence promotion were reported.⁸

Not surprisingly, recent studies have indicated that poor adherence to CF medication therapy is associated with longer hospital stays, higher respiratory exacerbation cost, increased hospitalizations, increased number of pulmonary exacerbations requiring



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intravenous antibiotics, and lower baseline lung function. Adherence is generally highest among children, because of the extent of parental control. As the child's world expands (and parental control decreases) during adolescence, adherence begins to decline and reaches a nadir among young adults (ages 18 to 25).^{9,10}

Attempts to improve adherence in other chronic disease such as diabetes and asthma have brought about certification programs for diabetes educators and asthma action plans. In the CF arena, programs to enhance adherence, including comprehensive behavioral interventions, have met with mixed success.

Advances in therapy, treatment delivery systems, and data capture technology offer the potential for enhancing adherence by providing immediate and more frequent feedback to the patient regarding his or her fidelity to the prescribed treatment regimen. Remote patient monitoring is continuing to evolve.

In this context, the Ahead of the Curve (AOTC) Adherence Lab at the 2017 North American Cystic Fibrosis Conference was even more relevant. Having been involved in open innovation and early adoption of medical devices for the better part of four decades, I did not hesitate when asked to help curate and coordinate the Adherence Lab along with Alexandra Quittner, MD. Each device and application demonstrated at the Adherence Lab was examined through the lens of the control or cure of CF.

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Attain Health

One of the greatest difficulties for people living with CF is implementing the daily requirements necessary for effective disease management. Patients may be overwhelmed by the demands of their disease; they may feel out of control and (from fear of cross-contamination) feel isolated and without peer support.

Attain Health is a virtual telehealth platform that offers clients the opportunity to set personal health goals, develop implementation plans, establish habits, and overcome inevitable setbacks to achieve their health goals through Integrative Health and Physical Performance Coaching. Clients meet with a performance coach and integrative health coach in weekly virtual meetings; in addition, they can participate in weekly group coaching sessions and educational webinars led by experts in the CF community.

Results of a three-month pilot study of Attain Health's program ($n = 15$) reported a mean increase in FEV_1 of 3.3% (range, 2%-15%); one patient was able to increase FEV_1 to 33% of predicted and was taken off the transplant list. BMI improved in 10 of 15 patients, and two overweight or obese patients (BMIs of 29 and 31) were successful in reaching their weight loss goals.¹¹ At the Adherence Lab, Attain Health cofounder Kat Porco reported discussions with clinicians whose patients had benefited from the program, with improvements in metrics such as FEV_1 and BMI, reduced hospitalizations, and a noticeable increase in the quality of life.

eTrack and PARtrack.com

Adherence monitoring is a unique feature of the investigational eTrack Controller, part of the eFlow Technology platform.¹² Compatible with eFlow Technology Nebulizer Handsets, the eTrack controller uploads data on each inhalation directly from the device, reporting on date and time, duration, and the reason for switch-off (eg, inhalation finished, manual switch-off, switch-off from a failure mode). Using wireless data transmission technologies, the device automatically sends encrypted data on each nebulization to the PARtrack web portal, where the clinician can access and evaluate the nebulization data and show graphical results. Providing this overall adherence information will allow investigators to intervene quickly when nonadherence is detected in any individual patient.

Currently, eTrack is not 510(k) cleared and is not sold commercially. It can only be used within a clinical trial setting as an investigational device.

Dr. Landon comments...

At the 2017 AOTC Adherence Lab, I was reunited with team members from Dr. Martin Wildman's group at Sheffield University in the UK. Since 2013, we had both been looking the potential of the PARI eFlow for improving adherence to 3x daily inhaled aztreonam. Dr. Wildman's group at Sheffield designed a program to measure overall adherence by providing the device to all appropriate patients ($n > 100$). Our approach was to link eFlow-provided inhalation use information with personalized feedback. We purposely selected the most non-adherent patients in our clinic—patients most at risk of misunderstanding optimum nebulizer usage due to education, language, or social barriers. Through the PARI eFlow we tracked their usage for one week. We then used that information (i.e. "I see you used it on Monday and Friday") in the second week to provide brief (ten minute) specific motivational interviewing to promote a new goal of three times weekly, twice a day. We continued the patient-specific motivational tactics the third week ("I see you are up at midnight. Did you know you can use it a third time then?") to further promote adherence to the most effective regimen. Our overall findings—that better adherence was generated through the combination of machine plus human intervention—led to the development of both the M.O.M.M.I. and F.A.T.H.E.R. programs.

The VisiView® Health Portal by Hill-Rom

Airway clearance therapy (ACT) is an extremely important component in treating chronic lung disease, but airway clearance techniques are time-consuming and cumbersome for patients to complete daily. Consequently, adherence to therapy is often a hurdle: one study



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found adherence to daily physiotherapy to be as low as 38.4% among a cohort of patients with CF ranging in age from 1.6 to 40.6 years.¹³ The lack of objective adherence measurements for ACT has been noted as a limitation not only for researchers trying to establish an evidence base on the effectiveness of ACT but also for health care providers trying to identify whether efforts to improve adherence are needed to ensure patients are benefiting fully from their prescribed therapies.

With this difficult situation in mind, Hill-Rom created the VisiView® Health Portal, a digital health product designed to motivate patients and enhance communication between health care teams and their patients. The secure, cloud-based system automatically receives information from high-frequency chest wall oscillation (HFCWO) devices in the patient's home. Whether patients use The VisiVest® System or the new mobile therapy device (the Monarch™ System), detailed therapy data are automatically transmitted to the VisiView® Health Portal. Patients and health care teams share a user-friendly dashboard to view therapy data and trends, connecting them in care. The VisiView® Portal provides therapy adherence data that may help inform decisions caregivers make for their patients that could result in reduced risk of respiratory infections, hospitalizations, and medical costs.

The Monarch™ System



The VisiVest® System



DoseCast

Dosecast is an easy-to-use medication reminder and adherence app that helps patients manage medications, vitamins, or supplements. In addition to reminding users to take the right dose at the right time, Dosecast logs the date and time of doses taken, skipped, or postponed. The information is sent to a cloud-based data platform where the user and health care provider can view or email the history at any time.

The platform bridges the gap between patients and health providers, building a medication adherence history as well as recording a log of symptoms, side effects, and notes. It can also aggregate anonymous patient behavior data for health care institutions and pharmaceutical companies.

iCAN (I Commit to Adherence and Nutrition)

The iCAN program was created in close partnership with 15 clinician advisors from across the multidisciplinary care team to facilitate the frequently uncomfortable discussions that occur in clinic involving gastrointestinal (GI) symptoms and also to address critical knowledge gaps within the CF patient community that were negatively impacting rates of

adherence to pancreatic enzymes. The program comprises three instruments: (1) GI Symptom Tracker, (2) CF Knowledge Assessment, and (3) CF Questionnaire. The objective of each tool is to create efficiencies and structure around conversations that care teams are already having with patients to ensure that time is not added to the clinic visit. In addition, a library of 18 videos featuring actual CF patients discussing best practices and successful home care routines is available throughout the iCAN website. The program is available online and in offline (paper) formats. More than 100 care teams in the United States have been trained on the iCAN program to date.

At the 2017 North American Conference, data from a psychometric evaluation of the GI Symptom Tracker instrument were presented and indicated positive results that “support[ed] use of the GI Symptom Tracker to evaluate symptoms related to abdominal pain, digestion, stools, eating challenges, and adherence to pancreatic enzyme replacement therapies (PERT).” The data further showed that “this tool can be used systematically and unobtrusively to assess GI symptoms and enzyme adherence, which may facilitate recognition and treatment of these concerns.”

In 2018, new educational resources and videos will be added to the iCAN program website (www.icanportal.com) to extend its value to the CF patient and clinician communities. Care teams interested in learning more about the iCAN program or in being trained in its use can contact Alexandra Quittner, PhD, at Alexandra.Quittner@mch.com.

Soteria™

Soteria™ is a patient-centric mobile clinical documentation interface designed to support CF-oriented clinical workflows across care venues inside a single integrated delivery network with multiple EMRs. Clinicians can easily document their CF clinic consultations within a team note, while allowing the whole CF team to contribute data during clinic — providing a universal and actionable patient-centric record with real-time CF data reporting.

SoteriaMe™ is an intuitive, patient-centric mobile application, allowing patients access to their clinical records and care teams from an Android or iOS smartphone. Patients can access visit summaries, active problems, latest vitals, and medications for continued patient engagement. SoteriaMe provides a messaging service within a contained clinical environment, for patient-reported outcomes, satisfaction surveys, support groups, and adherence. SoteriaMe also links to a web portal to give service providers access to patient engagement, surveys, and adherence data and to oversee support group interactions.

Dr. Daniel Stegmann, founder of Soteria Intelligent Clinical Documentation Solution, and Dr. Preston Arndt, Associate Director, Ventura Cystic Fibrosis Clinic at the Pediatric Diagnostic Center, were present at the AOTC Adherence Lab to demonstrate how a clinical CF team workflow would allow the entire CF care team to contribute to the registries at the point of care.

CareMessage

Similar to diabetes, CF is an all-encompassing chronic disease that requires coordinated efforts among patients, caregivers, and health care providers to optimize treatment adherence, nutrition, lifestyle choices, and social support systems.

CareMessage is an interactive mobile health information service that supports patient-empowerment strategies through educating participants, encouraging behavioral change, and promoting adherence with their treatment protocols. While a number of technically sophisticated applications exist, CareMessage provides a less complicated approach, with an interactive and personalized text-based message system that delivers actionable and tailored health content to participants, including office visit appointment reminders, medication adherence reminders, and general health education messages.

In the first trial — in a real-world CF clinic setting that treats a significant minority patient population — the investigators evaluated the impact of this collaborative active intervention program in improving adherence to specific chronic medications and improving clinical outcomes in patients with CF.¹⁴ The supporting clinic staff (nurse practitioners, case managers, care coordinators) reported being better able to connect with patients and create conversations around behavior-centered goals.

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CONCLUSION

From the 743 CF practitioners from 18 different countries who visited the AOTC 2017 Adherence Lab, I learned that 90% found adherence challenging or very challenging in their practice. But it was encouraging to learn that the vast majority — 92% of those who visited the Lab — planned to make changes to their practice based on their visit to the Adherence Lab, which was rated *excellent* or *very good* by 93%.¹⁵

Incorporating technology into CF care and adherence management makes sense. People living with CF are already using technology, including smart phone apps, in their daily living and are looking for more. In one study, people with CF indicated that they want apps to support CF self-management with characteristics that are specific to CF, such as pharmacy refills, CF-specific health information, enhanced communication with health care team, and socialization with the CF community.¹⁶ Another study demonstrated the feasibility and acceptability of video and text messaging.¹⁷

Existing data support the use of many of the specific technologies and platforms showcased at the AOTC Adherence Lab.

In our digital future, we will need to simplify the medical record and harness it to patient-centered data-driven treatment guidelines that can be harmonized across all providers. New uses of artificial intelligence, such as Healthymize (<http://healthymize.com/>), may predict exacerbations with 20 seconds of recorded normal conversation and with personal robots like Pillo (<http://pillohealth.com/>) interacting in Alexa skill sets. A tremendous opportunity exists for adding humanomics to adherence technology through certified educators, much like those who work with people with other chronic diseases like diabetes and asthma. Pharmacists also have an opportunity to become involved in programs that may improve adherence rates.

As new technologies, treatments, and platforms emerge, I look forward to finding with my colleagues and families new Ideas for Patient Care that can improve the lives of all people with CF.

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For additional information on adherence in patients with cystic fibrosis, Dr. Landon recommends:

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