Technology for Self-Management of Rosacea: A Survey and Field Trial

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Abstract

Rosacea is a chronic skin condition with multiple signs and symptoms, but typically associated with reddening of the face. Sufferers usually want to avoid and reduce flare-ups of the condition, and so will try to identify and limit possible triggers. In this paper we report an investigation into technology for managing rosacea, particularly for identifying and tracking triggers. Our study has included: a survey of the existing technology; a survey of the attitudes and opinions of people with rosacea on technology; and finally, the production and evaluation of a prototype for identifying triggers. This work is investigatory and so our formative evaluation and discussion focus on understanding the problem space and establishing directions for future development work.

Author Keywords

Personal tracking; Self management; Survey; Prototype.

ACM Classification Keywords

H.5.m [Information interfaces and presentation (e.g.,HCI)]: Miscellaneous

Introduction

Rosacea is a chronic inflammatory disease of the skin affecting the face. Rosacea is not fully understood [20] and there are some controversies over its causes and treatment. Medication and laser therapy are sometimes used

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to limit the negative effects of rosacea [20, 22, 24], but behavioural approaches are often said to be key to its management [9, 16, 18, 22]. Organisations such as the National Rosacea Society (www.rosacea.org) encourage sufferers to identify and reduce factors that may trigger or exacerbate flare ups of the condition.

Rosacea

Rosacea is an inflammatory facial skin disorder that comprises multiple clinical features–any of which may predominate in a particular person [3, 10, 20]. These may include flushing or more persistent erythema (reddening of the skin), inflammatory papules and pustules, and telangiectasia (sometimes called ”spider veins”). Rosacea can also include sensations of burning and stinging, dryness of the face, inflammation of the eyelids and, in rare cases, enlargement of the nose [16]. Rosacea is thought to be more common among women than men (particularly between ages 35 to 50) [16], and is mainly prevalent among people with fair skin in northwest Europe. Co-morbidities include migraine and depression [20].

Rosacea sufferers report feelings of embarrassment, emotional distress, anxiety, low self-esteem and stigmatisation [8, 14, 21].

In this paper we review the existing technology for self–management of rosacea and report a survey (n=117) of sufferers' opinions on such technology. We then report a field trial (n=29) of a prototype system for tracking rosacea and identifying possible triggers. We have conducted an expert evaluation of the prototype (n=9). From this work we draw out complexities and challenges for designing for rosacea. Our work was motivated by personal interest in rosacea and the idea that personal tracking data could be used to generate individual insights for people with the condition.

Background: Self Management of Rosacea

Rosacea sufferers are commonly advised to identify and avoid environmental, physical and psychological factors that trigger or exacerbate flare ups of the condition (see [3, 16, 23]). Online support sites and forums also often focus on so called ”triggers” or ”tripwires”. A survey reported by the National Rosacea Society [18] found that the most common triggers include sun exposure, emotional stress, hot weather, wind, spicy foods, intense exercise and alcohol. This list describes the general trends; it is not exhaustive and it is also not predictive of the factors that might play a role in each individual case: Drinking alcohol might cause flushing and redness for one individual but not necessarily for another. The challenge for the rosacea sufferer is to discover the factors that trigger or worsen their rosacea symptoms.

There is no research that we are aware of on technologies and practices of tracking and self-management of rosacea. However, there is a growing body of broadly relevant research in HCI. Bardram et al [2] report a field trial of an app for people with bipolar disorder for tracking potential triggers and giving warnings. A body of work also exists on tracking and predicting mood [1, 7] and promoting general wellbeing [12]. Kakar et al [11] have produced a generic framework for self-experimentation for self-diagnosis, applying this to areas such as Irritable Bowel Syndrome. There is also a growing body of relevant research on management of chronic conditions including HIV [5] and diabetes [15], although this work tends to focus on monitoring established metrics. Rooksby et al [17] have also noted that general personal informatics technologies can be used for ”diagnostic tracking”. As a condition affecting the face, 'selfie' style photographs are also sometimes collected by rosacea sufferers, but practices associated with these likely differ to those discussed in the HCI literature (e.g. [19]).

Existing Technologies

We have reviewed what technologies and services are available for rosacea sufferers. We found three active, web-based community forums and support groups on which rosacea sufferers can read articles on rosacea, follow the latest research news and new treatment methods developed, as well as discuss issues with fellow sufferers. The forums have similar features to those discussed by [13, 25] and likely play an important role in social support. We also found seven information sites, created by health providers, pharmaceutical companies, and support organisations.

We did not find online tools for trigger tracking, but we did find several diaries that people can download, print and fill out. Diaries can be taken to the doctor or used personally to track symptoms and triggers. The available diaries hold similarities, containing a list of most frequently cited trig-

Suggested feature	%
Record relevant daily events	84
Record rosacea intensity	84
Get suggestions of potential triggers	80
Trigger experiments	67
Take and store photos	67
Display history of triggers	65
Visual data display	63
Reminders to record triggers	57
Share data with other users	46
Aggregate data from other self-tracking apps	45

Table 1: Positive responses to a suggested feature for a rosacea app

ger factors and an option to add any unlisted ones under ’other’. Disadvantages of paper diaries are noted in [2].

In searches of the Apple App Store and Google Play we found nine apps specifically designed for rosacea sufferers. We examined these, and identified three general types of functionality:

- *Informational*: Seven of the nine apps gave information and advice about rosacea. Five of the apps were exclusively informational. These apps contain similar information to the websites but present it in a somewhat more interactive way.
- *Trigger diary*: Three of the apps enable users to track triggers. However, the assumption seems to be that the person already knows their existing triggers, or knows what caused their current rosacea flare-up. There is no support for trigger discovery.
- *Photographs*: Two of the apps also enable the collection of ’selfie’ photographs in order to track flare-ups or the effects of treatment.

An important note about these apps is that most of them appear unfinished and have bugs. Four of the apps were on version 1.0, meaning they have not been updated since release. The apps with trigger diaries had multiple problems on the devices we tested them on (Google Nexus 5, Android 6.0.1; iPhone 5, iOS 9.3.2). The most accomplished app was a selfie app produced by a pharmaceutical company for encouraging and supporting use of their skin product.

In summary, we find that support for rosacea sufferers is primarily informational. Apps for tracking triggers and keeping a diary are available, but paper diaries currently appear to be the most viable way to manage rosacea. The quality of apps is low, with several appearing to be built with good intentions but insufficient resources.

Survey of Rosacea Sufferers’ Opinions

For the second part of the study, we developed a survey to understand the opinions and preferences of rosacea sufferers regarding technology. We used Google Forms for the survey and distributed this via the relevant online forums identified in the first part of the study. A total of 122 people completed the survey, but one was excluded because they did not confirm they had a diagnosis of rosacea. 74% of participants were female and 26% were male, and the mean age was 50.4.

Use of rosacea apps among respondents was low: 17% of survey respondents had used a mobile or web application for rosacea before. However 64% of respondents said they would be interested in using a self-tracking application designed for rosacea, and 34% were unsure. Only 2% said they would not be interested. The responses may reflect the lack of available apps and average age of participants.

Survey participants were presented with a list of potential functionality for an app. The full list, and percentage of respondents who thought each item was desirable is summarised in table 1. We also asked respondents to define desirable functionality using free text. We categorised the free text responses and found the most popular to be ”tracking potential triggers” (45%), ”tracking rosacea symptoms” (38%), ”tracking food” (23%) and ”providing information on rosacea treatments and management” (18%).

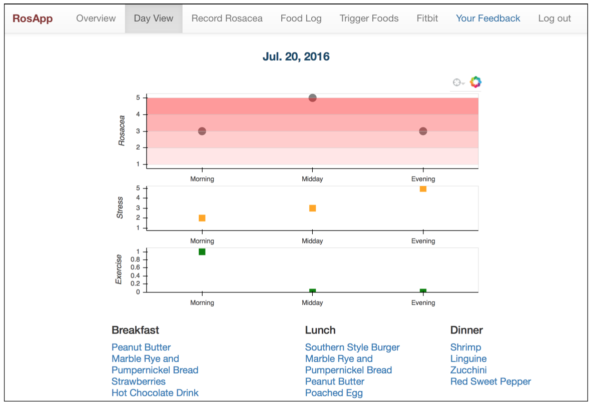
Given that rosacea is a complex condition we asked if sufferers would like a solution that integrates data from multiple external sources (e.g. FitBit data). 28% agreed but 60% were not sure – possibly reflecting that our proposition was difficult to envisage or understand.

The survey results demonstrate that there is interest in using applications for tracking and self-management of rosacea, but also that only a limited number of people have tried the available apps. The most desirable functionality relates to keeping track of day-to-day events and rosacea activity. Our survey did not consider that people may want information apps, but we note that 18% of respondents wrote this into the free text part of the survey. Our interest is in innovating with new technology, particularly with respect to identifying and tracking triggers. But we should not underestimate the importance of things like giving information and social support.

RosApp Prototype

For the third part of this study we designed, implemented and deployed a prototype web app *RosApp* for self-management of rosacea. Our aim with RosApp was to rapidly create and evaluate a simple prototype in order to further probe the design space, as opposed to creating a fully featured release. The design decisions we made were pragmatic, with a view to creating something from which we can learn design lessons (an approach discussed in [4, 6]).

We designed RosApp to enable users to track their rosacea and identify triggers relating to food, stress and exercise. The primary emphasis of RosApp is on food, with the other factors currently holding a secondary position. Rather than implement food tracking directly, we built upon an existing food diary. We chose the FitBit food dairy for this because it has a relatively open API (as opposed to apps such as MyFitnessPal). In this way, users of RosApp can use the FitBit food diary to log meals and snacks, and these are automatically imported into RosApp.



Breakfast

Peanut Butter
Marble Rye and Pumpernickel Bread
Strawberries
Hot Chocolate Drink

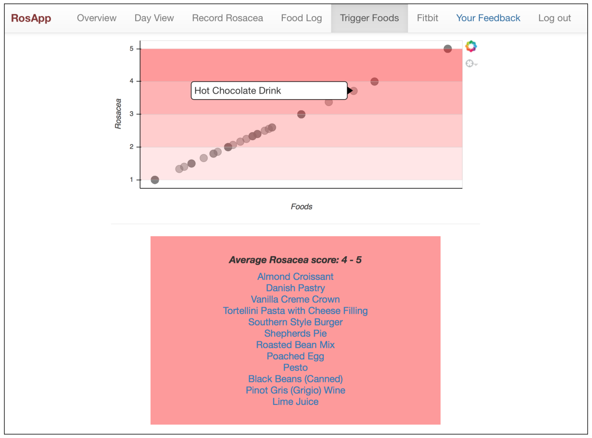
Lunch

Southern Style Burger
Marble Rye and Pumpernickel Bread
Peanut Butter
Poached Egg

Dinner

Shrimp
Linguine
Zucchini
Red Sweet Pepper

Figure 1: RosApp ”Day View”, showing visualisations of rosacea (top), stress (middle) and exercise (bottom) log data. Meals and snacks listed at bottom.



Average Rosacea score: 4 - 5

Almond Croissant
Danish Pastry
Vanilla Creme Crown
Tortellini Pasta with Cheese Filling
Southern Style Burger
Shepherds Pie
Roasted Bean Mix
Poached Egg
Pesto
Black Beans (Canned)
Pinot Gris (Grigio) Wine
Lime Juice

Figure 2: RosApp ”Trigger Foods View”, showing plot of the rosacea score for each food item and a list beneath.

Implementation

RosApp was implemented as a web app using HTML5, CSS, JQuery and Bootstrap on the client side. On the server side we used Python (including the Django framework, Pandas, Bokeh and Requests) and a PostgreSQL database.

As noted earlier, we use the FitBit food diary for logging meals. If users link their FitBit account in RosApp, logs made in the FitBit app or on their website also appear in RosApp.

Information about the study was presented in-app, and users were asked for consent to participate. All data was transferred securely over HTTPS and stored in a secure database. Secure authentication with FitBit was supported by OAuth2.

Functionality

RosApp is a web app accessible via web browsers on computers and mobile devices. Users can create an account and optionally link this to a FitBit account. Users must go to the FitBit app or website to record meals, and their data will be automatically imported and plotted in RosApp.

In RosApp, users can record their rosacea level on a 5-point scale. Users can also record their stress level on a similar 5-point scale, and log whether or not they have engaged in vigorous exercise. Rosacea, stress and exercise can be recorded for three periods each day (morning, daytime, evening). Design challenges with RosApp included enabling routine logging, and integrating heterogenous information. Our decision to use 5-point scales as opposed to more detailed recording, or using photographs, was to simplify the input process and keep it consistent with paper diaries. Our decision to enable logs for three periods each day reflects the structure used by FitBit for food logs, which associates meals and snacks with these periods.

In RosApp, users can view their data via interactive plots. The main *overview* page presents a scrollable summary of data recorded for each day. Users can drill down into a *day view* to see their data for the three periods of a single day. Food items consumed are listed on the day view, and these are clickable to bring up a *food view* that shows the days on which that particular food item was eaten.

To support identification of possible triggers, we created a view called *trigger foods.* This view presents a plot of the average rosacea score for each food item consumed. Below this plot, food items are listed in order of their average rosacea score. Foods associated with a high rosacea score appear towards the top of the list. This type of visual representation was chosen pragmatically as the simplest starting point supporting trigger identification.

The design we describe here was created in response to the key findings of the survey (table 1). The app enables users to record relevant daily events, record rosacea intensity, and supports identification of triggers. Food was specifically mentioned by several people in the survey and appeared to be a good initial focus. Building upon a third party application enabled us to avoid implementing our own food tracker, however we should also note that our decision to do this relates to the least popular item in table 1, and to a question about integration on which 64% said they were unsure. As such, we were not working with clear or certain requirements with RosApp but engaging in pragmatic and exploratory research by design.

Evaluation

We deployed RosApp on the web and invited an initial cohort of volunteers to try RosApp via the same channels by which we advertised our survey. We did not offer incentives and asked for no minimum engagement levels, simply for people to try the app. A total of 39 people registered with RosApp during the field trial and 29 consented to inclusion in the study. Ten of these participants authorised a FitBit account. Thirteen participants logged rosacea score at least one time, and seven created a food log at least once.

We interviewed one of the users of RosApp. The inteviewee was supportive, but had not fully understood the functionality of the app. He also felt his assessment was premature: *"I probably did not log enough to see the full benefit of it"*.

To gain further feedback we conducted an expert evaluation with nine people. We conducted this as two focus groups, the first with 4 postgraduate Computing Science students, and the second with a PhD student and 4 researchers from Computing and Health. We structured the focus groups around four issues that had emerged during the design process, and performed deductive analysis:

Data presentation: The visual presentation was generally praised, but could be further improved by incorporation of elements such as a calendar view. Support for identification of triggers was seen as useful but our implementation as basic. Presentation of triggers in this way should reflect the sample size for each food plotted, and stress and exercise information should also be incorporated to ease manual interpretation.

Data logging: We were told to pay more attention to the ”work” of logging. We should reduce and streamline this by either having all logging done natively, or via third party apps. Supporting user-preferred apps rather than those with the simplest APIs is also preferable. Adding customisable reminders is also good for encouraging engagement. One person argued that paper based logging still holds advantages over digital approaches.

Field trial: Our field trial was ecologically valid, but could have been better designed. We could have provided more guidance and support, and possibly a tutorial or video to explain the app. This would help with an initial hurdle of having to discover the functionality by trial and error. The value of the app does not become clear until data is built up in it. Simplifying logging may also have encouraged engagement –effectively we were asking people to use two apps. Finally, it is appropriate to offer incentives for field trials in return for engagement and feedback.

Releasing a rosacea app: The presentation and logging issues need to be addressed before launching an app such as this. We should also look to make Android and iOS specific versions rather than rely on a web app.

Discussion

We have presented an investigation into self-tracking and management of rosacea. This is a complex condition for which there can be triggers that are difficult to identify. In our work on surveying the technology and sufferers' opinions, and on creating and evaluating a prototype we have made some steps to clarify the problem area. In particular we have found:

- Most applications are informational. The value of these should not be ignored, but support for tracking and identifying triggers is currently lacking.
- Many of the existing technologies are incomplete or unsupported. When prototyping in this area we must be careful not to create yet another of these.
- In order to use data to identify triggers, that data must first be recorded or gathered. Usable logging is an important design challenge.
- The other important challenge is the presentation of data. Effectively, a usable, 'end-user analytics' is required.

Our work reveals and explores the problem space of designing for rosacea, a complex and relatively poorly understood chronic condition. Sufferers may benefit from digital support for identifying and tracking personal triggers, but in order to achieve this there are multiple remaining design challenges and issues to work through. We have identified some next steps in this paper for RosApp, but many of the issues raised in this work may not be unique to rosacea. Therefore, further work in HCI might reasonably look at more general themes and issues to do with trigger identification and tracking (across a range of conditions).

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