Use of a disease-specific mobile health application in the care of adults with congenital heart disease

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ABSTRACT

We completed a pilot study of a novel adult congenital heart disease–specific mobile application. Twenty-eight patients with congenital heart disease from across the US were identified by the Adult Congenital Heart Association, a patient advocacy organization. These patients were asked to complete a 6-month trial of the MyHeartApp mobile application (app), to use the app as part of their clinical care, and to complete a survey at the conclusion of the pilot period. We found that app use is potentially helpful in improving care quality with good ease of use and the potential to facilitate patient-provider communication, but compliance with regular use is poor. Although potentially beneficial, the clinical utility of mobile health apps, even in a young and motivated population, will depend on developing techniques aimed at improving compliance.

KEYWORDS Adult congenital heart disease; mobile health; patient-reported outcomes

In clinical care, as currently practiced, there is a seemingly insurmountable barrier between providers and vitally important health information. This “fourth wall” exists because patients live most of their lives outside the formal health care structure. Providers make most decisions based on snapshots of information, separated in time by months or years, which may or may not actually relate to patients’ daily experiences. Recognition that it is these experiences that should be the focus of medical care has led to an increased focus on patient-sourced information and the development of patient-reported outcome metrics (PROMs). Perhaps not surprisingly, these PROMs frequently outperform traditional medical testing in anticipating clinical deterioration.¹ Nevertheless, PROMs are dependent on patient recall and psychological state at the time of administration.²

Mobile health technology offers a potential solution to this problem. The widening use of smartphones has created an opportunity for providers to access powerful patient-sourced information contemporaneously with patient experience. In recognition of the great potential to facilitate accurate and efficient patient-provider communication and improve health care quality, the American Heart Association and European Society of Cardiology recently produced white papers describing the status of evidence supporting such technology.^{3,4} Currently available mobile health applications in

the field of cardiovascular disease, however, have limited utility and evidence to support their use in regular clinical practice.^{5,6} In the present study, we sought to begin the process of capitalizing on the availability of smartphone mobile applications (apps) by creating a tool designed to facilitate accurate communication of symptoms and biometrics between adults with congenital heart disease (ACHD) and their providers.

METHODS

We conducted a pilot study in a test population of 28 ACHD patients from around the USA to assess interest in and usefulness of an ACHD specific app. This study was approved by the institutional review board at Baylor University Medical Center.

The MyHeartApp (MHA) was developed by a collaboration between an ACHD patient (C.B.) and an ACHD health care provider (A.C.) with cooperation and input from members of the national patient advocacy group for ACHD, the Adult Congenital Heart Association (ACHA). MHA collects the following data: (1) incidence of those symptoms identified as most significant based on survey data from ACHD patients⁷; (2) a newly developed ACHD disease-specific PROM⁸; (3) pedometry; (4) vital signs; (5) medication, salt intake, and exercise compliance; and (6) daily clinical status.

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Figure 1. Representative screenshots from MyHeartApp as used in the pilot study. From left to right: symptom entry, daily check-in for well-being, calendar data summary, graphic symptom and biometric data trends, and sending data to providers.

In addition, MHA provides reminders to take medications (at times entered by users at the time of app onboarding), to complete daily check-ins and to complete an ACHD disease-specific PROM every 2 weeks (Figure 1). MHA produces a summary of all data collected during a period indicated by the user, which users may then send to health care providers in the form of a report.

Patients were recruited from among individuals who act as ambassadors in the ACHA via email correspondence with the authors. Interested subjects needed to be over 18 years old, self-report having ACHD, have an iPhone capable of downloading the mobile application, and be willing to use the mobile application for 6 months and complete a survey afterward. The study included no additional health information from subjects.

Interested subjects received an invitation to download a test version of MHA, as well as specific instructions on how to set up MHA. Authors and app developers addressed any problems with app function via email correspondence. Once all subjects had received MHA, the authors sent monthly reminders via email to encourage continued use of the MHA. At the end of 6 months, subjects received a 10-item survey via email. To improve response rates, authors sent repeat invitations to complete the survey every week for 4 weeks. All app entries and survey data were anonymous. We then analyzed responses and response rates.

RESULTS

Of the 28 subjects who responded to emails expressing an interest in participating in the study, 15 (54%) completed the test period and survey. Among those who failed to complete the study, five had problems with MHA download or

function and one withdrew from the study. The seven other individuals who failed to complete the protocol provided no reason for their failure to do so.

Among those who completed the study, 18 entered at least one symptom during the study period, varying from 1 symptom episode (4 subjects) to 18 episodes (1 subject), with a median of 3. The number of days on which episodes of symptoms were entered varied from 1 (7 subjects) to 14 (1 subject), with a median of 2. Fifteen subjects completed at least one daily check-in, varying from 1 (3 subjects) to 53 (1 subject), with a median of 2. Eleven completed at least 1 biweekly check-in, varying from 1 (8 subjects) to 5 (1 subject), with a median of 1.

Among the 15 patients who completed the final survey, 6 reported using MHA as a part of their clinical care, and 4 solicited feedback from their providers. Findings from the 10-item survey are shown in Table 1.

DISCUSSION

In the present pilot study, we investigated the patient-reported utility of the ACHD specific health care app MHA in a small pilot group of ACHD patients. We found low rates of participation and low rates of app use among those who did participate. Nevertheless, participants generally reported that the app was easy to use and useful in helping to monitor their symptoms. The few patients who used MHA to communicate with providers as a part of clinical care found it useful to both themselves and their providers.

Mobile health apps have great potential to facilitate care in ACHD. ACHD patients are younger than most individuals with chronic heart disease and more likely familiar with and enthusiastic about mobile technology.⁹ The present data

Table 1. Summary of responses to the pilot survey assessing satisfaction with MHA use

MyHeartApp survey questions	Number of responses					
How easy did you find MyHeartApp to set up?	10 Very easy	5 Easy	0 Neither easy nor difficult	0 Difficult	0 Very difficult	
How easy did you find MyHeartApp to use?	7 Very easy	8 Easy	0 Neither easy nor difficult	0 Difficult	0 Very difficult	
How effective was MyHeartApp in helping you track your symptoms?	4 Effective	11 Somewhat effective	0 Little help at all	0 Made things more difficult		
How time consuming was it to use MyHeartApp?	0 Very time consuming	5 A little time consuming	3 Neither efficient nor time consuming	5 Quite efficient	2 Very efficient	
How useful did you find the MyHeartApp status summaries emailed to you?	3 Very useful	5 Somewhat useful	6 Neither useful nor non-useful	1 Not useful	0 More harm than good	
How useful did your provider find the MyHeartApp status summaries emailed to him/her (please ask him/her)?	4 Somewhat useful	0 Neither useful nor non-useful	0 Not useful	0 More harm than good	11 I did not share data or use with my provider	
Do you feel like using MyHeartApp made your time with your health care provider more or less efficient?	1 Much more efficient	3 Somewhat more efficient	2 No effect	0 Somewhat less efficient	0 Much less efficient	8 I did not use with my provider
Ask your health care provider if your use of MyHeartApp made your visit with him/her more or less efficient.	1 Much more efficient	2 Somewhat more efficient	1 No effect	0 Somewhat less efficient	0 Much less efficient	10 I did not use with my provider
How effective was MyHeartApp in helping you communicate with your health care provider in your opinion?	1 Very effective	5 Effective	0 Somewhat effective	0 Little help at all	0 Made things more difficult	9 I did not use to help communicate with my provider
How effective was MyHeartApp in helping you communicate with your health care provider in the opinion of your health care provider (please ask him/her)?	1 Very effective	3 Effective	0 Somewhat effective	0 Little help at all	0 Made things more difficult	11 I did not use to help communicate with my provider

suggest that, when appropriately executed, these apps can potentially be useful in helping patients track their health and communicate with their providers.

The pilot data highlight a major limitation of mobile health technology, specifically difficulties with patient use and engagement. This impediment has been identified in a previous investigation of a mobile health application, in which as few as 9.3% of individuals completed a 7-day protocol.¹⁰ The fact that 54% of individuals in the present study completed a 6-month test period suggests that having an engaged population improves compliance. Realization of the promise offered by mobile health technology, however, will likely require improved research software³ and most importantly patient education. MHA has attempted to confront this challenge through patient-developed and -centered disease-specific software and active engagement of the ACHD population through cooperation with the ACHA. Although this is the most straightforward strategy to improve app use, the present data suggest that it remains inadequate and we thus plan to pilot three other strategies. First, we will attempt to create a virtual ACHD community with interuser challenges based on compliance with app use and potentially with app-tracked healthy lifestyle goals. Second, we would like the app to be a hub for targeted health-related information based on a user's diagnosis to improve user value and hence frequency of patient-app interaction. Third, we will attempt to integrate the app into routine clinical care, where a patient's provider introduces the app and asks for compliance to help improve communication and care. Based on the results of the pilot study, it is clear that multiple techniques will need to be brought to bear for success in realizing the promise of mobile health.

The present study was intentionally a limited pilot project intended to assess patient and provider acceptance of mobile app-facilitated clinical care. Future studies will focus on the accuracy with which MHA records patient experiences, novel techniques to improve the frequency of app use, and the possible impact of MHA use on care quality.

In conclusion, though MHA has the potential to improve health care quality in the ACHD population, much work is needed to increase its implementation and use through a series of additional strategies to increase compliance with

regular app use. At the conclusion of development and testing, MHA will be provided to all users free of charge, and data derived from MHA will become the property of the national patient advocacy group ACHA.

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