Bridging Dermatologists With Patient Advocacy Organizations Through Smartphones

A. Shadi Kourosh, MD; Evan D. Schoenberg, MD; Jean M. Dejace, MD; Paul R. Bergstresser, MD

This study represents one step in a movement that began with patients who realized that their efforts to live successfully with skin disease were strengthened by collaborating with others who were making that same effort. For decades, advocacy organizations for diseases such as psoriasis, alopecia areata, ichthyosis, and epidermolysis bullosa have supported patients and research initiatives to improve health and quality of life. In the 1980s, several of these organizations joined together, with the assistance of Peyton Weary, MD (University of Virginia), to form the Coalition of Patient Advocates for Skin Disease Research, with the hope that partnering with physicians could help further their goals and that a unified voice would affect policy. Likewise, dermatologists realized that partnering with patients would provide novel insights into research and clinical practice and would animate their lobbying efforts with faces and personal stories. Fifteen patient advocacy organizations currently comprise the Coalition of Skin Diseases (CSD), which has affiliate relationships with the American Academy of Dermatology, Society for Investigative Dermatology (SID), and Dermatology Nurses Association. Together, these organizations have been instrumental in characterizing the burden of skin disease in the scientific, clinical, and political arenas.

Despite efforts to establish partnerships with physicians, the organizations that were members of the CSD in 2011 expressed concern that many dermatologists and residents remained unaware of their existence and the resources they offer patients. In surveying leaders of CSD organizations, it became apparent that the Internet had been the greatest factor...
facilitating patient participation. Each organization reported that most patients found them through Internet searches after receiving their diagnosis.

The Skin Advocate iPhone App was developed by the authors, with support from the SID, as a mechanism to connect CSD member organizations with the young dermatologists they were hoping to reach. The Skin Advocate iPhone App was developed as an iPhone app based on the wide use of iPhone-compatible devices among physicians. This study was designed to measure the effect of the iPhone app in raising physician awareness and increasing referrals of patients to the advocacy organizations.

Methods

We present the results of an institutional review board-exempted investigation conducted among member organizations of the CSD and among dermatologists and dermatology residents in Texas from April 1, 2011, through March 31, 2013. Preliminary data for the purpose of needs assessment were collected via surveys of heads of CSD organizations about dermatologists’ involvement and referral of patients based on the demographics of registrants (patients vs physicians vs others) and interviews they conducted with patients concerning their means of initial contact (physician referrals vs independent searches). From April 1 through June 30, 2011, an anonymous questionnaire was made available to dermatologists and dermatology residents at meetings of the Dallas/Ft Worth and Texas dermatologic societies, surveying their use of iPhone-compatible devices and their awareness and frequency of referral to CSD organizations (eAppendix in the Supplement).

In September 2011, the Skin Advocate iPhone App was released as a free download in the Apple application store, and survey respondents and members of the Texas Dermatologic Society were notified of its availability via e-mail (Figure 1). This iPhone app contains the contact information of CSD organizations in the form of direct links that enable users to contact these organizations via telephone or e-mail or to register for more information with only 2 “clicks.” The app also has a “share” function by which users can send the same contact information to other parties via an anonymous e-mail. E-mail messages are routed through the SID server, masking the addresses of senders. Patients then receive “do-not-reply” e-mail messages from the SID with contact information for the identified CSD organization in the form of direct links, enabling patients to contact or register for the relevant organization with 1 “click.” The app tracks the number of downloads and users and the number of times it is used; these numbers were recorded monthly.

Although the intention was to conduct the study for 6 months (October 1, 2011, through March 31, 2012), in December 2011, the investigators became aware that use of the Skin Advocate iPhone App had spread outside the study population of Texas dermatologists and residents. Because the anonymous user design prevented identification of users outside Texas, the study period was truncated to minimize contamination of the data. In January 2012, approximately 3 months after the app was released, a follow-up post-intervention questionnaire was sent via Survey Monkey (an online survey tool; www.surveymonkey.com) to the original respondents regarding their awareness and frequency of patient referrals to advocacy organizations. Pre-intervention and post-intervention responses to the questionnaire were compared in a masked fashion.

Before the intervention, 5 CSD organizations with the most complete prestudy data were selected for inclusion because the prestudy data could serve as historical controls (eg, number of patient registrations by month from 2009 or before). Their infrastructure for tracking registrations and the inclusion of common and rare skin conditions were also factors in this selection. We included the National Eczema Association (NEA), National Alopecia Areata Foundation (NAAP), Foundation for Ichthyosis and Related Skin Types (FIRST), National Foundation for Ectodermal Dysplasias (NFED), and Sturge-Weber Foundation (SWF). These organizations provided information, including the number of registrants by month from Texas from January 1, 2009, through December 2011. The Skin Advocate iPhone App was released to the public in April 2011, and because the participants were members of the CSD, they were notified of its availability. The Skin Advocate iPhone App was developed as a mechanism for dermatologic organizations to connect with patients at the time of diagnosis. During the CSD campaign, the Skin Advocate iPhone App was available as a free download in the Apple application store. The Skin Advocate iPhone App was promoted to dermatologists and dermatology residents at meetings of the Dallas/Ft Worth and Texas dermatologic societies, surveying their use of iPhone-compatible devices and their awareness and frequency of referral to CSD organizations (eAppendix in the Supplement).

Figure 1. The Skin Advocate iPhone App Icon Enlarged From the iPhone Home Screen
31, 2011. For those organizations that had registration data from before 2009, registrations from 2008 were also included. The number of patient registrants by month in the study period was compared with the corresponding months for at least 2 years before the intervention. Follow-up queries were then conducted in March 2013 for which these same organizations provided the number of annual registrations from Texas and total worldwide annual registrations from January 1, 2008, through December 31, 2012, to determine the effect and possible trends in registrations 1 year later.

Results

Baseline Needs Assessment
Heads of all CSD organizations responded to the pre-intervention organization survey (100% response rate), reporting that before the intervention less than 10% of those registering for their mailing lists were physicians and that less than 10% of patients cited physician referral as their means of contact. From April 1 through June 30, 2011, the investigators received 115 completed pre-intervention questionnaires (100% response rate). These surveys were administered at dermatology meetings and collected at the end of the meetings. Gender and practice demographics were similar in the survey respondents, with 52% male and 48% female and with 49% practicing in academic settings, 45% in private practice, and 6% in both settings. The age distribution of the study population peaked in the 30s (approximately 55%), indicating that our emphasis on the target age demographic of dermatology residents and recent graduates had been achieved. Among survey respondents, 85% used smartphones, 90% of which were iPhone compatible (76% of the total). Of those with iPhone-compatible devices, 90% used these devices for medical work-related purposes. Among all respondents, 28% could not identify any skin disease corresponding to an existing patient advocacy organization. At least 30% had never referred a patient to an advocacy organization, where referral was defined as simply mentioning the existence of an advocacy organization to a patient. Of those who had referred patients, 64% did so at most 3 times per year. The most common reasons for not referring patients were lack of awareness of the organizations and the time-consuming nature of making referrals. When asked whether they would use an iPhone app that streamlined referrals, 85% reported that they would, and 85% reported that the iPhone app would likely increase their referrals to advocacy organizations.5

App Use and Referrals
One month after its introduction, the Skin Advocate iPhone App had been downloaded by 304 users and used 1006 times (3.3 times per user). This indicated improvement in referral behavior compared with the self-reported referrals for 95% of Texas dermatologists. After 3 months (January 1, 2012), there had been 590 downloads and 1985 uses of the app (3.4 uses per user per month). By 6 months (March 31, 2012), there had been 1056 downloads and 3641 uses (3.4 uses per user per month). Throughout the study, mean app use ranged from 3.3 to 3.6 uses per user per month, maintaining the 3-fold improvement compared with self-reported referral for 90% of the study population and a 12-fold improvement for 64% of the study population.

For the post-intervention survey sent to the original respondents in January 2012, complete surveys were received from approximately 50% of the study population. There was 10% attrition due to e-mail addresses that failed to reach destinations. More than 95% of post-intervention respondents reported awareness of 1 or more of the patient advocacy organizations in the CSD, and 80% reported having referred patients to 1 or more of these organizations, with improvement in both awareness and referral reported with respect to all CSD organizations (Figure 2). At follow-up, 60% reported having used the Skin Advocate iPhone App, including 40% who had become regular users (defined as using the app at least once monthly); 20% reported not having iPhones, leaving 20% who had iPhones and did not use the app.

Registrations for CSD Organizations
Comparisons of patient registrations from Texas for the study period of October 1 through December 31, 2011, with the corresponding period of months in the previous 3 years (2008, 2009, and 2010), revealed a substantial increase for NEA, with November 2011 having a record number of registrations and an increase in mean monthly registrations by 10-fold (Figure 3). Total yearly registrations for NEA in 2011 were more than double that of the next highest yearly registrations (in 2010), and these numbers reflected a change in the slope of the line for increase in registrations from 2010 to 2011 compared with exponentially smaller increases from year to year during the previous 3 years (Figure 4).

A small increase in registrations was experienced by NAAF during November and December of 2011 compared with those months in 2009 and 2010. Registrations in October 2011 were decreased from October 2010, which NAAF leaders attributed to their having held a conference with an onsite patient registration drive in Texas in October 2010. Correcting for this confounding variable led to the conclusion that there was no post-intervention decrease. An increase in registrations was seen for NFED in October 2011 but not in November or December 2011. For SWF and FIRST, the numbers were insufficient to reach valid conclusions.

A follow-up query of these 5 patient advocacy organizations was conducted in early 2013 to assess patient registrations in 2012 (the year after the original 3-month study period). By that time, more than 2700 users had used the Skin Advocate iPhone App more than 10,000 times; more than 1100 of these referrals came from outside North America. Reported registrations from NEA indicated that peaks in both Texas and worldwide registrations occurred in 2011 (>2 and >2.6 times greater than registrations for the next highest year [2010], respectively). The 2012 Texas and total worldwide registrations (>1.8 and 1.9 times those of 2010, respectively) indicated a substantial and sustained post-intervention increase in patient registrations, although not to the level of the peak in 2011 soon after the Skin Advocate iPhone App release. For NAAF, Texas registrations in 2012 equaled that of 2010 (the year...
of onsite registration drives in Texas); total worldwide registrations increased by 19\% compared with the next highest year (2011), the largest incremental increase the organization had experienced. In the initial 3-month study period, patient registrations did not change considerably for FIRST, SWF, and NFED; however, in 2012, Texas registrations increased by 43\% for FIRST and 36\% for NFED compared with the previous year. The SWF also reported an unexpected 3.5-fold increase in 2012 total worldwide registrations compared with 2011 and a 6-fold increase compared with registrations before 2011. These organizations did not report any other factors or changes with respect to their efforts to promote patient registrations during the study period other than those noted above.

**Discussion**

**App Use and Effect on Referrals**

Both self-reported data and objective data tracking downloads and use of the Skin Advocate iPhone App reflect a sub-

---

**Figure 2. Awareness and Referral to Coalition of Skin Diseases (CSD) Organizations**

Pre-intervention and post-intervention percentage of awareness and referral to CSD organizations among Texas dermatologists and residents. BCCNS indicates Basal Cell Carcinoma Nevus Syndrome; CARF, Cicatricial Alopecia Research Foundation; CLF, Cutaneous Lymphoma Foundation; DEBRA, Dystrophic Epidermolysis Bullosa Research Association of America; FIRST, Foundation for Ichthyosis and Related Skin Types; IPPF, International Pemphigus & Pemphigoid Foundation; ISDI, Inflammatory Skin Disease Institute; NAAF, National Alopecia Areata Foundation; NEA, National Eczema Association; NFED, National Foundation for Ectodermal Dysplasias; PC, Pachyonychia Congenita Project; SWF, Sturge-Weber Foundation; VSI, Vitiligo Support International; XP, Xeroderma Pigmentosa Family Support Group.

**Figure 3. National Eczema Association Monthly Texas Registrations**

Monthly registrations for the National Eczema Association comparing the intervention year (2011) and the 3 prior years.

**Figure 4. National Eczema Association Annual Texas Registrations**

Annual registrations for the National Eczema Association comparing intervention year (2011) and 3 prior years.
stantial increase in physician awareness and referrals to CSD organizations among Texas dermatologists and dermatology residents after introducing the Skin Advocate iPhone App. These observations correspond with data collected by other investigators in a process identified as the Diffusion of Innovations Curve for new technologies. Specifically, the 40% of post-intervention respondents who reported becoming regular users of the Skin Advocate iPhone App is substantially higher than the standard (expected) percentage of early adopters for new technologies (13.5%). We hesitate to conclude from this that dermatologists are necessarily among the most willing adopters of new technologies; it is possible that the app was simply useful. This high percentage may also reflect some degree of selection bias in the follow-up survey respondents because those who became regular users of the app may be more likely to respond to a follow-up survey. Adopting a new technology and responding to a follow-up survey may be behaviors characteristic of early adopter-type individuals. Tracking data for use of the app at the close of the study period also indicated that most referrals from the app were generated by approximately 20% of the users; this finding could suggest varying degrees of the early adopter phenotype in the study population and the existence of a subset of “superusers.”

The authors received feedback from some dermatologists that indicated they did not notice the “share” button, which sends referral e-mails to patients. Some used the app to access patient advocacy organization contact information, which was handwritten for patients rather than using the referral e-mail capability of the app. Others used this strategy for patients who did not use e-mail regularly. Thus, there may have been a larger effect on physician referral behavior than the app was able to track electronically because of these low-tech referrals.

Effect on Registrations for CSD Organizations
Patient registration data reflected a relatively immediate increase for the organizations that represented more common diseases, with the greatest effect for the most common condition, eczema (NEA), followed by alopecia areata (NAAF) (once corrected for confounding variables). An increase in registrations was reported by NFED in the initial 3 months after app release, whereas for the other rare conditions, ichthyosis (FIRST) and Sturge-Weber syndrome (SWF), the data were insufficient to detect differences.

At the 1-year post-intervention follow-up (in 2012), NEA’s Texas and total worldwide annual registrations compared with pre-intervention numbers reflected a substantial and sustained effect, although not to the extent of the initial registration peak in 2011 after release of the app. Initial publicity at dermatology meetings and novelty of the innovation may have contributed to the initial peak, and perhaps reminders or other reinforcing factors may be required to promote referrals after the novelty of an innovation wears off. The relatively high number of registrations at onsite registration drives held by NAAF at their October 2010 conference (the year before the app release) suggests that conventional methods of outreach (eg, in-person conversations at conferences) are also effective. The Skin Advocate iPhone App is intended to complement conventional methods. For NAAF, the 2012 Texas annual registrations, which equaled the 2010 peak, suggests that over time patient referral tools, such as the Skin Advocate iPhone App, could help to compensate for the absence of conventional high-effect and labor-intensive methods (eg, on-site registration drives). The 2012 increase in registrations for FIRST and NFED compared with the absence of similar changes during the first 3 months after intervention could indicate that for less common diseases, a longer period may be required for affected patients to be identified and referred to relevant organizations. Thus, the effect of a referral tool, such as the Skin Advocate iPhone App, may be delayed compared with that for more common diseases. For a rare condition, such as Sturge-Weber syndrome, only a few health care professionals in a given state (eg, Texas) may be responsible for most of the diagnosed cases and referrals to patient advocacy organizations; lack of change in patient registrations could be attributed to the sheer rarity of a condition and the possibility that relatively fewer health care professionals in a region might have iPhones, brochures, and other patient referral tools.

After release of the app, SWF leaders began to report relatively large numbers of registrations coming from unexpected places, such as Africa, and later from Asia. Their total worldwide registrations increased 75% between 2010 and 2011, followed by a 3.5-fold increase in 2012 compared with 2011 (this meant a 6-fold increase in 2012 compared with registrations before 2011). This increase corresponded chronologically to tracking data for international use of the Skin Advocate iPhone App, which showed that it had been used outside North America more than 1100 times. This finding is also interesting in light of reports of global information technology use that indicate mobile phone use has leapfrogged over other means of Internet use, especially in the less-developed regions of the world.

Conclusions
This study demonstrates that an iPhone app that streamlines referrals to patient advocacy organizations for skin disease improved self-reported physician awareness and subsequent referrals to these organizations. It also increased patient registrations, with the most immediate and greatest effect on organizations that represent more common diseases.

ARTICLE INFORMATION
Accepted for Publication: July 22, 2013.
Authors Contributions: Dr Kourosh had full access to all the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

Copyright 2014 American Medical Association. All rights reserved.

jamadermatology.com
In 1916, the dermatologist Richard Lightburn Sutton described 2 young women with pigmentary changes he called "leukoderma acquisitum centrifugum," better known as Sutton nevus or halo nevus. He thought that the cases he presented were varieties of vitiligo, not nevi. The correlation of leukoderma acquisitum centrifugum with melanocytic nevus was made by John H. Stokes, as reported by the editors of the Year Book of Dermatology and Syphilology (1923 Year Book).

Sutton, a son of a minister, was born in 1878 near Rockport, Missouri. He studied at the University of Missouri, and in 1901 he graduated from the University Medical College in Kansas City. He was a veteran of the Spanish American War and served in the US Navy from 1903 to 1905 as a lieutenant. Sutton did additional training at George Washington University, the US Naval Medical School, and Johns Hopkins University. He traveled to study in London, Vienna, Paris, Berlin, and Hamburg, where he worked with Paul Gerson Unna.

Sutton headed the Department of Dermatology at the University of Kansas Medical School from 1912 until 1936, and he was chairman of the Section on Dermatology of the American Medical Association in 1913 and 1914. Moreover, he was a member of a great variety of dermatologic and geographic societies. He authored 64 articles on dermatology and syphilology, the text Disease of the Skin (1916), and also wrote with his son An Introduction to Dermatology and Syphilology and Synopsis of Diseases of the Skin. He married Lena Igel, and they had 2 children: Emma Louise and Richard L. Sutton Jr, who also became an important dermatologist. In addition to his dermatological career, he was a big-game hunter, deep-sea fisherman, and nature photographer. He published several books and articles about travel and sport, and he also tried to write poems. The last year of his life was tormented by health problems, and in 1952 Sutton died after a myocardial infarction.