ALLERGY QUALITY OF LIFE QUESTIONNAIRE (E-SURVEY) USE IN

SMART PHONES: YES, THERE IS AN APP FOR THAT

By

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A CAPSTONE PROJECT PAPER

Presented to the Department of Medical Informatics & Clinical Epidemiology

and the Oregon Health & Science University School of Medicine

in partial fulfillment of the requirements for the degree of

Master in Biomedical Informatics

November 2012

CERTIFICATE OF APPROVAL

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This is to certify that the Master's Capstone of

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ABSTRACT

Allergic rhinitis is a chronic disease that may be easily monitored at home using Web-Health 2.0 concepts and tools such as smartphones, which are popular due to their portability, wireless and multimedia capabilities. Health-related apps are undergoing rapid development, but many remain unproven and have yet to be evaluated for widespread use. Although much of the hardware associated with healthcare apps are usable, few software applications for medicine have been established and are best designed with additional patient input. I report the results of a usability and qualitative study of allergic rhinitis patients' use of a mobile app involving a quality of life questionnaire (eSurvey) that sought information on factors that are important in successful and adherent use. Patient use experiences demonstrated satisfaction, learnability, ease, trust, and willingness. The doctor-patient-relationship facilitates this trust of a new virtual encounter. Traditional face-to-face clinic encounters can be transformed through simulated use and monitoring of allergy patients. A universal web app platform promotes general use in all smartphones. Transfer of paper surveys to personal computers to smartphones requires redesign unique to the patient, device, and its interface. The adaptation of the eSurvey to smartphones required one-at-a-time question presentation, which, for some patients, added therapeutic meaning to the experience. Information obtained from a survey in this manner can be considered a patient's personal health record as an adjunct to the patient's health status and improves access to health care when limited by geography and time. These novel findings of eSurvey benefit in allergic rhinitis interventions, contribute to effectiveness research necessary to improve and promote monitoring of diseases through mobile health technology.

INTRODUCTION

A rapidly growing number of households have mobile phones[1] or use apps on other mobile platforms such as tablet computers[2] to engage in mHealth—the use of mobile computing and communication technologies in medicine and public health.[3] An online search indicated that the number of medical apps available ranges from over 3,000 at the App Store[4] to over 7,000,[5] although the authors, Pho[4] & Kailas et al.[5] are concerned with their relevance and authenticity for use.

These software applications or "apps" are being rapidly developed, advertising health and wellness management, to such an extent that the Federal Drug Administration (FDA) has issued recommended draft guidance concerning the definition and use of mobile medical apps[6] with expectations regarding the regulation and protection of the public from unintended events. The Healthcare Innovation and Marketplace Technologies Act is a bill ready to be presented in the House of Representatives, which would establish an Office of Mobile Health at the FDA. It is to provide recommendations on mobile health app issues and create a mobile health developer support program.[7]

Similar app validity concerns have been expressed in academic reviews, as very little research has been conducted regarding the value of such applications of technology,[3,6] prompting Free et al.[3] to suggest topics important in effectiveness research. This eSurvey research meets one of their criteria: to improve or promote health or service through interventions designed to improve the monitoring of diseases.

As technology advances and alters the way healthcare is delivered, digital communications between patients and providers have the potential to greatly improve access to many types of healthcare services.[1,2] Boulos et al.[1] & Fortney et al.[2] suggest usability and input recommendations from patients, which may help with adherence and ability to learn app use in the long run--methods of qualitative study described by Berg.[8]

Free et al.[3] summarize several systematic reviews on the use of mobile phones, many of which are in the field of chronic diseases. Key features that afford mobile phones advantages over other communication technologies are the following: wireless capability, portability due to size, and computing power in supporting multimedia software. These technology platforms are often standardized, however each specific disease entities, like allergic rhinitis, require their own unique outcomes measure.

Many functional health measures have yet to be developed or vetted for meaningful use.[9] I aimed to engage patients in their home environment and encourage more real-time monitoring; hence, I validated the online use of an electronic rhinitis outcomes questionnaire, an allergy-specific health survey.[10,11] This eSurvey is frequently used in our clinic kiosk but had not been used outside our clinic.

Often, allergic rhinitis patients are not seen in our clinic for several months to over a year; thus, this population is well suited to home monitoring. Frequently exacerbated by environmental factors such as pollens and molds, allergic rhinitis is an ideal disease model for Health-Web 2.0 use case development. Most patients are younger, presenting with their condition in childhood or the teen years. Smartphone technology, given its widespread use, mobility, and portability, might be able to reach this younger, healthy population in order to promote healthy behavior change,[1] as previously demonstrated in our e-mail alert online survey study on allergy.[10]

Currently, there are no validated allergic rhinitis outcomes questionnaire apps on the market. The purpose of this research is to explore the familiarity, desires, attitudes, and behavior toward smartphones for health supervision in patients with allergic rhinitis, with the intent of providing this service to the public, health care and allergy providers.

A case study showed promise in a developmental eSurvey iPad app.[12] Lessons learned in that study validates grounded theory in that new and unexpected findings continue to be

discovered, prompting this sequential analysis to further analyze an interface redesign and the use of a universal web app for smartphones.

RESEARCH QUESTION

What is the patient's perception of monitoring their allergic rhinitis through use of eSurvey apps on Smartphones? What are motivating factors that may lead to successful and adherent use?

THEORY

The actual process and use of mobile technology may make a difference in allergy patients' preferences concerning participation. There is no prior experience of allergy patient use of this technology therefore Grounded Theory applies. New findings often occur only after observing and interviewing the subjects. However, diffusion of innovation theory appears to be relevant. Relative advantage, image, compatibility, complexity, ease of use, visibility, result, demonstrability, trial ability, and voluntariness are concepts of Roger's theory.[13] Patients quickly say they will use technology like smartphones when seen on demonstration, perhaps swayed by peers or public hype, but only when they experience its worth in their health and lives will they actually use and accept eSurvey app.

METHOD

Dan Newland and his staff at Northwood Consulting, Fargo, North Dakota, using current standard security and privacy technology, formatted the eSurvey into a multiplatform web app for smartphones and personal computer devices. The current working address at the time of this writing, is https://www.myallergymonitor.com and all patients used test@aacc.com and 1234 as a login.

I am the treating physician for all allergic rhinitis patients returning for their visits at the Allergy & Asthma Care Center, a private practice clinic in Fargo, North Dakota. I served as gate keeper for this study. Oregon Health & Science University Institutional Review Board approved an exempt status for this study October 2012.

All allergic rhinitis patients are routinely asked to fill out the eSurvey on a waiting room kiosk desktop computer as part of their visit. Patients were asked to participate in an interview that was being conducted as preliminary work. Information safety and anonymity were offered as part of the informed consent process. All patient information has been de-identified. Lori, the clinic's lead nurse, was a key informant, identifying patients who would be likely to participate.

Consecutive candidate patients were asked to participate in the study, given an information sheet about the study approved by OHSU eIRB, and only those with Smartphones were accepted; 17 agreed, and 3 completed a focus group interview.   Triangulation methods consisted of the combined use of observation, personal and focus group interviews, the same methodologies used in my previous paper on iPad apps.[10]

INTERVIEW AND FOCUS GROUP QUESTIONS

Open-ended grand tour questioning began the interview, as follows:

Thank you for joining us in this research about allergy surveys. We believe this is important information that we can all use to improve the communication, evaluation, and treatment of allergy conditions.

How do you feel about taking surveys about your allergies in general?

(Probing questions were asked when responses were minimal.)

There is no right or wrong answer. Be brutally honest. How do you feel about taking the survey away from the clinic? What is good or bad about it? Do you have a cell or Smartphone? Would you be willing to take the eSurvey on your phone away from the clinic? Tell me more.

Is there anything at all you would like to add about taking surveys? Is there anything we can do to improve the process? To debrief, you have been very helpful. As we get more information about this process, we will tell you about our summary and post it on our blog.

HYPOTHESES

Most patients will follow their doctor's advice, whether it is to take medicines or complete surveys online or smartphones.

REFLEXIVE JOURNAL

My assumption is that the patients will complete surveys because they are asked to do so.

My bias is that I feel a sense of authority in any medical evaluation or treatment.

I value the use of technology, and I think taking surveys online will make it efficient for patients and for us to monitor and document patients' subjective perceptions of their allergies.

I am optimistic that after time, practice, and education in the online survey method, more and more patients will participate in the process.

I am concerned that I might influence the patients by prompting them to say what I want them to say.

ETHICS AND POWER

  I have authority twice at the physician and investigator levels. I plan for triangulation, rigor, and participatory action research with colleagues to validate and ensure the trustworthiness of our study and findings.

RESULTS

  Figure 1 show the demographics and characteristics of the 17 patients with smartphones who agreed to participate. The average age of participants was 39, median of 37, and ranged from 22 to 57 years. The sample gender distribution was 7, 41% females, 10 or 59% males. Most consider themselves expert or average expertise in the use of computers or smartphones, and 18% rated themselves as novice. The majority, 65% were on allergy shots.
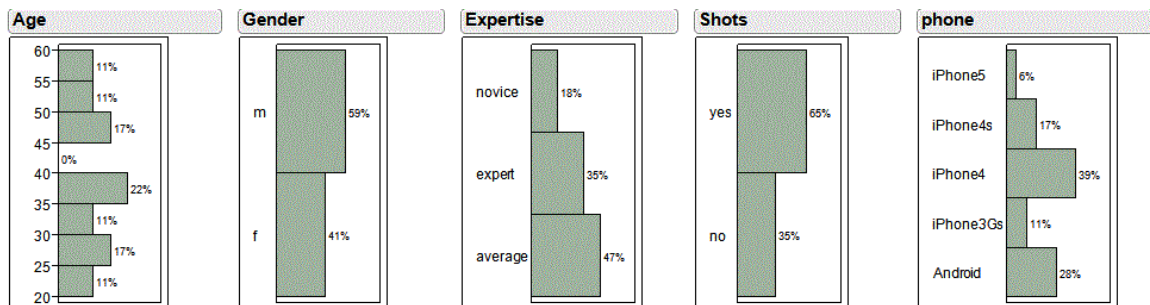

Figure 1. Distribution of age, gender, computer expertise, receiving allergy shots, and brand of smartphones of the 17 subjects participating.

  Field notes were obtained and transcribed, representing raw data. They were read and analyzed for themes, and the distribution was calculated using an Excel spreadsheet. Themes were coded as text.

MAJOR THEMES AND ANALYSIS

Three major redundant themes quickly reached saturation, identical to my previous findings,[12] which corroborate rigor and triangulation validity. At the saturation point, I no longer heard or saw anything new in the responses.

1. Attitude on survey.

The majority of patients had a positive attitude. The following theme emerged: "If it helps you help me, I will always do the survey." This inherent trust is also present in the few that asked whether I looked at their results at all, but will still fill out their surveys. One expert Six Sigma black belt software programmer said he will take the eSurvey but prefers yes/no answers for system improvements, but understands use and need of Likert surveys. Rhetorically he explains his situation. "Although I do not have the 'bandwidth' in my personal time to do these surveys, I will take the time to do it, consistent with my computer background."

Several patients used words that expressed a common positive theme: focus, narrows, teaches--actual words used by certain subjects in this group. Two participants reflect with the following quotes. "When I see the survey symptoms, it helps you think about yourself, and I don't mind doing it. It's similar to my line of questioning with my clients at my veterinary clinic." "It helps me focus on my condition, and myself which I don't do much between visits. I work off my phone anyways so it will be handy to do."

Many can vaguely remember only seasonal periods, like spring, summer or fall allergy exacerbations. They discover more about their allergies when their symptoms are graphed along with dates of good and bad allergy days . One exclaimed, Doc, I can actually narrow down to the actual days of the month when I get sick! Details and granularity that you get about yourself in this process validates the existence of my allergies, and desire to be healthier.

The majority of participants said that they could not think of any negative comments. A rare few said that there were too many questions, especially when they are irrelevant. One suggested a default answer of no or none as one button to make it faster for them, and not have to go through all questions individually. A few asked if I look at the results and how I use them. All participants were reassured that I view, analyze, and used the information during their care.

The majority of allergy shot patients had found relief from their allergies for the past months to years. These were the participants who reluctantly took the surveys. Many smiled during the interview stating their satisfaction, relieved from their ailments. They all remember what it was like years ago how their symptoms would have ranked higher then versus now. "Taking the surveys was helpful at the start. They are boring now." All came to realize that their tedium now, was a measure of improvement, as I showed them their graphs of previous months scores sloping downward. This was actually a good thing, I told them, a testament to their adherence and treatment.

One said the survey was subjective, arguing that his score of 5 for sneeze, maybe a 3 for another. Perhaps you should have a sliding bar scale and have the ability to rank your symptoms between numbers. "I'll do them on my phone, but one has to make the time and be reminded."

Several of the tech-savvy experts talked of potential problems involving signal cutoff and ISP or server availability. Most said that they will create sign-on names and passwords that were easy to remember and contained few words to type. You should have smart button login after the first time, says one expert. These same experts asked about safety measures. "Do you have standard security and certificates?" I reassured them yes, as I showed them the prefix "https:" on the website address right on their phone, as one of several measures.

2. Taking eSurvey on smartphones.

All agreed that taking the survey was helpful or did not mind completing the survey because it helped me to help them. The app was easier and faster to use because they had their Smartphone with them all the time. They agreed that the process was just as fast or faster once they logged on than the computer kiosk in the clinic, or for some who took the survey at home. Many says they don't mind taking them while waiting in clinic, but welcomes the chance of a faster clinic visit when some of their tasks can be done ahead of time before being seen in clinic.

The majority of participants were iPhone users. They were disappointed with the lack of an app icon on their desktop but agreed that a text link was the next best thing. Those with other phones said the same, but all agreed that once they were signed in, the process was much smoother and faster. An expert user and programmer told me that we can easily put the eSurvey app logo on the Android app store. One prefers to take the eSurvey online at Face book or social media because he is there often and more convenient to access.

A significant number of patients said that the symptoms asked about in the survey did not apply. "It's not really meaningful and can be a waste of time but other times I do get those symptoms so I guess I don't mind going through them." One person suggested having just one button to press if the user has no problems with any symptoms. Several suggest the need for additional narrative text capability to say more about themselves.

Most agreed that one-by-one questioning was acceptable. Most indicated that each question was more meaningful when presented individually in contrast with all questions presented at one time, on a computer monitor. See Figures 2 and 3.

Figure 2. All eSurvey questions in an example page on a personal computer screen.

Figure 3. Screenshot of eSurvey question asked individually.

3. Home eSurvey monitoring on smartphones.

Many say they will take the survey on their phone and indicated that access to it, outside the clinic would be helpful between visits. "I often don't have problems when I see you, but when I do, it's nice to be able to capture and report them as they occur." Most stated that the process would blend in with their personal activities, but only if you do not have to take it too often. "One to two times a month is acceptable."

Several participants suggested that the phone should be used for other clinic related access or communication--like appointment reminders they receive from other clinics, or medication requests. Some of the experts and nurses suggested that such activity might involve too many considerations related to privacy, security, and screen size for a phone, and that the patient portal and home computers might be a better platform.

Several participants wanted to take the survey at home. Many agreed that despite the many texts and e-mails they received, they would look for our reminders and did not feel that they represented an intrusion into their daily lives.

OBSERVATION

Subjects were observed as they used their smartphone during the start and finish of the eSurvey app. Formal data acquisition started when subjects began typing for login access, an example page is shown in Figure 4.

Figure 4. Example view of keyboard for typing in www.myallergymonitor.com log-in.

A common complaint regarding data input with the small screens were obvious on observation studies and comments. Several complain about their "fat fingers," getting in the way, especially for those not quite used to their phones. However, many nimble-fingered experts appeared eager and adept using fingers of one or two hands as they tried the new app. These veteran users from the start, exhibited ease while handling their devices.   Agility and dexterity are obvious in most of the users.

All liked the text hyperlink access with just a press at the link, and all suggested an app icon. The average time to take the eSurvey was between 2 and 3 minutes, ounce they are logged in. Clearly typing in the address was cumbersome; creating a text, e-mail link or favorite page for the address was the quickest way to access the logon page for everyone. I saw or sensed frustration in some of the subjects as they begin. See Figure 5 for a screenshot view of the login, the start, and the page which took the longest time to process during the survey.
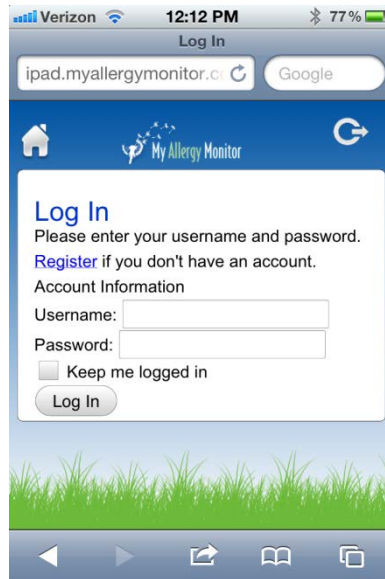
Figure 5. Login page, immediately shown after www.myallergymonitor.com activated.

FOCUS GROUP

I interviewed a focus group total of three subjects. Whether group or personal interviews, identical or similar themes quickly reached saturation, validating results from previous eSurvey studies. [12]

All said that they could blend the use of the app with their other activities, outside the clinic, but only if reminded. All were women and frequent eye contact between subjects occurred, especially when the topic of time management was discussed.
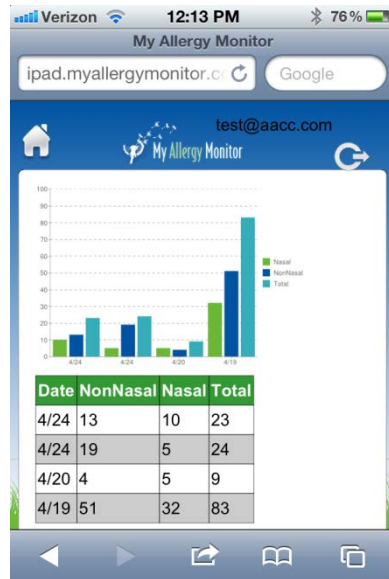
Figure 6. Screenshot of results page and graphed report.

Patients' tendency in this group, was to empathize with shared activities. This affinity created a collegiality that was pervasive. New findings were gathered that might not have been shown individually. One showed another how to graph her surveys, seen in Figure 6.

The same expert user quickly showed a novice how to use Siri on the iPhone 5 she recently acquired. The frustrated novice exclaims, Siri and I have a love hate relationship. She tried to get the eSurvey link unsuccessfully with Siri, see Figure 7.

Figure 7. Siri unsuccessful with "My allergy monitor" search.

Figure 8. Voice recognition text input in a Bing search for "My allergy monitor."

Instead of using Siri, the same expert showed her a more effective attempt by voice recognition text input "My allergy monitor" on the Bing browser search field, see Figure 8. She was all smiles and thrilled to discover these capabilities and thanked the other for her assistance.

DISCUSSION

The use of smartphones at home as monitoring tools for health conditions such as allergic rhinitis makes practical sense and exemplifies a review article by Fortney et al.[2] regarding a shift in the health care paradigm from face-to-face encounters to virtual asynchronous communication. Improvements in digital access could drastically diminish the geographic and temporal access problems faced by many allergy patients, especially in rural areas.

Although use of smartphones is not new to this patient population, agreement to use eSurvey apps away from the clinic was a novel and unanimous theme. Without a priori experience, grounded theory applies. Patient ease and willingness to use mobile apps for their allergies was discovered after the analysis of data. But Roger's theory also applies in that although acceptance is stated, verified trust with tangible return needs to occur before individuals actually do it. There is often a gap between saying and doing.

Many patients still do not know the power and amount of information they can gather from the app, as they are unfamiliar with it and have not seen their graphical trends. Once fully realized, such value-added capability should also aid their use. A few individuals found this capacity and utilized this function, which enabled them to see their symptoms graphed to match the times of year when they are most symptomatic. This prompted them to take action and experience additional allergy relief, as previously demonstrated in our adherence and outcomes study using alerts and the same survey.[10]

However, the majority seemed to be satisfied with reporting their survey scores and did not think much of the results until prompted. When shown their eSurvey results, most asked questions concerning their meaning and relevance. Consistent with Sarasohn-Kahn's findings,[14] patients need or desire personal contact with their physician. Akin to personal health records,

these eSurvey results should be considered adjunct information in allergy care to be reviewed with the utilization of medicines, physical examination, and other objective measures when patients are seen in the clinic.

There was also a misperception that the results were unappealing or boring when there were minimal if any scores to report. Education and interpretation of the eSurvey use and results for current and future users need to be continually emphasized.

We need to respect the naysayers and those who grudgingly take these surveys. Although such responses are probably accurate, choosing all symptoms as absent is an easy way out. Many more patients say that focusing individually on each question sheds new light on their condition, inspiring them to think of something new that they had not considered until prompted by the question. This is consistent with the majority finding that answering one question at a time is acceptable.

This theme of focus is telling of the survey's impact and process. So perhaps the interface requirement of one question at a time on a smartphone is logistically necessary, but serendipitously, a therapeutic experience is obtained--another example of new findings in this grounded study approach and emphasizes the importance of proper human-computer interface design.

Mobile apps appear to be suitable for this age group of allergy patients studied. The ability to use these apps on a universal web platform in any smartphone, facilitates widespread use. Many subjects are agile and found the eSurvey easy and handy to use, especially when they are on the move. However, they may not be amenable for some, and those excluded through a digital divide.

Unlike general online survey invitations in public, a request to take eSurveys will be better accepted and used due to the formed trust relationship between patient and doctor. Simple online reminders and alerts by e-mail or text, will help remind patients to monitor themselves. Many welcome the request and do not see it as intrusive or spam.

Mobile medical app development is in its infancy. We are seeing an explosion in the use of such apps by the public and health care providers. The continued use of standard technology will help to secure privacy and security for patients who, like those in this study, show continued concern and need reassurance and demonstration of safety. Additional effectiveness research in allergy and other specialties of medicine are needed to help insure proper use of this new intervention.

It is also prudent to define terms. According to the FDA App Draft Guidance,[6] software that runs on a mobile platform or a web-based software application executed on a server is a mobile app. A mobile medical app is a mobile app that meets the definition of a medical device and is either used as an accessory to a regulated medical device or transforms a mobile platform into one. Based on this definition, the eSurvey is a mobile app, but not a mobile medical app. This eSurvey mobile app is the only validated functional health measure currently available.

Feedback from patients shows that such surveys are in need of further refinement as they are translated from paper to personal computers, smartphones, and other devices. For example, less and more relevant questions with narrative optional entries were suggested on previous studies.[12] As a result, we redesigned the eSurvey to a one-question-at-a-time format. But additional text, comments, or questions are probably better addressed face-to-face, live with the doctor.

Results reveal a patient use case demonstrating satisfaction, learnability, ease, trust, and willingness. More than five consecutive patients confirmed ease of use and stated their intent to use the eSurvey, which meets the criteria for usability. The small sample size and demographics

of this study may not reflect all allergic rhinitis patients, although the quick to saturate themes compels further investigations. Because there is no a priori experience and data, this study could be considered a pilot study and fodder for additional sequential or parallel research in combination with quantative methods for a more robust analysis of the true allergic rhinitis population. The continued vetting and use of this eSurvey will help meet the need and requirements of meaningful use for allergists in the near future.

Gathering eSurvey information away from the clinic will be a new phenotype facilitating research of environment-patient-pheno-genotype relationships, the mainstay of allergy practice. [15] Findings of this study and process can be a prototype for app and syndromic surveillance database development for allergy organizations. Multilanguage versions can harmonize standard rhinitis surveys, facilitating universal use of validated and tested e-measures.

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