

Facebook Extension: Creating a Supportive Online Community for the Rare Disease Population (OUTLINE)*

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ABSTRACT

The rare diseases population is often faced with many challenges, the biggest one being finding a sufficient amount of support in their lives. Finding a method in which the population's insights can be used to effectively develop a system that can ease these challenges is particularly difficult. This paper presents a scenario-based method for evaluating what features would be most beneficial in creating a place where those with rare diseases can provide one another with social, emotional, and informational support. This method uses participants' responses to the scenarios as the focus of analysis. Our results *fill in later*. We propose that the addition of a social-matching algorithm would be beneficial for this application.

CCS Concepts

•Computer systems organization → Embedded systems; Redundancy; Robotics; •Networks → Network reliability;

Keywords

ACM proceedings; L^AT_EX; text tagging

1. INTRODUCTION

Although considered to be "rare," at least 10 percent of the world's population has a rare disease. There are many studies that deal with common diseases which help create

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awareness to provide information and support. Whereas the rare disease population does not receive the same amount of attention that is necessary to create effective awareness. Due to this, there is a lack of information and resources provided by health professionals, along with a lack of understanding, people with rare diseases do not receive adequate support due to the lack of information and resources.

Numerous research has been done in efforts to provide support in online health communities and It is difficult but essential that we expand this research to the rare disease population without manufacturing feelings of seclusion or invaded privacy. It may be hard to avoid manufacturing unwanted feelings in an individual with a rare disease since these feelings may be uncomfortable or make them feel as if their privacy is being exploited. That is why we will make efforts to prevent this from happening with implemented security measures. The already enforced Facebook terms and conditions will apply to our application along with further granted permissions from Facebook, therefore this will assist with mending these unwanted feelings. [Provided by Facebook justifications]

While researchers have investigated the lack of support among those with rare diseases, few have offered a technological solution that enables users to obtain support from one another through online support communities.

In this paper, we will discuss how we found information through a preliminary scenario based survey given to voluntary rare disease persons which allowed us to implement necessary features in a web based application developed through Facebook for Developers *à*Đć. By creating an application which uses a matching algorithm based on user profile information, we may create a supportive online community for the rare disease population. The application will implement a matching algorithm based on desired features as well as user's profile similarities such as those used on dating websites. This web based community may serve as a source for finding information and resources from like individuals. Through the matching algorithm implemented into our application, the rare disease population may use our application to also seek social support. This will pro-

vide the research community with the knowledge of what features and aspects are found to be the most effective in an online health community application specifically for the rare disease population.

2. RELATED WORK

As the use of the Internet soars, many groups have gone from meeting in physical support groups to joining online communities that foster a safe area for users to ask questions, relay their experiences, and communicate with others about their health problems. These online health communities are especially pertinent to the rare disease population, as many do not receive necessary information from their doctors and necessary support from their family and friends. Many turn to online health communities to access more information about their diseases and to form friendships with those who understand what they are going through. Here we investigate if online health communities offer an advantage when it comes to the amount of accurate information and adequate support received. Also, we explore what kind of support is most beneficial to those with rare diseases through scenario based evaluation, and how we can design an application that implements an algorithm to find potential matches among the rare disease population.

2.1 Online Health Communities

The development of online health communities using social media sites such as Facebook [6] and PatientsLikeMe [21] have combined a mixture of social media and health management to encourage the sharing of information and support between patients [1]. For instance, PatientsLikeMe, a site that is now the world's largest online health data sharing platform, uses tools similar to Facebook such as user profiles, comments, and private messages to facilitate information sharing between patients. Also, it's openness of personal health record systems allows users to track their own progress when it comes to their condition - using tools that can actually follow relevant and disease-specific information such as symptoms, treatments, and medical data. In a similar study done by Greene et al. [7], they evaluated the content of health-seeking behaviors and information-sharing on Facebook amongst a group of patients with diabetes. Greene et al. findings indicated that the use of a Facebook group engaged participants in multiple public health benefits. The use of social networking tools like wall posts and discussion threads lets users gain both interpersonal and community support. Participants with diabetes in Greene et al.'s study stated that the Facebook community led them to the ability to access specific disease-related information that ultimately enabled them to make better decisions when it came to managing their disease. With the development of a Facebook Extension Application, we hope to extend this type of information and support sharing into the rare disease community.

2.1.1 Rare Disease Community

A disease is considered to be rare when it affects less than 200,000 people [12]. Because there is not a huge population of people that suffer from a specific rare disease, the information they are often given is scarce or completely obsolete [11]. However, although many may not be affected by the same rare disease, the number of people who have rare diseases amount to 10% of the world's total population

[20]. Since those in the rare disease population suffer from diverse diseases and various symptoms, the biggest issue this population has is delay of diagnosis. A study by Knight and Senior [9] revealed from a European survey of around 6000 rare disease patients that 25% of respondents waited 5 to 30 years for a proper diagnosis. Because of either no diagnosis or an improper one, around 16% of them were given inappropriate surgeries, medications, and even psychological care. The same survey taken from a European rare disease population revealed that although dealing with different diseases, all participants faced similar issues, including: lack of access to the correct diagnosis, lack of information, lack of scientific knowledge, social consequences, lack of appropriate quality health care, high cost of the few existing drugs and care, and inequities in treatment in care [9].

2.1.2 Web-Based Support

As those with rare diseases face a multitude of challenges, it has become essential for this population to find a way to overcome them. Doyle [4] studied a population that had the rare disease cystinosis to explore their experience and interaction with others as their disease progressed in order to introduce a better concept of peer support into their lives. In this study, Doyle emphasizes the concept of peer support and mentorship, as both individuals diagnosed with a disease along with their families can benefit from sharing their experiences with the illness. Disease-specific advocacy groups and interaction and participation in the online disease community can ultimately help provide rare disease patients with connections and information they may not be able to encounter in the offline world.

A study by Cutrona et. al [3] examined different kinds of support between marriage partners in order to determine which type seemed to be most beneficial when dealing with different types of stressful events. Because of the stressful situations those affected by rare diseases are often put in due to lack of information regarding their health, it seems that social support would be highly beneficial after being in such stressful situations. Cutrona et. al converged on five different types of support, which included: informational, tangible, esteem, emotional, and social network support [3]. Their findings indicated that different kinds of social support are most useful in the context of different kinds of stressful life events. Therefore, depending on the current situation a person with a rare disease is dealing with, different types of support may be needed. For example, a patient with lack of information about their disease needs informational support, versus a patient who's friends do not care to understand their lifestyle with the disease may turn to online communities in order to gain a network of social support. A study by Liang et. al [10] investigated the need for this social support amongst elderly people and the affect it had on their well-being. Their results showed that social exchanges have both positive and negative consequences on well being - for instance, receiving needed support is effective for reducing psychological distress, but too much assistance provided to an individual could actually increase the amount of distress. Liang et. al describes three implications that could be useful for the rare disease population in order to reduce overall stress and produce the most beneficial amount of support. First, encouraging those with rare diseases to adopt helping roles to one another by providing support to those dealing with similar issues could decrease psychological distress and

boost their esteem. Second, when helping another individual with a rare disease, not too much help should be provided so that the person feels that they are a burden - as that could increase the amount of stress for the individual. Also, the individual being helped should reciprocate in giving some form of support the other individual needs in order to facilitate a stronger support connection. Finally, those with rare diseases should reinforce the sense of available support and minimize negative interactions, as these two components appear to influence well-being the most. By using an application that groups those with similarities together, those in similar situations that need different types of support due to stress will hopefully obtain the specific support they need.

2.2 Social Matching in Online Communities

Social matching systems refer people to people. Julia M. Mayer et al. proposed the idea of making these matching systems context aware [14, 15, 19]. The authors conducted a series of interviews where they found that by going beyond simple similarity matching techniques, [19, 14] they were able to present a framework of relational, social and personal context as a predictor for matching opportunities. Unlike traditional matching [5], their mechanisms proposed a more effective solution to connecting individuals. They explored these three types of context by collecting data from numerous iterations of semi-structured interviews which revealed that by making social matching systems more aware of the user's context and proximity, more valuable new connections can be made [19]. We plan on using the results pertaining to matching like individuals, to build an algorithm which can match individuals with rare diseases more adequately. We will use their findings to enhance how we will construct our online health community for the rare disease population.

Matching individuals based on similar interest has always been a shared approach among many dating websites and services. In addition to traditional matching [5, 14], Hyunggu Jung et al. [8] found that taking into consideration the times in which an individual is most active on services such as dating websites, Facebook and Lyft can contribute to a stronger match. Hyunggu Jung et al. determined that by creating MAST, a Matching Algorithm for Service Transactions, they were able to match individuals more accurately. They created this algorithm by implementing timebanking into a web-based community, which evaluated the quality of MAST matches with time bankers as participants. Timebanking [17] is a term used to describe a type of peer to peer service trade which allows individuals to carry out random acts of kindness, especially to an unknown person. They collected data from the users profiles which was then used to match profiles with profiles of others who could provide each other services. By doing this, the authors found that a network that assures benefits can contribute to creating a stronger, more supportive community. These authors also found that some participants mentioned that not being able to meet diverse types of people due to filtering for similarities felt like a loss. However, since this study was for time banking specifically, this would be more of a concern to us if we were replicating the same type of work. Instead, we believe that since our efforts are to collect data from profiles to match them with other similar profiles who can provide support for each other, that this filtering will not be a big issue. Another solution our study proposed is the fact that they will

be matched to other participants with a rare disease not specifically matching participants with the same rare disease. We will also collect data of the time stamp in order to match users based on the times they are most active. This will help create diversity in our online health community for the rare disease population.

2.2.1 Using Similarities in Data

McPherson et al.'s study [16] introduced the homophily principle, which states that similarity breeds connection. He goes on to mention how this principle structures every type of network ties, which creates homogeneous personal networks with regard to many sociodemographic, behavioral, and intrapersonal characteristics. In the article, McPherson et al. discusses that when it comes to studies of close friendships, homophily on age can be stronger than any other dimension. McPherson adds that age homophilous ties tend to be more close, longer lived, to involve a larger number of exchanges, and to be more personal. A study done by Marsden in 1988 [13] found that in confiding relations, there was a strong tendency to confide in someone of one's own age and a social distance effect, which described that the further away someone was in age, the less likely that they were someone with whom one discussed important matters. In a study by Park et. al [?], the relationship between the likeness of words used on thread posts and those users' future interactions with one another in online health communities. This study provides evidence that the similarity in vocabulary between users' posts are crucial when it comes to engagement in online health communities. A study by Fiore et. al [5] analyzed the online dating community and found that those in the dating community sought after people similar to them more often than chance would predict. As applications such as dating websites tend to match their users based on this principle of sharing similarities with one another, we infer from these papers that an application that matches users based on the similarity of data could increase the chances of actually creating a strong bond between users.

3. METHODS AND PROCEDURE

In order to ensure that the web based application could adequately serve as a resource for the rare disease population, we conducted scenario-based evaluations [2]. By asking participants to evaluate and reflect on three possible scenarios we will be better equipped with what types of features to implement into our web based application. The scenarios were based upon the user's interactions with an application. The scenarios were utilized among participants to evaluate whether or not an application would be capable in an operational context in their everyday lives. The participants' evaluations will be used in the future as part of the development process when building the web based application. We first obtained permission to use Facebook Graph API by providing citations to justify why we needed access to specific user-data such as their birthdays, tagged-places, and likes. We also constructed a mock-up application to provide Facebook with a simple visual on how users would interact with the possible application.

We then created the scenario based survey we would use as reference. These scenarios were used to determine what features participants deemed necessary and effective for promoting and facilitating support. We also asked participants about challenges they faced now, so that we could address

these issues in the design of our application. In certain scenarios, we also presented the idea of being matched to others in the online health community. Since there is a large amount of data that could be manipulated in order to match users, we asked participants who they get the most support from now, and other questions that determined demographics of people they are closest to. Scenarios also included sample pictures of the mock-up application, so that participants could understand how they would interact with it if this application actually existed. (Will include figure of sample scenario once completed.) Based on the data collected from the scenario-based survey, we issued a beta test to a small population of students to evaluate the needs specified from the survey. From these evaluations, we became aware of certain aspects that could aid in the design of a more beneficial application for those who lack social support in the rare disease community.

We then created an algorithm based on user profiles and group post patterns [14, 18] to display social matching results on the Facebook protocol developed using Facebook for Developers™. The algorithm was then used as a tool for social matching amongst a group of people who suffer from rare diseases. Much like that of an online dating website, this algorithm matched users with others based on similarities in their user-data. These matches will facilitate new ties and create a community where users receive an adequate amount of support and relationships that can fully fulfill their needs.

4. FINDINGS

4.1 Detailed Design of Web-Based Application

We offer a detailed design method of a web-based application prototype that will provide the rare disease population with the support they often have trouble obtaining in their lives. We present [this many] new design features that participants believe will enhance the original model of an online health community. This detailed design model engages users in social matching to provide themselves with the support they need. By implementing [this feature, this feature, and this feature], we aim to stop common challenges in the rare disease community and instead provide the population with support and others with awareness of rare diseases. We provide descriptions of the main new design features and why they were developed below.

4.1.1 Feature 1

4.1.2 Feature 2

4.1.3 Feature 3

4.2 Evaluating the Scenarios

To evaluate the proposed web-based application, we applied the method of scenario-based design. To design the prototype, we created 3 scenarios that demonstrate a typical challenge a person with a rare disease can face and how our web-based application could offer help or support to that individual. Each scenario would be fully supported by the web-based application if our proposed design method were to be included in the application. The three scenarios are presented below.

Scenario 1 (crisis): Michelle would like someone to help her make a decision regarding her current medication. She creates a new post in the Rare Disease Facebook Extension application asking if anyone has ever tried the drug she is on [drug 1], the previous drug she was taking [drug 2]. She posted about the medication so that she could receive reviews from someone due to their own past personal experience with the medications. Jane, another person afflicted by a rare disease, is notified that Michelle posted on the timeline seeking assistance for a drug she had previously used. Jane comments on Michelle's post and tells her why she switched to drug 1 rather than drug 2 and how each affected her differently. Michelle decides to give drug 1 a try due to Jane's predominantly positive experience. Now Michelle and Jane realize they have much in common and continue to communicate, which manifests feelings of support between the two of them and community throughout the whole group because people see that Michelle received a reply (support).

Scenario 2 (social support): Molly is a 42 year old mother with Hereditary Angioedema. Due to recurrent episodes of swelling in her limbs, she is unable to comfortably complete daily tasks such as washing the dishes and cleaning the home. Her husband usually helps her complete the tasks, but because of his mannerisms, she feels that she is a burden to him. As Molly has to work from home due to her disease, she feels isolated and that she doesn't have anyone to communicate with about her disease. She often talks to her husband, but she often feels that he doesn't understand since he does not have the disease. She would like to talk to someone who really understands how the disease affects her not only physically but mentally. After conversing with a therapist, he mentions how Facebook features an application that can find those similar to you. He says that this application could help Molly find support from others who have her disease. Molly joined immediately and meets 3 other women who are affected by their disease. She meets them because the application recommended her friends based on their similar diagnoses. All of them were unable to bear children, and all three face the problem of not knowing anyone in particular with their disease who understands their daily pains. Molly not only forms a friendship with these women, but also formed a community to exchange the mental and physical journey of having a rare disease.

Scenario 3 (depression): Frank suffers from an extremely rare disease known as Hereditary Spastic Paraplegia. Due to his sickness, he is not able to participate in normal everyday activity and hence does not meet as many people as he would like to. Since he does not meet many people, he yearns for friendship outside of his immediate family which causes him to feel depressed. One day Frank sees a poster that tells about the rare disease facebook community at his local clinic and decides to join. Here he sees many people who also have rare disease and others who also suffer with depression. He decides to post a link to an online game and asks the rare disease community if anyone would like to play. John's profile information states that he likes online video games. John is notified about this post and sees it then clicks the link and also begins to play. Frank is then notified that a member from the group, John, has begun playing this game. John and Frank soon become online friends which helps both clients feel as if they have a friend who understands which soothes their feelings of depression

caused by loneliness.

From these scenarios, we made a survey that asked participants whether or not our proposed design method would be beneficial for the rare disease population. Responses from the survey were either short answer or on a likert scale from 1-5. The survey took around [blank] minutes to complete. The survey was distributed among [this many] participants, who were all undergraduate students from Indiana University. Below, we include the results from the survey questions

4.3 Survey Results

[Insert results from survey - should be able to make a table or two from the data] - state overall opinion from participants and any interesting findings - state what participants found to be beneficial and why - state what participants found to not be beneficial and why

5. DISCUSSION

In this paper we reiterated challenges that the rare disease community faces, and created a detailed design for a web-based application based off of a scenario-based evaluation. By integrating [blank, blank, and blank] into the design of our web-based application, we directly address the issue of those in the rare disease population not receiving enough support. Below, we indicate the broader picture of our proposed designs and how the web-based application could steer the rare disease population away from feeling lonely and misunderstood. First however, we will describe the direct impacts from each design.

5.0.1 Direct Impacts of Detailed Design

1. Design method - why is it important? 2. Design method - why is it important? 3. Design method - why is it important?

5.0.2 The Broader Picture

Describe additional broader impacts of the detailed design here 1. One broader impact of design is.... 2. Another issue that is addressed by this application is....

6. ACKNOWLEDGMENTS

Later.

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