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Mobile Peer Support in Diabetes

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Abstract. As in other domains, there has been unprecedented growth in diabetes-related social media in the past decade. Although there is not yet enough evidence for the clinical benefits of patient-to-patient dialogue using emergent social media, patient empowerment through easier access to information has been proven to foster healthy lifestyles, and to delay or even prevent progression of secondary illnesses. In the design of diabetes-related social media, we need access to personal health data for modelling the core disease-related characteristics of the user. We discuss design aspects of mobile peer support, including acquisition of personal health data, and design artefacts for a healthcare recommender system. We also explore mentoring models as a tool for managing the transient relationships among peers with diabetes. Intermediate results suggest acquiring health data for modelling patients' health status is feasible for implementing a personalized and mobile peer-support system.

Keywords. Social media, personalization, mHealth, diabetes self-management

1. Introduction

To improve self-management for a large population with lifestyle-related diseases such as diabetes, it is ideal that users can always access health information [1] in a ubiquitous manner, quickly and easily. Mobile phones are now highly pervasive and becoming more powerful with various new technologies, increasing their potential as universal devices for chronic disease self-management. However, the information and support services must be personalized and tailored to avoid cognitive overload, and to enhance user experience.

Several techniques have been developed for filtering and personalizing Internet information. It has been shown repeatedly that user models can be used in recommender systems [9] to personalize web information, as in popular shopping websites. We are increasingly getting used to seeing recommender systems in use, for example, in e-business applications such as online shops (e.g. Amazon) and entertainment systems (e.g. Pandora Internet Radio). There are many trade-offs that need to be made, for instance regarding performance versus precision, and recommendations versus predictions (which are more demanding). Knowing that even straightforward matching of genre and topic sometimes yields unexpected recommendations, we must be particularly aware of trust and privacy issues in the context of health-related systems. One criticism of much of the literature is that too

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little attention has been paid to the practicalities of user profile management regarding privacy concerns in healthcare, especially given integration with social media [10]. Recent research confirms results from earlier studies indicating that users' disclosure of personal data depended on how sensitive they perceived the data to be, and how much they trusted or stood to benefit from disclosure and use of the system [6].

This paper discusses the design of mobile peer support in a self-help system for people with diabetes. Two main issues are addressed. The first issue relates to improvement of the user profile management model from the European Telecommunications Standards Institute (ETSI) (technical specification, TS 102 747), through consideration of the health status use case. This concerted effort to model core disease-oriented properties of the user represents a paradigm shift. This new paradigm emphasizes relevance of recommendations to the health status of the patient and not necessarily recommendations that reflect the user's conscious interests.

Secondly, the ideas for fostering social engagement with family and friends put forward by Morris et al. [11] are here extended to establishing temporary, conditional friendships with strangers. New ideas about methods for exploring ad hoc social networks involving short-term relationships with peers are investigated. Mentoring models [5] are explored as potentially useful tools for motivating and sustaining participation for both the patient with a specific health challenge (protégé) and her/his mentor. The "Few Touch Application" (FTA) [3], originally developed as a self-help system for Type 2 diabetes, forms the background for the presented work.

2. Methods

The presented system is designed to create a dynamic user model that can reason about a lifelong patient, and is used in personalizing health information and interaction with peers, inspired by the "Patients-Like-Me" [12] concept.

The research methods for designing the FTA platform have been multidisciplinary, with an engineering approach in the design of the mobile application, user profile and recommender frameworks. Focus group meetings were used for facilitating participatory design methods; brainstorming, paper prototyping, interviews, questionnaires, and usability testing. A scheduled clinical trial will provide evidence of the impact that peer interactions in social networking websites have on clinical outcomes.

The FTA platform was designed to collect the following personal information:

- personal aims for food habits and physical activity [3]
- blood glucose values using a wireless glucometer system [14]
- dietary habits information [4]
- physical activity using both a step counter [2] and manual registration
- weight monitoring using a wireless weight scale (planned FTA add-on)

This information forms part of the critical health indicators for both Type 1 and Type 2 diabetes, and comprises more or less mandatory parameters that users are monitoring on a daily basis. The health data are modelled and encapsulated in the user profile, which is applied to Internet social media content using a recommender system.

3. Results

3.1. User Profile Management and Peer Support

The first task involved in managing a user profile is often creating the profile, followed by making updates. User profiles have traditionally contained information about the user (alias, age, gender, language, etc.), preferences (layout, navigation, etc.), usage behaviour (clicked links, user-created tags, content rating, etc.), and recently social data (information about friends, their usage behaviour, folksonomy, etc.) and context of use (at work/home, driving/shopping, weather, in a meeting, etc.), and presence (available for chat, away, do not disturb, etc.) information. This study adds validated diabetes health data (blood glucose, HbA1c, weight, etc.). The data is a fragment of the health status, the new dimension in managing user profiles for healthcare use. These diabetes-related data are pivotal in construction of recommendations regarding relevant peers and communities.

3.2. The Mobility Aspect and Recommender Systems

A salient aspect to consider when designing mobile applications is the rapid changes in the context of use. Traditional recommender systems do not consider the complex contexts of the user environment. Context modelling techniques are still immature and their use in recommender systems is still relatively undeveloped. In this work, we consider a few high-level contexts, mentioned in the preceding section.

3.3. Healthcare Recommender System

Figure 1 illustrates the design of the healthcare recommender system, where the recommender engine is based on a hybrid algorithm, comprising both collaborative filtering and content-based approaches. In the figure, the context of use is related to the user model and fed to the recommender engine, where this knowledge about the user is mapped onto Internet social media content and user profiles. The output is personalized information, presented as recommendations of vital content and predictions about potentially interesting peers or communities.

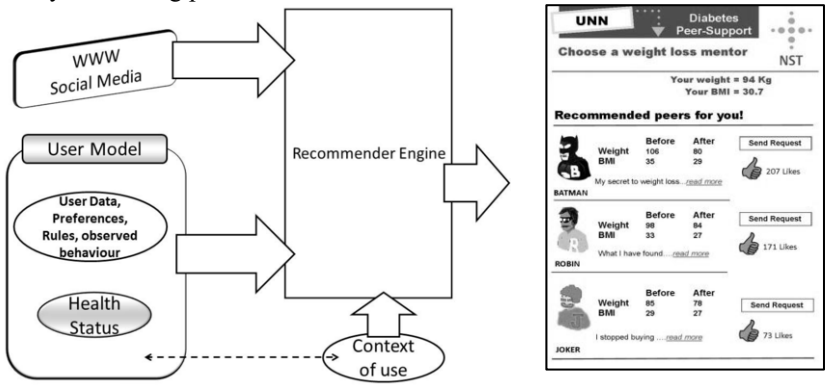

Figure 1. Recommender framework for the mobile peer-support system.

The presentation of recommendations regarding potentially relevant content is based on aggregated ratings by the community. To increase the usefulness of recommended content, users are requested to rate and tag content, and these new ratings are fed back to the recommender system using learning algorithms. The discreet and easy rating mechanism suitable for small screens uses the Facebook style of "Like".

Quality assuring user-generated content and processing it into actionable knowledge is vital. Generally, current health-related social media is not proactive about quality assuring user contributions. One drawback of much of the media, albeit in the spirit of patient safety, is the reliance on manual moderation of user-generated content, with only a few options for automation tools. As user-generated content increases, manual moderation will become increasingly impractical, but natural language processing research is a promising alternative.

4. Discussion

Defining a sufficiently comprehensive representation of a patient is not an easy task because many variables affect the person's total health status. Innovative representations must be extensible and be able to abstract all the relevant health aspects. Intermediate results confirm feasibility of acquiring and modelling diabetes-related health data – as input to a mobile peer-support system. One important outcome emerging from this work is that automatically acquiring health data significantly reduces threats to data validity. Automatic data acquisition using sensors overcomes two challenges faced in healthcare social media. The first challenge is that of data validity, where users register symptoms, medications or outcomes manually [7; 12]. Some healthcare social networks allow users to manually register and see each other's health data, but the value of such data is degraded by legitimate questions regarding its validity. The other challenge that is potentially addressed by automatic data acquisition is that of motivating users to manually provide their health data frequently over substantial periods of time.

Using recommender systems is one of the more practical ways of implementing intelligent web applications. In this work, decoupling the health status and context of use from the user model has scaling advantages. The respective modelling complexities are transparent to the management of the core profile. These design artefacts for applying diabetes data to recommender systems can be generalized to chronic health information systems, making the artefacts appealing and relevant to a wider audience. Recent researchers have gone as far as proposing full integration of recommender systems with Personal Health Records (PHR) [8; 13]. This approach is promising, but is still largely immature, and suffers from inherent information redundancy and severe security risks.

The concepts explored in this work for managing pseudonymised, transient and conditional relationships are, however, rather challenging. Mentoring models [5] are promising as implements for managing such relationships. Mentoring relationships are informal and allow a user to mentor or be mentored by another user who has demonstrated consistent control over a particular health aspect such as weight management. Mentoring relationships may be suitable for maintaining high morale in the community and for sustaining the motivation to succeed in a specific health issue. Further work is needed for elaborating social [11] and psychology theories to design algorithms for managing relationship dynamics and motivation.

5. Conclusion

Coping with the substantial demands for lifestyle changes among diabetes patients requires the right information and sound motivational tools. Given that patients possess appropriate tools for cooperation, sharing everyday experiences with similar-profiled patients may be more effective for enhancing self-management and increasing self-efficacy than relying on generic information found in books and the Internet. Although this paper was not designed specifically to evaluate factors related to relevance or usefulness of peer recommendations, the new diabetes-related dimensions that are addressed add to a growing body of literature on social media and its application aspects in the healthcare domain. The authors foresee great opportunities using mobile phones as means for peer support in enhancing the quality of life of people with diabetes and other chronic diseases.

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