JOHNS HOPKINS MEDICINE eLITERATURE REVIEW

eCysticFibrosis Review

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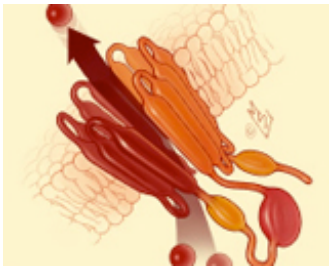

eCysticFibrosis Review VOLUME 4, ISSUE 1

Adherence to Chronic Inhaled Therapies

In this Issue...

Nonadherence to any medical regimen is common particularly among adolescents and young adults, and cystic fibrosis (CF) is no exception. There are many barriers to following the complex daily regimen that CF management requires, and researchers and clinicians have not yet found the ideal approach for counseling and supporting patients to improve and maintain their level of adherence. Research is continuing to better understand how care teams can best support people with CF and their families to ensure optimal treatment benefit.

In this issue, we review the most recent data on the importance of adherence in maintaining good health; the challenges and best practices for assessing patient adherence in the clinic setting; the most common barriers to adherence that adolescents and young adults face; and the current data on the efficacy of self-management interventions to improved knowledge, adherence and health outcomes; and we look at the feasibility and acceptability of a new cellphone-based adherence intervention under development.

LEARNING OBJECTIVES

After participating in this activity, the participant will demonstrate the ability to:

- Discuss the impact of nonadherence on health outcomes, including pulmonary exacerbations and lung function
- Describe the challenges of accurately assessing for medication nonadherence
- Identify risk factors for nonadherence and strategies for supporting patients to improve adherence

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1 contact hour Nurses

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February 27, 2015

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STATEMENT OF NEED

Based on a review of the current literature, including national and regional measures, detailed conversations with expert educators at Johns Hopkins, and a survey of potential program participants, this program will address the following core patient care gaps:

Disease-Modifying Therapies

- Clinicians may be unfamiliar with recently introduced disease-modifying therapies and how they are altering the therapeutic landscape for patients with cystic fibrosis.
- Clinicians may be uncertain how to integrate genotyping into therapeutic decisions and how to communicate with patients and families about the relationship between genotype and therapy

Nutrition

- Many clinicians lack strategies to persuade patients to adhere to CF nutritional requirements, resulting in low body weight and nutritional failure in patients with cystic fibrosis.
- Many clinicians remain uncertain how to optimize pancreatic function in patients with cystic fibrosis.

Treating CF Patients with Inhaled Antibiotics

- Clinicians lack knowledge about the use of existing and emerging inhaled ABX to treat chronic pulmonary infections.
- Clinicians need more information to make informed decisions about the use of inhaled ABX in combination.
- Clinicians lack information about best practices for scheduling ABX therapy to suppress chronic airway infections.

No other planners have indicated that they have any financial interests or relationships with a commercial entity.

Guest Author's Disclosures

This activity is supported by educational grants from Aptalis Pharma, Gilead Sciences, Inc, and Vertex Pharmaceuticals.

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- Common clinician assumptions about treating pulmonary exacerbations lack supporting evidence.
- CF clinicians are not aware of and/or are not actively advocating inhaled ABX patient-adherence strategies.

IN THIS ISSUE

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Commentary & Reviews:

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Guest Faculty Disclosures

The author has indicated that she has served as a consultant for Gilead, Inc. and Novartis, Inc.

Unlabeled/Unapproved Uses

The author has indicated that there will be no references to unlabeled or unapproved uses of drugs or products.

Planning Committee Disclosures

COMMENTARY

When a drug is developed, the expectation is that a person with cystic fibrosis (CF) will adhere fully to the prescribed regimen. Unfortunately, in the real world this expectation is unrealistic given the complexity and time burden of the typical CF regimen. Adherence to chronic pulmonary medication ranges between 35-75% depending on the drug and person's age.[1,2] People with CF, their families, and even their care teams often wonder how much adherence is enough and if what they are doing is making a difference. The study by Eakin and colleagues[1] reviewed in this issue demonstrated that higher adherence is associated with better health outcomes — specifically less need for IV antibiotics for pulmonary exacerbations. This first-of-its-kind paper will have to be replicated with larger samples to better understand the impact of adherence to each drug and among subgroups. For example: does the strength of the association between adherence and health outcomes vary by disease severity, age, gender, and other factors? Regardless of its limitations, this study has confirmed that medication adherence matters.

Logically, then, it seems imperative that adherence be assessed at each clinic visit to both inform treatment decisions and to provide adherence-promoting interventions. In other illnesses, it is known that patient-reported adherence is consistently higher compared to objectively measured adherence (eg, pharmacy records or electronic monitoring) and that physician judgments of adherence may be biased.[3,4] The work by Daniels and colleagues,[4] discussed in this issue, showed that when reporting on nebulized medication use, these biases are found among people with CF and the various members of the care team. Therefore, having an objective measure of adherence available would be ideal.

Pharmacy refill records offer an objective estimate using existing data that is increasingly becoming available without charge to physicians through e-prescribing and electronic health records. The limitation, however, is that refill records require at least a year of data to get a stable estimate; and a substantial and sustained behavior change to produce changes in refill-based adherence scores. In contrast, electronic monitoring of adherence, such as the I-Neb used by Daniels *et al*, provides a date/time stamp that reveals patterns of use and short-term increases or decreases in adherence, which is helpful in identifying barriers and facilitators of adherence. Unfortunately, electronic monitors can be costly, require additional staffing to manage, and are not yet widely approved for use as a drug delivery device. Regardless, electronic devices should continue to be developed and tested, as they provide the most comprehensive adherence information possible.

After identifying that a patient is not optimally adhering to therapy, the next essential step is to understand the specific barriers the patient encountered so that effective counseling and support may be provided. George *et al*[5] and Bregnballe *et al*[6] both evaluated potential adherence barriers and facilitators of adherence among adolescents and young adults with CF using qualitative interviews and a web-based survey (respectively). What is clear from their results is that people face a wide variety of challenges and more often than not several barriers at a time. These barriers range from easy fixes that require a one-time intervention to more complicated psychosocial challenges that will require ongoing support and possible referral to behavioral health counseling.

The most challenging aspect of adherence is finding the right intervention for each specific individual. Systematic reviews have concluded that across the spectrum of illnesses and behaviors (medication, diet, etc), education-only interventions are less effective than multicomponent interventions in improving adherence and illness self-management.[7,8] Multicomponent interventions almost always include education, but also provide one or more additional components: behavior modification, parent training, problem-solving, motivational enhancement, behavioral and health feedback, and social support.

A recent Cochrane review of self-management education interventions for CF by Savage *et al*,[9] reviewed in this issue, concluded that despite methodological limitations of the studies, there was evidence that the interventions increased patient knowledge immediately after intervention delivery. Unfortunately, changes in knowledge did not effectively translate into sustained behavior change or improve health outcomes. Thus, much like other illnesses, interventions to support adherence in CF will probably have to reduce their focus on education and become increasingly multicomponent.

Exciting opportunities for new interventions lie in the use of technology, particularly cell phones and smartphones. There is great interest in developing mobile health (mHealth) applications such as social networking and gaming, and evaluating whether these high-use technologies can be used to support adherence. As discussed in this issue, the report by Marciel and colleagues[10] provides preliminary evidence that their CFFONE™ program is of high interest to people with CF and is perceived by patients, families, care teams, and technology experts as potentially likely to improve adherence. A randomized trial is currently under way.

In just the past few years, the field of CF adherence research has progressed dramatically. There is greater understanding about the importance of adherence, how to measure it, and which interventions might be effective. With several adherence trials in progress, our knowledge and our ability to help people with CF balance the need to follow their complex regimens while continuing to have a “normal” life is likely to increase in the coming years.

Commentary References

1. Eakin MN, Bilderback A, Boyle MP, Mogayzel PJ, Riekert KA. Longitudinal association between medication adherence and lung function among people with cystic fibrosis. *J Cyst Fibros*. 2011;10: 258–264.
2. Daniels T, Goodacre L, Sutton C, Pollard K, Conway S, Peckham D. Accurate assessment of adherence: self-report and clinician report vs electronic monitoring of nebulizers. *CHEST*. 2011;425-432.
3. Stone AA, Turkkan JS, Bachrach CA, Jobe JB, Kurtzman HS, Cain VS (Eds). The Science of Self-Report: Implications for Research and Practice. Mahwah NJ:Lawrence Erlbaum Associates Inc. 2000.
4. Miller LG, Liu H, Hays RD, et al. How well do clinicians estimate patients' adherence to combination antiretroviral therapy? *J Gen Intern Med*. 2002;Jan;17(1):1-11.
5. George M, Rand-Giovannetti D, Eakin MN, et al. Perceptions of barriers and facilitators: self-management decisions by older adolescents and adults with CF. *J Cyst Fibros*. 2010;9:425-432.
6. Bregnballe V, Schiotz PO, Boisen KA, et al. Barriers to adherence in adolescents and young adults with cystic fibrosis: a questionnaire study in young patients and their parents. Patient Prefer Adherence. 2011;507-515.
7. Haynes RB, Ackloo E, Sahota N, et al. Interventions for enhancing medication adherence. *Cochrane Database Syst Rev*. 2008;Apr 16;(2).
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9. Savage E, Beirne PV, Ni Chroinin M, et al. Self-management education for cystic fibrosis. Cochrane Database of Syst Rev. 2011, Issue 7. Art. No.: CD007641. DOI: 10.1002/14651858.CD007641.pub2
10. Marciel KK, Saiman L, Quittell LM, Dawkins K, Quittner AQ. Cell phone intervention to improve adherence: cystic fibrosis care team, patient, and parent perspectives. *Pediatr Pulmonol*. 2010;157-164.

back to top

DOES ADHERENCE TO CHRONIC PULMONARY MEDICATIONS MATTER?

Eakin MN, Bilderback A, Boyle MP, Mogayzel PJ, Riekert KA. **Longitudinal association between medication adherence and lung function among people with cystic fibrosis.** *J Cyst Fibros.* 2011; 10: 258–264.

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The goal of adhering to a treatment regimen is better health; however, in many illnesses the degree to which adherence is associated with clinical outcomes is unclear. This study examined the relationship between adherence to chronic pulmonary medications and relevant CF outcomes, including the frequency of intravenous (IV) antibiotics to treat pulmonary exacerbations and change in the forced expiratory volume in 1 second FEV_1% predicted over a concurrent 12-month period. Participants were age 6 years or older and had been prescribed at least one of the following medications for 12 months: dornase alfa, inhaled tobramycin, azithromycin, or hypertonic saline. These medications were selected because there is strong evidence of their efficacy in improving pulmonary health.[1] A retrospective review of medical records was conducted to obtain health outcomes, and pharmacy records were obtained to calculate adherence. A Medication Possession Ratio (MPR) was calculated for each medication and averaged across all prescribed medications to create a composite score (cMPR). [Note: MPR is defined as the sum of all days of medication supply received, divided by the number of days the medication was prescribed during the study period.]

The final sample included 95 participants (approximately half aged 7 to 18 years, half over 18 years of age), with an overall baseline FEV_1% predicted of 80% ± 25%. The median MPR for

each drug ranged from 49% (hypertonic saline) to 76% (azithromycin), with a median cMPR of 63%. During the concurrent year 40% (N = 38) participants had at least one course of IV antibiotics to treat a pulmonary exacerbation. After controlling for other factors, cMPR significantly predicted having one or more courses of IV antibiotics ($P < .05$). cMPR was also a significant predictor of baseline FEV_1% predicted after controlling for other relevant variables ($P < .01$), but did not predict change in lung function over the year. Interestingly, individuals with cMPR ≥ 80% did not experience a decline in lung function while those in the 50% to 80% and < 50% cMPR groups did have a decline over the year (2.22% and 0.39% respectively); however, the declines did not reach statistical significance.

The authors conclude that there is sufficient evidence to support the hypothesis that higher adherence to chronic pulmonary medications is associated with better outcomes, specifically less need for IV antibiotics. However, the small sample size and use of retrospective chart reviews prohibited adequately powered post hoc analyses such as comparisons by individual drug or relevant subgroup. Thus, further study is warranted to better understand the relative value of adhering to each individual medication. In addition, as this study only observed outcomes during one year, further investigation is needed to understand the cumulative effect of sustained or periodic nonadherence over several years. Regardless of these considerations, the results of this study highlight the need for CF care teams to assess adherence at every clinic visit and to intervene as necessary to support adherence in order to maximize the health benefits of the regimen.

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1. Flume PA, O'Sullivan BP, Robinson KA, Goss CH, Mogayzel PJ Jr, Willey-Courand DB, Bujan J, Finder J, Lester M, Quittell L, Rosenblatt R, Vender RL, Hazle L, Sabadosa K, Marshall B; Cystic Fibrosis Foundation, Pulmonary Therapies Committee. Cystic fibrosis pulmonary guidelines: chronic medications for maintenance of lung health. *Am J Respir Crit Care Med*. 2007 Nov 15;176(10):957-969.

back to top

MEASURING ADHERENCE: ARE CF CARE TEAM MEMBERS AND PATIENTS ACCURATE INFORMANTS?

Daniels T, Goodacre L, Sutton C, Pollard K, Conway S, Peckham D. **Accurate assessment of adherence: self-report and clinician report vs electronic monitoring of nebulizers**. *CHEST*. 2011;425-432.

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Accurately assessing adherence is essential to providing the appropriate level of adherence counseling and support to patients. In this study, the investigators sought to assess rates of adherence to nebulized CF treatments using self-report, care team report, and electronic monitoring. The investigators also sought to understand the extent and direction of discrepancies between methodologies. The electronic monitor used in this study was the I-neb AAD (adaptive aerosol delivery) nebulizer system (Philips Respironics). The I-neb stores date, time, duration, and completeness of the dose, which was then downloaded at a subsequent clinic visit and was used by patients as part of regular clinical care at the study location to deliver all nebulized pulmonary medications. I-neb data was obtained for 78 adults with CF, who also completed a survey about their adherence to nebulized therapy. Each member of the care team (physician, dietitian, physiotherapist, inpatient and outpatient nurses, and pharmacist) was asked to assess patients' adherence over the three months before seeing the I-neb or patient-reported data.

Median adherence was lowest for electronic monitoring (36%) and highest for patient-report (80%). The bias between patient-report and electronic monitoring was significant, with patient report on average about 25% (95% CI, 18.7% - 31.9%) higher than the objective measure. It is notable that under-reporting of adherence was extremely rare, and that patient-report of 100% adherence had a corresponding objective measure ranging from 0 to 100%. Overall, regardless of the care team's role, the clinicians' median estimated adherence (50% to 60%)

was higher than the objectively measured level but lower than the patients' report. At the group level, agreement with the electronic monitor ranged from fair (ICC = .28 for pharmacist) to moderate (ICC = .54 for physiotherapist). At the individual patient level, clinician estimate was extremely inaccurate, with over- and underestimates of adherence being common.

The authors conclude that both patient- and clinician-reports show extreme inaccuracies. The patient data demonstrates a predictable bias; the estimate is consistently at or, more typically, much below the objectively measured level. Thus, any patient report of nonadherence can safely be interpreted to be significant nonadherence. Conversely, a patient-reported 100% adherence does not provide meaningful information about the true level of adherence. Further, at the individual patient level, a clinician's estimate of adherence is likely to be no better than chance. This is troubling, because a patient who is highly adherent but perceived by the care team as poorly adherent (or vice versa; ie, poorly adherent but perceived as highly adherent) may receive education and counseling that inadvertently contributes to subsequent poor adherence. The authors propose that objectively measured adherence be used regularly to allow for open and honest discussion between the patient and clinician, which may likely affect treatment decisions.

back to top

ADOLESCENTS AND ADULTS IDENTIFY A WIDE VARIETY OF FACILITATORS AND BARRIERS TO ADHERENCE

George M, Rand-Giovannetti D, Eakin MN, Borrelli B, Zettler M, Riekert KA. **Perceptions of barriers and facilitators: self-management decisions by older adolescents and adults with CF**. *J of Cyst Fibros*. 2010;9:425-432. Abstract

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Bregnballe V, Schiotz PO, Boisen KA, Pressler T, Thastum M. **Barriers to adherence in adolescents and young adults with cystic fibrosis: a questionnaire study in young patients and their parents.** *Patient Preference and Adherence*. 2011;507-515.

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The CF regimen is expensive, complex, and time consuming, often requiring over two hours a day to complete. Further, as a patient ages and new therapies are developed, regimens continue to become more burdensome. Thus, it is not surprising that people with CF face many challenges in executing the necessary tasks each day. The goal of these two studies was to understand the types and frequency of facilitators and barriers to adherence faced by adolescents and young adults, with the hopes of identifying opportunities for intervention development.

George and colleagues followed an iterative, qualitative approach to explore barriers and facilitators. Twenty-five people age 16 to 35 with a mean age of 24 years and mean FEV_1% predicted of 68% from a US care center individually completed a semistructured interview. Themes were identified by all the authors, and then the transcribed interviews were independently coded by three reviewers.

In contrast, Bregnballe *et al* studied a younger and healthier Dutch sample of 88 people age 14 to 25 (mean age 19 years) and a mean FEV_1% predicted of 83%. Participants and their parents (93 mothers and 54 fathers) completed a web-based survey that asked about five barriers (time, forgetting, fatigue, refusal to take treatments in public, choosing socialization over treatments), as well as self-reported adherence.

Of participants studied by George *et al*, 96% identified one or more barriers to adherence, including treatment burden (64%), social demands (60%), work demands (60%), forgetting (60%), absence of perceived health benefits (56%), and fatigue (56%). All but one participant (96%) identified facilitators of adherence that included attending CF clinic/getting pulmonary function testing results (76%), support from significant others and reminders (68%), and the presence of perceived health benefits (68%). Interestingly 32% of participants reported being intentionally nonadherent to rebel against having a routine, permit spontaneity, or reward themselves for high adherence at other times.

Bregnballe *et al* found a similarly high level of barriers. Most participants endorsed one or more barriers (61%), as did their parents (59% mothers, 60% fathers). The top three barriers endorsed by all groups were forgetfulness (35% participants, 33% mothers, 14% fathers), time (35% participants, 27% mothers, 21% fathers), and refusing to take treatment in public (29% participants, 26% mothers, 25% fathers). Importantly, participant report of barriers was shown to be associated with poorer adherence.

Both papers conclude that there is a wide variety of barriers to following a CF regimen that ultimately negatively affect adherence among adolescents and young adults. Despite different populations and methodologies, common barriers were identified by both investigations. George *et al* also examined what helped patients adhere, providing additional insight into what types of strength-based interventions may promote improved adherence. The most common facilitator identified was the importance of CF clinic visits. This finding highlights the critical role care team members can play in supporting adherence and suggests that even if interventions are not delivered in the clinic, it is important to keep team members engaged in the process. Both papers encourage the assessment of barriers to adherence with subsequent provision of counseling and medical advice that is tailored to the person's unique set of barriers and strengths. Future research is needed to understand the cumulative impact and longitudinal influence of barriers and facilitators on objectively measured adherence. Furthermore, interventions that target these barriers should be evaluated to determine whether they reduce the barrier and subsequently improve adherence.

back to top

IMPROVING CF KNOWLEDGE MAY NOT RESULT IN IMPROVED ADHERENCE OR BETTER HEALTH OUTCOMES

Savage E, Beirne PV, Ni Chroinin M, Duff A, Fitzgerald T, Farrell D. **Self-management education for cystic fibrosis.** *Cochrane Database Syst Rev.* 2011 Jul 6;(7).

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As noted elsewhere in this issue, systematic reviews of adherence interventions have concluded that education-only interventions are less effective than multicomponent interventions in improving adherence across a variety of illnesses and behaviors.[1,2] Savage *et al* set out to evaluate whether self-management education interventions are effective in improving CF health outcomes. The aim of self-management as defined by the authors was "to help [patients and their families] achieve the best possible health and to fit treatment requirements into their everyday activities around a flexible management plan." To be included in the review, a study had to:

1. be a randomized, controlled trial; a quasi-randomized controlled trial; or a controlled clinical trial
2. include individuals of all ages with a CF diagnosis and/or their family members
3. explicitly state the program was focused on self-management
4. target any aspect of the CF regimen including dietary management, physiotherapy, and medication management.

The primary outcomes of interest were health-focused (lung function or nutritional status), while secondary outcomes included self-management behaviors, adherence to CF treatments, knowledge, health related quality of life, and health care use.

Only four studies met the eligibility criteria; these cumulatively included 152 people with CF and 117 parents. There was great heterogeneity between the studies, including the targeted age group (children to adults), intervention content (type of education provided, skills taught), setting, modality and duration of the intervention, and types of outcomes measures used (eg, no study used the same self-management measure). No study found changes in health outcomes, albeit only two studies assessed them. All four studies found that patients in the intervention group had higher knowledge immediately after the intervention compared to the control group; however, this improvement was sustained long-term in only one study, and there were no increases in parental knowledge. Furthermore, there was little evidence the interventions improved self-management or adherence, and no study presented data assessing the intervention's impact on health related quality of life or health care use.

The authors concluded that the heterogeneity between studies combined with the small number of trials, the small sample sizes (all < 50 people), and concerns about bias limited the conclusions that can be drawn. However, the consistency of the results with those found in other illnesses suggest that some broad conclusions can be made. First, that education focused self-management programs do improve patient knowledge, but those knowledge gains may not be sustained. Second, despite gains in knowledge, there is limited evidence of improvement in self-management behaviors, adherence, or health outcomes. And finally, any gains are short-lived, suggesting that ongoing education, counseling, and support may be necessary to realize enduring change.

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1. Haynes RB, Ackloo E, Sahota N, McDonald HP, Yao X. Interventions for enhancing medication adherence. Cochrane Database Syst Rev. 2008 Apr 16;(2).
2. Kahana SY, Drotar D, Frazier T. Meta-analysis of psychological interventions to promote adherence to treatment in pediatric chronic health conditions. J Pediatr Psychol. 2008 Jul;33(6):590-611.

back to top

OPPORTUNITY TO USE CELL PHONE TECHNOLOGY TO SUPPORT ADHERENCE

Marciel KK, Saiman L, Quittell LM, Dawkins K, Quittner AQ. **Cell phone intervention to improve adherence: cystic fibrosis care team, patient, and parent perspectives.** *Pediatr Pulmonol.* 2010;157-164.

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The availability of social support has been found to be a strong predictor of treatment adherence in many illnesses.[1] However, because of infection control practices, people with CF are advised to avoid settings where they may encounter another person with CF, thus limiting the availability of peer support from someone who understands what it means to live with the disease. Fortunately, the proliferation of technology-based social networking provides an opportunity to reintroduce peer support, and was investigated by Marciel *et al*. Their study focused on four goals:

1. to gather data on the acceptability, feasibility and utility of a web-enabled cell phone program for adolescents (called CFFONE™) from the CF care team, patients, and parents
2. to determine the optimal content and format for the CFFONE
3. to gather expert opinion on the technical design and feasibility of CFFONE
4. to build and evaluate the usability of a CFFONE prototype

Care team members (17 physicians, nurses, and social workers) felt that the CFFONE would be an appropriate source of CF information and that a live "chatbot" feature would allow teens to communicate safely with other teens with CF (although the care team advised that the content be moderated). They also felt that the CFFONE was "likely" to be used by teens, increase knowledge, and improve social support, but only "somewhat likely" to improve adherence.

The majority of adolescents with CF (N = 12; 11 to 18 years) considered the CFFONE concept “helpful” (58%). Specific features that were appealing were the “chatbot” to obtain information about their specific CF question, instant messaging other teens with CF, and using a calendar to schedule treatments and set reminders.

All the participating adults with CF (N = 6; 21 to 36 years) rated the CFFONE concept as ‘very helpful.” They felt the CFFONE would improve their knowledge about CF (67%) and enable them to speak with peers with CF (67%). They also perceived the disease- management supports as beneficial (33%), including the calendar and reminder features.

Parents (N = 12) were also highly supportive of the CFFONE concept and proposed functions.

The adolescents (N = 8; 10 to 17 years) who evaluated the prototype were overwhelmingly positive about the ease of use and helpfulness.

The eight technology experts involved were also highly enthusiastic; however, they highlighted possible barriers such as cost, concern about sharing private information, and the role of parents.

The authors concluded that these results support the acceptability, feasibility and utility of the CFFONE. While no data have yet been published on whether the CFFONE is efficacious for improving social support, knowledge or adherence, a randomized trial is under way. A plus of the CFFONE™ concept is that it does not require specialized equipment, only a web-enabled cell phone. Recent data shows that 77% of adolescents have a cell phone and half went online via their phone in the past 30 days,[2] indicating that this intervention has the potential for widespread accessibility. This highly novel social networking concept is not without risk, however: it will necessitate the presence of a regular moderator to identify possibly adverse effects such as misinformation or inappropriate content being shared, adolescents planning to violate infection control practices by meeting, etc.

References

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back to top

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