Case Workflow and Interaction Studies of A Tele-Consultation System for Rare Dermatology Diseases

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***Abstract*—We established an expert advisory system utilizing store and forward teledermatology to allow communication and consultation between physicians with expertise in the rare inherited skin disease Ichthyosis and physicians caring for afflicted patients. We analyzed experts' behavior and involvement in case consultation by calculating key variables, accessing comment structures and quality, and applying concepts from the field of social networking. Preliminary findings suggest that a user-oriented tele-consultation system for dermatology benefits from active participation, detailed case description, sufficient images and good leadership of case moderators.**

Keywords-teledermatology; store-and-forward telemedicine; social networking; user behavior understanding

I. INTRODUCTION

Telemedicine, as defined by American Telemedicine Association [1], "is the use of medical information exchanged from one site to another via electronic communications to improve patients' health status". It can be utilized as a bridge between primary care doctors and experts with specific medical knowledge and experience, allowing evaluation and treatment of difficult medical cases through telecommunication technology. In dermatology, telemedicine has already played a crucial component in delivering efficient service of diagnosis and management of dermatologic diseases for patients and also providing advisories for physicians in primary care settings [2]. Store-and-forward telemedicine (SAFT) [3] is a commonly employed modality in which medical cases are submitted by primary care providers into a central system and subsequently attended by geographically-distant consulting experts when they are most available to provide suggestions for treatment of the patient. During the telemedicine process, communication happens over the web or via email asynchronously. SAFT is perceived by healthcare providers as an economical operation compared to conventional face-to-face care [4]. To make such a SAFT system widely used by the medical community, continuous efforts are expected to be made to ensure security, robustness, user-friendliness, and affordability [5]. Over the past years, there are SAFT systems developed to create platforms for tele-consultation and educational knowledge exchange in the area of dermatology. A prominent system called TeleDerm [6] demonstrates a certain degree of success. Most of the existing applications have a general purpose of serving the community with all sorts of images from patient with diseases in dermatology. On the other hand, the need of having a platform for tele-consultations with focused disease cases has not been addressed as much.

We have developed a non-commercial SAFT expert advisory system for physicians caring for Ichthyosis patients, a rare inherited skin disease (Fig. 1). Ichthyosis [7] is a group of inherited skin diseases characterized by dry, thickened, scaling of the skin. Patients with this disease often experience difficulty obtaining proper diagnoses and management as many physicians have little knowledge or experience with this rare skin disease. The Foundation for Ichthyosis & Related Skin Types (FIRST) is a patient support organization for patients with different forms of Ichthyosis. FIRST considers store-and-forward teledermatology as a viable option for connecting primary care providers caring for Ichthyosis patients with experts who have the most experience caring for such patients.

The general purpose of this system is to provide a secure and easy tele-consultation environment for experts to discuss dermatological cases submitted worldwide. In this study, we perform an analysis of experts' activities across two years of teledermatology cases to discover behavioral patterns which could be used to provide feedback to users for future involvement and improve the development of new features and workflows for the existing system. The interaction between experts and cases is modeled using the theory of social networking [8], which can systematically identify central users as well as those who remain isolated by constructing a graph. In such a network graph, composed of nodes and edges, a node represents a participating expert, while an edge represents an instance of communication between two experts. Consequently, we can observe the density of a node by counting the connections. This gives us a sense of the level of interaction for participating experts.

II. SYSTEM DESIGN

Our web-based expert advisory board is hosted on a Linux/Apache server. The system front-end uses a proprietary PHP framework to handle case and user management and present case content from a relational MySQL database which stores the data and their relationships. Security measures include SSL encryption for all data hosted and received by the server and standard md5-based encryption and authentication mechanisms to protect the privacy and integrity of patient data and imagery. The system conforms to HIPAA regulations to assure safety and quality of consultation, and to protect experts' identity as well as patients' personal information. By design, all

discussion about cases is performed online during forum commenting to avoid leaking patient information and medical details. Personal and medical information with additional photos are stored behind a firewall in a secure facility and accessed through encrypted protocols. In the following subsections we introduce several system design aspects:

Figure 1. Screenshots fo a case discussion.

A. Expert Domain and Users

This SAFT system is dedicated to delivering a formatted case consultation related to Ichthyosis and similar skin diseases. Dermatologists are invited to either participate in case discussions in which they have expertise, or to submit cases requiring recommendations from additional specialists. There are two main groups of users using this SAFT system: (1) dermatologists specialized in Ichthyosis, primarily invited from the FIRST, and (2) dermatologists or other expert doctors seeing patients with skin diseases from their clinical settings. Any user can submit interesting and/or difficult cases to the website for consultation so expert users may also submit cases from their own practices to benefit from online discussion from additional experts.

B. Administration and Communication

Because SAFT is a non-commercial website system available to the general public, potential users must be reviewed by a system administrator to gain access to restricted sections. During the user registration process, applicants provide information and credentials in order to get approval by system administrators. Users can also request to become experts if they specialized in Ichthyosis. Case leaders must be an expert in order to moderate the discussion process with professional knowledge. All notifications are sent out to participants through emails so that everyone is kept updated at each step throughout the process of registration, case assignment, case leadership, case consultation and case feedback.

C. System Architecture

In our system, the teledermatology is divided into several distinct modules. From the system architecture shown in Fig. 2, the primary modules for case consultation include submission, discussion, final report, voting, and feedback.

1) Case Submission: During submission, the case author is required to provide crucial information related to the patient's condition, including medical history, past treatment, symptoms and medications, etc. Clinical images may be uploaded allowing participating experts to view pertinent findings. After creating the medical case, the author submits the case for approval by one of the system administrators, who are the moderators responsible for the daily functioning of the SAFT system. If the administrator considers the case description insufficient, the author will be asked to provide additional information or make modifications.

2) Case Discussion: Once the case is suitable for discussion, it is assigned to an expert who will select several other experts for case discussion. Each expert submits comments to the forum until a satisfactory decision can be reached. If it is determined that more information is required, the leader will correspond with the author to provide additional details. Because all correspondence with the author goes through the case leader, we protect the identities of contributing experts so that they will feel more comfortable providing feedback in the forum setting.

3) Case Report: After determining that the discussion is complete, the case leader will compose a final report to summarize the main points including disease concept explanation, diagnosis (if reached), and treatment suggestions to be sent to the case author.

4) Case Voting: Before sending out the case report, all of the participating experts will be asked to approve the summary through a voting system. The confidential voting results will be sent out along with the final report to the author.

5) Case Feedback: As the last stage of the teledermatology process, the case leader will close the case, compile the final report and voting results, and provide the feedback to the case author. The final report will be sent to the case author without leaking identitites of participating experts and the closed case casen be shared within the system to fulfill the education purpose.

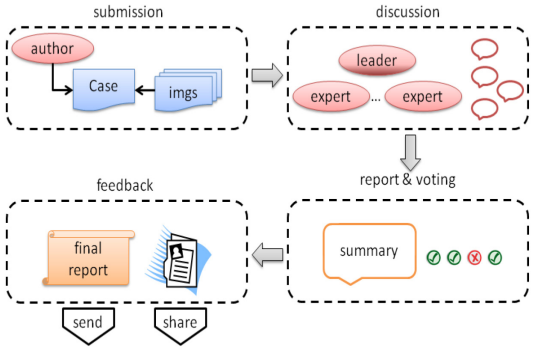

Figure 2. System Architecture

III. METHOD

In this study, we review two years' cases discussed in the SAFT system to understand experts' involvement in each case using concepts from social networking and user behavioral patterns. Each case consultation involves a case author, a case leader and several participating experts. The number of participants, comments, additional pictures and case request types vary among cases existing in the system collection. The request type for a submitted case can be *asking for differential*

diagnosis, treatment and management, or a general purpose of discussion for an interesting case. We use those basic variables as observational evidence to extract common patterns across the whole collection of cases.

It is not uncommon to see that in any forum-style discussion some comments are a direct response to a previous comment. The interactions between participants in commenting are grouped into two levels – comments with direct-responded targets are level 2 while those that simply introduce new inputs are level 1. A measurement of these leveled comments is defined as comment linearity, L – the ratio of level 1 comments and total comments, $L \in (0, 1]$. A case with only level 1 comments ($L = 1$) is considered as a linear discussion case while the one with level 2 comments will have smaller L value indicating a less linear discussion.

$$L = \frac{\#level1\,(linear)\,comments}{\#all\ comments} \quad (1)$$

There are 12 closed cases and two open cases currently in our system (as of March 30th, 2011). Only closed cases were used for this study. Each case was reviewed to first calculate case variables, as listed in Table I, and then each comment was manually classified into two levels. We report our observations from the interactions among participants of the system.

TABLE I. CASE VARIABLES

Case #	# expert	# comment	# images	request type	
				diagnosis	*treatment*
Case 19	5	9	10	×	√
Case 20	3	6	4	√	√
Case 26	5	9	25	√	√
Case 27	3	4	3	√	×
Case 30	4	4	0	×	√
Case 31	4	8	2	×	√
Case 34	3	4	0	×	√
Case 39	1	1	0	√	×
Case 42	1	1	0	×	√
Case 44	5	5	0	√	×
Case 45	1	1	5	√	√
Case 47	1	1	0	√	√
average	3.0	4.4	4.1	0.58	0.75

IV. RESULTS

There are 12 closed cases and two open cases currently in our system (as of March 30th, 2011). Only closed cases were used for this study. Each case was reviewed to first calculate case variables, as listed in Table I, and then each comment was manually classified into two levels. We report our observations from the interactions among participants of the system.

Comment linearity, L, of each case was first calculated and the average is 0.91 which indicates that the comments for case consultation in this teledermatology system are generally having a linear form. Participants either add new information or opinions in the discussion or comment on the input of other participants. For example, case 20 shown in Fig. 3, which was submitted with four images asking for differential diagnosis and treatment, has two level 2 comments replying to two comments posted by other experts, which gives a value of L = 0.67; while case 34 shown in Fig. 4 with no image asking for suggestions on treatment has a discussion consisting of only level 1 comments, resulting in a value of $L = 1$.

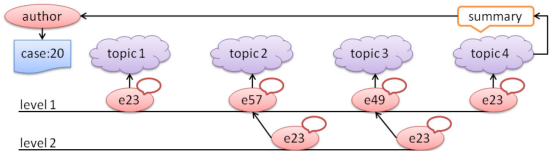

Figure 3. Dicussion flow of case 20 (L = 4/6 = 0.67).

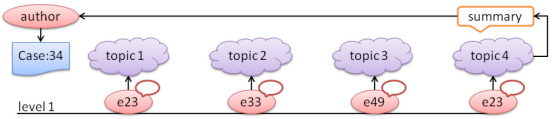

Figure 4. Discussion flow of case 34 (L = 4/4 = 1).

There are six cases which do not have images provided with the case, three of them (50%) were initially requesting for treatment and management. In this scenario, patients were diagnosed but the primary care doctor was uncertain or had difficulty discerning appropriate care solutions. Therefore images are not required for the discussion. However, out of three other diagnosis requests, the first case was updated with images through communication outside the system, which limits the level of discussion and poses a potential security risk; the second case has the situation that the patient refused to take pictures due to stress and physical condition; and in the third case, the primary care doctor failed to provide photos upon the case leader's request.

Weak conclusions fell into three categories: 1) case request type is not specifically for diagnosis or treatment but for evoking a discussion on any interesting or unusual thoughts; 2) teaching purposes; for example, one expert who is specialized in a disease or has more experience with a patient's population would contribute to the discussion as others learn from the knowledge; and 3) cases are not complete enough for diagnosis or treatment recommendations and/or need further tests, i.e. biopsies, pathological testing, blood works. In our case collection, there are three cases without a clear conclusion: one fits in Categories 1 and 2; one falls into Category 3 and is ongoing patient care waiting for more tests and consultation; and in the third case the primary doctor failed to provide responses to the leader's request for more information.

Using Prefuse, a Java open-source data visualization package, we plotted the social network between experts and cases. Expert nodes are connected via various numbers of connections to cases. Expert 23, the central node in Fig. 5, for example, has the largest number of collaborations, and acts as the hub of the social network. Some other experts are associated with expert 23 through case collaborations. A hub node has an important role in a social network, as it frequently serves as an intermediary between unconnected nodes. We observed that expert nodes 43 and 44 and case nodes 39, 45, and 47 have single edges indicating singular involvement of an expert. Such aspects provide a valuable insight into potential reasons why either experts or cases are isolated. A successful leader requires good understanding of his/her obligation, familiarity of key functions of the system, and proactive leadership qualities for moderating the consultation process.

The final feedback is composed by the case leader collecting key points from all the comments and is sent to the case author. Case authors benefit most from responses which contain insights based on the collective experience of the experts and rich medical analysis and explanation. Sometimes the inquiry problems are not fully addressed in the final responses because of lack of consensus form all participants. Those responses are considered as weak responses. There 42% of cases concluded with weak final. However, the most active leader participated in seven cases with only two weak responses.

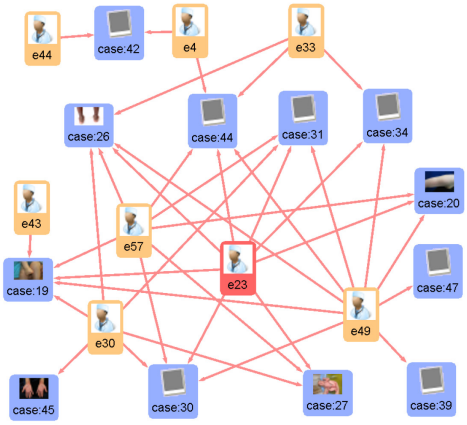

Figure 5. Networks of cases

We listed four measurements across cases with and without images (Table II). Based on this small sample set and intuition, we would empirically argue that cases in which the author provide photos tend to have more in-depth (6.2 comments per case) and richer (less linear comment structure, 0.82 compared to 1.0) discussion, attract more attentions from experts (3.5 compared to 2.5), and eventually have better chance getting a clear conclusion (67% compared to 50%). Despite the small sample size, comment linearity was 1.0 for cases without images, which may indicate that experts do not feel comfortable disputing suggestions without ample evidence. This may inhibit the discussions which are critical for effective treatment and diagnosis. There are several further discoveries based on our observation: (1) cases submitted with detailed patient history, past treatment with reactions, pictures, biopsies and pathological tests tend to stimulate more active discussion; (2) in case discussion, we have observed a pattern that multiple comments occur in a single day followed by a periods of low activity; (3) images are critical to the discussion, especially for cases which require a diagnosis, but also in cases requiring treatment, because experts may find important phenotypes, unknown to the case author, which indicate particular treatments; and (4) in many cases, participants, who give valuable opinions that most peers agreed on and were eventually accepted as the base of feedback report, will be considered as the major contributor of the case.

V. DISCUSSION

In this study we proposed a workflow analysis of a store-and-forward tele-medicine expert advisory system for dermatologists caring for patients with Ichthyosis and other related skin diseases. The system architecture brings a convenient and secure platform for dermatologists to perform tele-consultation as well as education and knowledge-sharing. This system could also be easily adapted to other appropriate clinical domains. Social networking tools were utilized to identify most active users and interactions during the consultation process.

Based on our analysis of cases in our teledermatology system, we have arrived at the following suggestions for the design of telemedicine systems and potential improvements of our existing system: (1) certain types of cases would benefit from a customized workflow, such as simplified process for cases which can be answered by a single expert; (2) users can be identified and targeted for notifications or particular cases through social networking tools; (3) users can be asked to categorize their own cases for more specialized workflows for more suitable discussion group selection to lead to a better and faster discussion; (4) users should have a mechanism to provide a follow-up and feedback about the usefulness of expert's suggestions and system usability; (5) experts should be strongly encouraged to communicate within the system; and (6) social network graphs can identify critical experts and ensure robust and healthy communication in the event of an experts' absence.

TABLE II. COMPARISON BETWEEN CASES WITH OR WITHOUT IMAGES

Measurements	Cases with images (#=6)	Cases without images (#=6)
Average # comment	37/6=6.2 (per case)	16/6=2.7 (per case)
Average # expert	21/6=3.5 (per case)	15/6=2.5 (per case)
Clear conclusion	4 (67%)	3 (50%)
Comment linearity	0.82 (per case)	1.0 (per case)

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REFERENCES

[1] American Telemedicine Association (http://www.americantelemed.org).

[2] E. Warshaw, et al. "Teledermatology for diagnosis and management of skin conditions: a systematic review of the evidence" Evidence-based Synthesis Program. Washington (DC): Dept. VA. January 2010.

[3] M. S. Houston, et al. "Clinical consultations using store-and-forward telemedicine technology". Mayo Clin. Proc, vol. 74, pp. 764-769, August 1999.

[4] A. W. Armstrong, D. J. Dorer, N. E. Lugn, and J. C. Kvedar, "Economic evaluation of interactive teledermatology compared with conventional care". Journal of Telemedicine and e-Health, vol. 13, no. 2, May 2007.

[5] A. W. Armstrong, et al. "Evaluation and comparison of store-and-forward teledermatology applications". Journal of Telemedicine and e-Health, vol. 16, no. 4, pp. 424-438, May 2010.

[6] C. Massone et al. "Two years' experience with web-based teleconsulting in dermatology". Jounal of Telemedicine and Telecare, vol. 12, pp. 83-87, 2006.

[7] A. Du Vivier. Atlas of clinical dermatology. Philadelphia London, NY: Saunders; Gower Medical Pub, 1986.

[8] M.E.J. Newman, "The Structure and Function of Complex Networks," SIAM Rev., vol.19, no.1-42, pp 1-42, 2003.