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Cell Phone Intervention to Improve Adherence:

Cystic Fibrosis Care Team, Patient, and Parent Perspectives

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Summary

Background—Treatment regimens for patients with cystic fibrosis (CF) are time-consuming and complex, resulting in consistently low adherence rates. To date, few studies have evaluated innovative technologies to improve adherence in this population. Current infection control guidelines for patients with CF seek to minimize patient-to-patient transmission of potential pathogens. Thus, interventions must avoid face-to-face contact and be delivered individually, limiting opportunities for peer support. This study aimed to develop and assess a web-enabled cell phone, CFFONE™, designed to provide CF information and social support to improve adherence in adolescents with CF.

Methods—The acceptability, feasibility, and utility of CFFONE™ were evaluated with health care professionals (n = 17) adolescents with CF aged 11–18 years old (n = 12), adults with CF aged 21–36 years old (n = 6), parents of adolescents with CF (n = 12), and technology experts (n = 8). Adolescents also tested a prototype of CFFONE™ (n = 9). Qualitative and quantitative data were collected.

Results—Focus group data with health care = professionals indicated a need for this intervention, and indicated that CFFONE™ would be likely to improve knowledge and social support, and somewhat likely to improve adherence. Adolescent, adults, and parents all rated CFFONE™ as likely to improve adherence. Technology experts rated the prototype design and format as appropriate.

Conclusions—The current study provided some support from key stakeholders for this intervention to improve adherence in adolescents with CF. Next steps include a multi-center trial of the efficacy and safety of CFFONE™.

Keywords

cystic fibrosis; adolescents; adherence; cell phone; social support

INTRODUCTION

Cystic fibrosis (CF) is one of the most common, life-shortening genetic diseases.[1] In recent years, several novel therapies have been developed to treat this multi-organ illness and improve clinical outcomes and quality of life. These therapies target the infectious complications,

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inflammatory processes, nutrition deficiencies, as well as the basic defect, but the multitude of therapies increase the time and complexity of the daily treatment regimen.2

Adherence to current treatments is a major challenge for patients with CF. The daily regimen can include ingesting as many as 40–50 pills, inhalation treatments requiring up to 2 hr, and 2–3 airway clearance sessions lasting 20 min each. In addition, patients are encouraged to exercise and eat several high calorie, high fat meals each day. Adherence to this complex regimen can be particularly difficult during adolescence due in part to the normal, developmental tasks of establishing autonomy, and self-care independence.[2] Barriers to treatment adherence for adolescents with CF have been identified, including scheduling (e.g., unable to "fit in" an airway clearance treatment after school), forgetting, and gaps in knowledge of disease management.[3,4] In two large, multicenter studies, adolescents scored 55–60% on a knowledge measure of CF care management.3,4 Thus, a significant gap in knowledge exists. Although the relationship between knowledge of disease management and adherence has not been evaluated in this study, the positive association between knowledge of prescribed treatments and treatment-related behaviors has been described in other populations.[5]

Despite the effectiveness of psychological interventions to improve adherence in pediatric chronic illness,[6] few behavioral interventions to improve adherence have been developed and studied in CF. Recently, an educational intervention utilizing an interactive CD-ROM for children with CF was shown to remediate gaps in knowledge and increase coping skills, but this study did not evaluate changes in adherence behaviors.[7] Prior research has consistently shown that education alone is not sufficient to change behavior.[8] Behavioral interventions conducted in a group format, including both children and parents, successfully increased adherence to prescribed caloric intake in young children with CF.[9] Some of the success of this program may be due in part to the much-needed peer support between parents, which has been related to improved adherence.[10-12] However, programs including interactive group sessions are no longer considered safe because of the potential for patient-to-patient transmission of respiratory tract pathogens.[13,14] Thus, elimination of group-based activities and minimizing contact between patients has led to a loss of peer support. Although studies have not evaluated the impact of the current infection control guidelines on patients' social and emotional functioning,[14,2] social support has been shown to play a major role in facilitating adaptation to chronic diseases, including CF, and adherence to daily medical regimens.[15-18]

New technologies may provide a unique opportunity to deliver effective adherence interventions while promoting safe social interactions and peer support. Recent studies in patients with CF and patients infected with HIV-have utilized text messaging to increase adherence to daily treatments.19,[20] Most parents (85%) reported that their child with CF told them about the personalized text messages on their pagers. However, this study did not specify the type of medication or measure adherence behaviors. Parents appreciated that the pager could be taken to school by the children. The majority of the sample of adults with HIV (79%) reported that the pager messages had a positive effect on their adherence; however, self-reported adherence was not measured before the intervention. The adults with HIVenjoyed using the pager and 86% of the sample wanted to continue using the system. Thus, we sought to develop a web-enabled, cell phone technology for adolescents with CF, CFFONE™. Cell phone technology was chosen because it provides a high degree of mobility and access and avoids the risk of direct patient contact. Adolescents were chosen for this study because of their lower adherence to their treatment regimen, the inherent risk of decline in health outcomes, [18],21 and their high utilization of cell phone technology for social networking.22

The aims of this study were to: (1) gather qualitative and quantitative data on the acceptability, feasibility, and utility of a program for use on a web-enabled cell phone for adolescents with CF from the perspective of the CF interdisciplinary care team, patients, and parents; (2)

determine the optimal content and format for CFFONE™; (3) gather expert opinions on the technical design and feasibility of CFFONE™; and (4) build and evaluate the usability of a CFFONE™ prototype.

METHODS/RESULTS

Overview

Four phases in this study assessed the feasibility, usability, and utility of CFFONE™. Three sequential phases included the following (1) a focus group with health care professionals from the pediatric and adult CF care teams at Columbia University; (2) structured interviews and rating scales administered to adolescents with CF, adults with CF, and parents of adolescents with CF; and (3) evaluation of the CFFONE™ prototype with adolescent participants. Adults with CF were included during Phase II in order to collect their retrospective feedback regarding their experience with adherence and their impressions of CFFONE™. Institutional review board approval at Columbia University Medical Center was obtained for the three phases of CFFONE™ development. Informed consent and assent were obtained by a member of the research team for Phases II and III. In addition, a fourth phase was conducted concurrently with the other study phases, which consisted of anonymous online surveys with technology experts to evaluate the concept, design, and technical approach of CFFONE™.

The focus group and individual interviews were semi-structured, in order to cover the topics of adherence, family issues, and transition. Content analysis was used to extract themes from the focus group discussion and individual interviews. A member of the research team collated and summarized responses to open-ended questions. Saturation was achieved during the qualitative data collection. Surveys for the health care providers, adolescents, parents, and adults were developed by the authors for the current study. Although survey items were influenced by the literature, these surveys were not based on existing measures. The survey for technology experts was derived from the standard usability practices in the field.[23] Survey data are presented in terms of means (M) and standard deviations (SD) of Likert ratings. These results are interpreted based on the closest rating option (e.g., 1 = not at all useful, 2 = a little useful, 3 = somewhat useful, 4 = pretty useful, 5 = very useful).

Development of CFFONE™

Based on a review of the literature, the project PI (K.D.) and project consultants developed a set of proposed CFFONE™ features and content designed to enhance CF-related knowledge, adherence, and peer support among adolescents. These features were organized into five areas: CF Information, Care Management, Social Networking, Entertainment, and Communication. For example, the *CF Information* feature consists of the interactive chatbot (i.e., technology which simulates individualized conversations using verbal responses selected from a database), a Hot Topics section for private and personalized responses, and online information. The *Care Management* feature includes a personalized calendar which sends synchronized text message reminders to adolescents regarding treatments and appointments. The *Social Networking* feature includes a personal page to share comments, videos, and pictures, as well as a community message board. The *Entertainment* feature includes games, music, quizzes, and puzzles, intended to provide distraction during treatments, such as airway clearance. Finally, the *Communication* feature includes instant messaging, text messaging, and phone call capabilities.

Phase I: Focus Group With CF Health Care Professionals

Participants and Procedures—Informational flyers describing the study purpose and an invitation to participate in the focus group were emailed to the CF center team members at NewYork-Presbyterian Hospital, Columbia University Medical Center. Staff members from the pediatric and adult CF programs were invited to participate in the 90-min focus group and complete a 10-item anonymous survey rating the likely effectiveness of CFFONE™ on a scale from 1 (not at all likely) to 5 (highly likely).

K.D. inquired about adolescent adherence, self-care management, and transition to adulthood. He also reviewed the functions, website features, potential benefits, and risks of CFFONE™ with participants.

Results of Phase I—Seventeen staff members were invited and all participated. CF team members were mostly female (82%) and non-Hispanic White (71%). Participants included physicians (n = 8), pulmonary fellows (n = 3), nurses (n = 4), and social workers (n = 2), ranging in age from 21 to 65 years with 1–35 years of CF care experience.

Participants reported that adolescents tend to feel "invincible," are less adherent than other age groups and lack knowledge about the medical consequences of poor adherence. Additional issues considered by the CF care team included the need to give adolescents more control over their care, involve them in their treatment planning, and provide education directly to them rather than their parents. Staff wanted to encourage older adolescents to attend clinic visits alone and promote independence by reducing parental overprotection.

Staff participants thought CFFONE™ would be a good source of information about CF and would facilitate individualization of the adolescent's experience (e.g., discussing worries about their health). They thought the live chatbot feature would allow teens to "network" safely with other adolescents with CF, although concerns were raised about protection of anonymity and maintaining control over the content of these interactions. In response to these concerns, the chatbot concept was revised from direct communication (e.g., instant messaging only) between adolescents to simulated conversations to allow adolescents to receive personalized answers from databases based on responses from health care professionals.

The focus group also suggested adding several questions for Phase II participants. These included: Are adolescents currently using the Internet to gather information about CF? Do they communicate with friends with CF on-line? What are the most stressful aspects of managing CF? What would they like to ask health care professionals anonymously on-line? The research team incorporated these suggestions in the development of the survey instruments.

In the anonymous survey, health care providers rated CFFONE™ as "likely" to be used by adolescents (M = 3.88 of 5 points, SD = 0.60), "likely" to increase knowledge (M = 4.18, SD = 0.39), "likely" to improve social support (M = 4.18, SD = 0.53), and "somewhat likely" to improve adherence (M = 3.35, SD = 0.61; Table 1). Internal consistency, as measured by Cronbach's alpha, suggested strong reliability ($\alpha = 0.87$).

Phase II: Interviews With Adolescents With CF, Adults With CF, and Parents

Participants and Procedures—Eligible participants for Phase II included adolescents with CF 11–18 years of age, parents of adolescents with CF, and adults diagnosed with CF during childhood. Potential participants received a letter inviting them to complete the survey and the CF program directors also approached patients and parents in clinic. Informed consent and assent were obtained by a member of the research team. Participants completed a 45-min interview and an anonymous, self-administered survey inquiring about barriers to adherence, family interactions concerning CF, and their impressions of the CFFONE™ concept. Adults with CF were asked to consider how useful CFFONE™ would have been for them during their adolescence. Participants ranked the usefulness and helpfulness of CFFONE™ from 1 (not at all useful or helpful) to 5 (very useful or helpful).

Results of Phase II—Interviews—Twelve adolescents with CF, 12 parents of adolescents with CF, and 6 adults with CF participated in Phase II. These adolescents, parents, and adults were invited to participate based on a regular clinic visit scheduled during the study time period. All participants who were approached agreed to take part in the study. Adolescent participants were all non-Hispanic White, 83% were female, and ranged in age from 11 to 18 years (M = 15.7, SD = 2.23). Parent caregivers were also non-Hispanic White, 83% were female, all were married and ranged in age from 41 to 54 years (M age = 45.8, SD = 3.36). Five parents worked full-time and all parents had either a high school diploma (n = 3) or a college degree (n = 9). Adults with CF were non-Hispanic White, 50% were female, and ranged in age from 21 to 36 years (M = 30.7, SD = 4.72). Most were single (67%) and half were working (50%).

Adolescents stated that CF substantially impacted their daily lives and that they experienced a number of barriers to adhering to their prescribed treatments. They described CF as “interfering” with their lives (58%) and reported that their treatment regimens were time-consuming (50%). One participant reported that CF “makes them different” from their peers. Half of the adolescents reported frequent conflicts with their parents about their treatment regimens, and described several strategies for handling conflict, including “giving in to their parents,” talking it out, or leaving the room. When queried about their future goals and transition to adulthood, most adolescents were focused on attending college (75%). A couple of adolescents looked forward to having more control over their treatments and medical decisions as they got older (17%), while others were concerned about having less support and more responsibilities (42%).

When compared with adolescent respondents, parents reported more difficulties with adherence and described time constraints, lack of motivation, and forgetting treatments as barriers to adherence. Parents thought adherence improved when they provided their adolescents with privileges, reminders, and/or consequences (e.g., limiting their social activities). Most parents were concerned about their child’s transition to adulthood (75%), including their child’s ability to balance medical regimens and other adult responsibilities (50%). Only one parent mentioned that shortened life expectancy would affect their child’s future goals.

Adults with CF reported experiencing barriers to adherence similar to those reported by parents. Adults recalled that parental reminders and concerns about worsening health were motivating factors that led to eventual compliance. Adults commented that during adolescence, they were frustrated by time-consuming treatments and arguments with their parents. Half of the adults reported they knew others with CF when they were younger, whom they met in the hospital, in CF clinic, or at CF summer camp. Adults with CF identified increased knowledge about CF (83%), the ability to speak with others with CF (67%), and the disease management support (33%) as benefits of CFFONE™.

Most adolescent participants generally considered the CFFONE™ concept to be “helpful” (58%). In addition, a few adolescents also thought the concept was “useful” (25%),“fun” (17%), and “cool” (17%). Both adolescents and parents would recommend CFFONE™ for younger adolescents and parents reported they would be “very likely” to purchase a CFFONE™. Parents stated that talking on-line with other adolescents with CF would be beneficial for their children and they were not concerned that their children would want to meet other adolescents with CF in person. Adults with CF noted that CFFONE™ would be useful as an organizational strategy.

Results of Phase II—Survey—The survey inquired about the usefulness of CFFONE™ website features (seven items), cell phone features (five items), and potential to improve adherence to treatment regimens (three items; Table 2). All groups rated the chatbot as the most helpful web-enabled feature.

Overall, participants rated CFFONE™ as "pretty helpful" to "very helpful" in addressing barriers to adherence and managing their CF treatment regimen (Table 2). Both adolescents and adults with CF thought the ability to download games to pass the time during treatments would be "pretty helpful" (M = 3.83, SD = 1.12; M = 4.42, SD = 0.90; respectively). All rated the cell phone's calendar and alarm features as "pretty helpful," although the top-rated feature by both adolescents and adults with CF was the ability to call the CF care team (Table 2).

Phase III: Evaluation of the CFFONE™ Prototype

Participants and Procedures—Participants from Phase II and other patients were invited to participate, based on having a clinic visit within the time frame of Phase III. All participants from Phase II expressed interest in Phase III, but only three were eligible based on the time frame. All eligible patients participated. Informed consent and assent were obtained by a member of the research team. Nine adolescents with CF (aged 10–17 years, M = 13.9, SD = 2.23; 67% female) evaluated a prototype of CFFONE™ and were provided with a computer and a preprogrammed Apple iPhone®, which interfaced with the CFFONE™ program. Following recommended usability practices,[23] participants were prompted to try features, such as signing up for the CFFONE™ service or completing a profile on the website. Participants also completed a 60-min interview and survey which ranked ease of use, features, information, and comfort with the CFFONE™ prototype from 1 (strongly disagree) to 5 (strongly agree).

Results of Phase III—While participants had no difficulty signing up for the service, navigating the social networking feature and adding other users, they were all confused about how to use the profile page. All participants could use the calendar features, navigate the Hot Topics feature, and preferred the question/answer section to the general information section. The majority could use the video and game features.

The majority of participants (n = 8) completed the usability survey and strongly agreed that the CFFONE™ interface allowed them to find information easily (M = 4.75, SD = 0.46; Table 3), quickly navigate the website (M = 4.75, SD = 0.71), organize their health care (M = 4.62, SD = 0.52), and find trustworthy information (M = 5.00, SD = 0.00).

Phase IV: Technology Experts

Participants and Procedures—Experts in web and cell phone technology (n = 24) from two professional organizations, the Society for the Advancement of Learning Technology (SALT.org) and the Usability Professionals Association (upassoc.org), were invited by email to participate in an anonymous online survey. Potential participants were asked to reply to the invitation e-mail in order to receive the survey e-mail. Technology experts who replied to the invitation then received a one-page description of CFFONE™ and its features, a brief survey about CFFONE™, and questions about demographic characteristics. The survey included questions about the feasibility of CFFONE™, appropriateness of the design, ability to integrate features, and motivation of adolescents in general to use this technology. Responses were rated from 1 (not at all likely) to 5 (highly likely).

Results of Phase IV—Eight technology experts expressed interest (33% recruitment rate) and completed the survey. Participants for this Phase were between ages 21 and 65 years old, mostly Caucasian (88%), and half were female. All experts had at least a master's level of education. Areas of professional expertise included instructional design, computer information systems, web design, user interface design, information development, e-learning, interactive telecommunications, and mobile technology. Experts rated CFFONE™ as a "highly" feasible concept (M = 4.88, SD = 0.35, range: 4–5), with “highly” appropriate technical design (M = 4.62, SD = 0.52, range: 4–5), and features that would be easily integrated into web and cell phone format (M = 4.12, SD = 0.84, range: 3–5). They thought adolescents would be “quite” likely to be motivated to use CFFONE™ (M = 4.00, SD = 0.76, range: 3–5) although they identified cost, anxiety about sharing personal information, and the role of parents in the use of CFFONE™ as potential barriers.

DISCUSSION

The results of this study support the acceptability, feasibility, and utility of a web-enabled cell phone for adolescents with CF. Among health care professionals, there was consistent evidence that CFFONE™ was somewhat likely to improve adherence in this population. Similarly, adolescents with CF, parents of adolescents with CF, and adults with CF rated CFFONE™ as somewhat likely to improve adherence, and likely to improve knowledge of disease management and peer support. Adolescents were able to use the CFFONE™ prototype without difficulty and technology experts endorsed the design of the product.

Previous research indicates that both behavioral and technology-based interventions have been successful in improving adherence to nutritional guidelines, knowledge of disease management, and treatment skills. However, these interventions were developed and tested only with preschool and school-age children with CF and many included direct patient contact.[7,9] Although Stark’s group intervention improved nutritional outcomes,[9] this type of treatment is no longer permissible due to infection control policies.[14] To date, no interventions have been developed to simultaneously improve adherence and provide social support. CFFONE™ is designed to address both objectives, specifically with adolescents.

Technology interventions, which have included automated reminders (e.g., text messages, alarms) and use of video, have received positive feedback that the intervention may improve adherence behaviors in chronic illness populations (i.e., CF and HIV-AIDS).19,20 The Diab-Memory, a cell phone-based software application, is an example of a technology intervention which has demonstrated positive effects on adherence (i.e., improved metabolic control in patients with diabetes).24 CFFONE™ extends these technological features to include more interactive options. In fact, adolescents with CF, parents, and adults with CF all rated the chatbot as the most helpful web-enabled feature. Applying this type of technology to improve adherence among adolescents may be beneficial for several reasons. All participants in this study reported that adolescents would enjoy a web-enabled cell phone and would be likely to use it. Cell phones are commonly used by teens and thus, having a specially equipped cell phone is not likely to draw unwanted attention from peers or adults. Additionally, providing an adherence and social support intervention via a mobile cell phone and website would increase its use, since the features could be accessed at any time.

CFFONE™ offers several unique advantages over traditional education materials while avoiding face-to-face interventions. For example, CFFONE™ employs visual, tactile, auditory, and interactive modes of communication. Using a web-enabled cell phone may be appealing to adolescents, potentially resulting in more use. By incorporating multiple approaches to teaching, CFFONE™ is likely to reach adolescents with different learning styles. This intervention also focuses on peer-to-peer support, which could promote the exchange of beneficial strategies for improving adherence and increased perceptions of social support. While adolescents rated the social networking features as only “somewhat helpful,” parents and adults rated these features as “helpful.” Additionally, research in adolescents with diabetes supports a strong link between social support and treatment adherence.[16,17] Improvements in adherence may also reduce treatment-related conflict between adolescents and their parents.[25] Parents will not be given direct access to their adolescent’s CFFONE. However, if adolescents seek information about parent–adolescent conflict, the web-site moderators of CFFONE™ could provide suggestions about strategies to improve communication and referrals to relevant mental health professionals on their CF care team. Recommendations about getting along with parents or using problem-solving strategies could be included in web-site information as part of CFFONE™. Future research should examine the impact of CFFONE™ on social support and family functioning.

Communication with the health care team is another advantage of CFFONE™. Adolescents and adults with CF rated the ability to call their health care team as the most valuable feature of the phone. Direct communication between adolescents and health care professionals via cell phone technology may be an untapped resource to increase communication and improve the quality of care. Facilitating adolescents' ability to communicate with their health care team, independent of their parents, may also foster self-initiated disease management. While the ability to call the CF care team is not exclusive to CFFONE™, the combination of phone and web-based tools will provide individualized information about disease management. As adolescents prepare for transition to adult care, they need to take greater responsibility for their health care, including initiating calls to the CF team to report changes in symptoms or ask questions about their treatments.

Although CFFONE™ is a novel, interactive, and potentially effective intervention, there are some potential concerns. Adolescents may discover that an online friend is experiencing a decline in health, such as increased hospitalizations, the development of a CF-related complication (e.g., diabetes) or referral for lung transplantation. In anticipation of these consequences, CFFONE™ will include psychological and medical supervision and online moderators to provide guidance and support. In addition, CFFONE™ is intended to improve peer support; thus, there is the possibility that participants who meet online may want to meet in person. To avoid this consequence, CF team members and CFFONE™ moderators must anticipate this issue and educate adolescents about the associated risks in order to facilitate good decision-making. While the CF team did raise this concern, parents did not and, in contrast, identified CFFONE™ as an opportunity for social support. In addition, one adolescent reported that the availability of online peer interaction would likely obviate the temptation to meet in person.

Limitations

Limitations of this study included its small sample size and recruitment of participants from a single CF center. Further, all participants were Caucasian, predominantly female, and reported above average socioeconomic status. In addition, data could not be evaluated by dyad, because parent participants were not necessarily related to adolescent participants. These sampling issues limited the generalizability of the results. Also due to the small sample size, validity data on the measures used in this study are not available; a larger study using these measures would be needed to establish their validity. In addition, the low recruitment rate of the technology experts (33%) also restricted the conclusions based on the technology survey. However, the diverse technical expertise of the participants lent credence to the ratings provided by these participants. Across the Phases of the study, participants tended to use the upper proportion of the rating scales, resulting in positively skewed responses. Future research should include survey questions that use the full scale, as well as objective data on use of specific features.

The use of the Apple iPhone® may have influenced the results of the evaluation of the CFFONE™ prototype. While web-enabled cell phones have become more popular and widely available, the Apple iPhone® was likely new and exciting to most participants. However, the questions in Phase III referenced aspects of CFFONE™ which could be accessed on any web-enabled cell phone. These aspects included location and quality of the information, clarity of the website, and organization features. Following the efficacy study of CFFONE™, translational research using the cell phone and service provider of choice should be conducted to determine the effectiveness of CFFONE™ in real world situations.

Future Directions

Based on the results of this initial study, a randomized clinical trial with 180 adolescents aged 11–17 will be conducted at six geographically and demographically diverse sites. Participants will be recruited to more equally represent sex, race and ethnicity, and parental education. This study will test whether using a fully developed version of CFFONE™ will increase knowledge, adherence, peer support, health outcomes, and quality of life and be utilized safely. This efficacy study was recently funded by the National Heart, Lung and Blood Institute (NIH/ NHLBI grant #2R44HL088826-02). If successful, the CFFONE™ intervention will be disseminated to the CF community.

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TABLE 1

Phase I CF Care Team Focus Group Anonymous Survey Results

		M	SD	Range
1.	The CFFONE™ concept is a feasible idea	3.94	0.66	3–5
2.	Adolescents with CF will use this technology	3.88	0.60	3–5
3.	Adolescents will be motivated	3.82	0.73	3–5
4.	Product will be helpful in addressing adherence issues	3.47	0.72	2–4
5.	Product will enhance adherence	3.35	0.61	2–4
6.	Product will increase knowledge about CF	4.18	0.39	4–5
7.	Product will increase social support	4.18	0.53	3–5
8.	Product will reduce sense of social isolation	4.06	0.43	3–5
9.	Families will subscribe to a service like this	3.47	0.72	2–5
10.	Relevant commercial entities would advertise on this	4.24	0.83	2–5

Note. Likert scale from 1 = not all likely to 5 = highly likely.

TABLE 2

Phase II Survey Assessing Usefulness of the CFFONE™ Among Adolescents With CF, Their Parents, and Adults With CF

	Adolescents			Parent caregivers			Adults		
Items	**M**	**SD**	**Range**	**M**	**SD**	**Range**	**M**	**SD**	**Range**
Usefulness of website features									
1. The chatbot to ask questions about CF and get answers back, like using IM	4.33	0.65	3–5	4.69	0.46	4–5	4.71	0.45	4–5
2. Having a diary to keep track of treatment as they are completed each day	3.00	0.95	2–5	3.61	1.21	2–5	3.00	1.41	1–5
3. Being able to IM other kids who have CF	3.67	1.30	1–5	4.27	0.80	3–5	4.06	1.08	2–5
4. Having a personal page (like myspace) that only other kids with CF can see	3.00	1.48	1–5	4.54	0.75	3–5	3.71	1.16	2–5
5. Watching videos with the latest news and information about CF	3.50	0.91	2–5	4.19	1.03	2–5	4.56	0.73	3–5
6. Making and sharing videos and photos with kids who have CF	2.75	1.14	1–5	4.08	0.83	2–5	3.71	1.16	2–5
7. Downloading music, games or videos to help pass the time during therapy	3.83	1.12	2–5	3.85	1.03	2–5	4.42	0.90	3–5
Usefulness of cell phone features									
8. Reminders about when it’s time to do your treatments using personalized ring tones	3.92	1.17	1–5	3.92	1.07	2–5	4.15	0.64	3–5
9. Having a calendar to schedule the things, including treatments, you need to do each day	4.08	1.08	2–5	4.15	0.66	3–5	4.00	0.93	3–5
10. Being able to text message other kids with CF	3.58	1.31	2–5	4.11	1.08	2–5	4.06	1.08	2–5
11. Being able to make phone calls to other kids with CF	3.25	1.30	1–5	3.99	1.52	1–5	3.71	1.28	2–5
12. Making phone calls to people on your CF care team	4.25	0.75	3–5	3.80	1.38	1–5	4.71	0.45	4–5
Helpfulness of CFFONE™ to improve adherence									
13. How helpful do you think CFFONE™ would be in overcoming some of the problems doing your treatments that we talked about at the beginning of this interview?	3.50	1.09	1–5	3.77	0.58	3–5	3.65	1.03	2–5
14. Do you think CFFONE™ would help you to keep up with your treatments?	3.58	1.17	1–5	4.77	0.42	4–5	4.06	1.08	2–5
15. How helpful would CFFONE™ be?	3.62	0.74	3–5	4.19	0.87	3–5	5.00	0.00	5

Likert scale from 1 = not at all useful or helpful to 5 = very useful or helpful.

TABLE 3

Phase III Usability of CFFONE™ as Assessed by Adolescents With CF

	M	SD	Range
1. It was easy to find what I was looking for	4.75	0.46	4–5
2. I was quickly able to find my way around this web site	4.75	0.71	3–5
3. This site would help me keep track of my healthcare	4.62	0.52	4–5
4. The information on this web site was easy to understand	4.62	0.52	4–5
5. I trust the information that I found on this web site	5.00	0.00	5
6. The information on this web site seems to be up to date	4.75	0.46	4–5
7. This web site would fit well into my life	4.50	0.54	4–5
8. I felt confident using this site	4.50	0.76	3–5
9. Overall, this web site was easy to use	4.88	0.35	4–5

Likert scale from 1 = strongly disagree to 5 = strongly agree.