

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. Here we present a method in which the rare disease population's insights can be used to effectively develop a system that can eliminate these challenges. 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, along with *features identified as useful by participants*.

CCS Concepts

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

Keywords

Rare diseases; disease management; online health communities, support

1. INTRODUCTION

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Although considered rare, roughly 300 million people worldwide suffer from a rare disease [26]. To put this in perspective, if everyone with a rare disease lived in the same country, it would be the world's third most populous nation [17]. Compared to the large amount of people affected by a rare disease, the amount of awareness and information regarding rare diseases is slim. In fact, 95% of rare diseases do not even have treatments available¹. As this population suffers from both physical symptoms and coping with a lack of support, it is essential for them to reach out to one another. The widespread use of the Internet has contributed to this population switching from meeting in physical support groups to joining online health communities. These communities foster a safe environment 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 crucial support from their family and friends². Because of this, many turn to online health communities in order to access more information about their diseases and to form friendships with those who better understand what they are going through.

Here, we investigate if online health communities offer an advantage to the rare disease population when it comes to the amount of accurate information and adequate support received. Also, we explore what features in a web-based application could be most beneficial to enhance the amount of support in the rare disease community through scenario based evaluation. Finally, we address the addition of a social-matching algorithm in the web-based application and how it would benefit the sharing of information and support between similar people affected by rare diseases.

In the HCI community, there are many studies dealing with common diseases, such as diabetes [18, 29], asthma [31, 8], and coronary heart disease [28] that help to create awareness and to provide information and support for those affected by such conditions. However, the rare disease pop-

¹<https://globalgenes.org/rare-diseases-facts-statistics/>

²<http://rarecareuk.org/common-problems-of-rare-diseases/>

ulation fails to receive the same amount of attention necessary to create effective awareness [17]. Due to this small amount of awareness, there is a lack of information and resources provided by health professionals, along with a lack of understanding from family and friends. Because of this, people with rare diseases do not receive adequate support to make well-informed health decisions or to even have lasting relationships with those who should be supportive in their lives. To address this issue, the rare disease community often times looks for others in their own situation to provide better and more applicable information.

Numerous studies have been done in an effort to provide support in online health communities [27, 11, 10], yet it is completely essential that we expand this research to the rare disease population. This should be done in a way that limits the population from feeling secluded from others or vulnerable from the feeling that their privacy has been invaded. It may come as a challenge to avoid these feelings, especially if an individual with a rare disease is uncomfortable with sharing detailed information about their diagnosis and struggles. It is important when trying to develop an application for the rare disease population to assure the individuals of their security, as no individual should feel that their privacy is being invaded. We suggest an application through Facebook for Developers, as the already enforced Facebook terms and conditions will apply to our application, along with further granted permissions from Facebook for specific user data. These measures will assist in making sure that no individual with a rare disease has the unwanted feelings of being different or having their privacy violated.

While researchers have investigated the lack of support among those with rare diseases [14, 17], few have offered a technological solution that enables users to obtain support from one another through an online health community. In this paper, we will discuss the information found through a preliminary scenario based survey that was distributed online for participants to complete. This survey will eventually allow us to implement the most beneficial features selected by the participants into a web-based application developed through Facebook for Developers. In addition, we propose the implementation of a matching algorithm based on user profile information into the web-based application. With the use of this algorithm, we hope to create a supportive, online community for those with rare diseases that serves as a source for finding information and resources from like-individuals. Our main contributions are:

1. A proposal of implementing a matching algorithm into an online health community to facilitate the sharing of information and support between like individuals
2. The identification of beneficial features in a web-based application that will enhance the amount of support provided to those in the rare disease community

2. RELATED WORK

There has been an abundance of online health communities designed for the general public, along with communities for those affected by common ailments and conditions. Due to the lack of overall awareness of rare diseases, few solutions exist for the population to receive sufficient support. Hence, when trying to develop an application for the rare disease community, it is important to consider integrating a method that facilitates the most support possible. CHI researchers

have acknowledged the many challenges this population encounters [14, 17]. Here, we discuss some of these challenges, present research that has been done with online health communities, and investigate how implementing a social matching algorithm could be beneficial for an application.

2.1 Rare Disease Community

A disease is considered to be rare when it affects less than 200,000 people [17]. Because there is not a huge population of people that suffer from one particular rare disease, the information they are often given is scarce or completely obsolete [16]. Although many may not be affected by the same rare disease, the total number of people affected by rare diseases amounts to 10% of the world's total population [26]. Since those in the rare disease population suffer from diverse diseases and various symptoms, the main issue this population has is the delay of a proper diagnosis. A study by Knight and Senior [13] 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. These issues include: not receiving 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 [13].

2.2 Online Health Communities

The development of online health communities using social media sites such as Facebook [7] and PatientsLikeMe [30] 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. [9], researchers evaluated the content of health-seeking behaviors and information-sharing on Facebook amongst a group of patients with diabetes. Greene et al.'s 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. When developing a web-based application for the rare disease community, we believe it is imperative to integrate similar ways of information and support sharing.

2.2.1 Web-Based Support

As those with rare diseases face a multitude of challenges,

it has become essential for this population to be offered a solution to overcome them. A study by Doyle [5] investigated 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 emphasized the concept of peer support and mentorship, as individuals diagnosed with the disease along with their families benefited from sharing their experiences with the illness. Disease-specific 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. This also suggests evidence that matching users based on disease may be of use in the web-based application.

Often the diagnosis of a rare disease adds stress to the life of the patient due to the demands of a new illness. Individuals are suddenly forced to adapt to new roles and routines, all while dealing with a struggle to cope and the increased demands and strains on resources. In learning to manage their illness, many affected by rare diseases are thrown into many stressful situations. Dellve et al. [4] completed a prospective intervention study on the stress in parents of children with rare diseases. They found an increased amount of parental stress as well as physical and emotional strain on the mother's of children with rare diseases. This increased amount of stress was due to the amount of challenges those with rare diseases face - especially regarding the lack of information available on the life-consequences for affected children and their families [4]. 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. 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 whose 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. [15] 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 having access to a web-based 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.

2.3 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 [20, 21, 25] **[w6:explain what context aware means?]** . The authors conducted a series of interviews **[w6:from who?]** where they found that by going beyond simple similarity matching techniques, [25, 20] they were able to present a framework of relational, social and personal context as a predictor for matching opportunities. Unlike traditional matching [6], 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. This revealed that by making social matching systems more aware of the user's context and proximity, more valuable new connections can be made [25]. Using the results pertaining to matching like individuals, we propose an algorithm that may match individuals with rare diseases more adequately to one another on a web-based application. We hope that incorporating this algorithm into an online health community for the rare disease population will ultimately enhance the users' experience in finding support from similar individuals.

Matching individuals based on similar interest has always been a shared approach among many dating websites and services. In addition to traditional matching [6, 20], Hyunggu Jung et al. [12] 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 time-banking into a web-based community, which evaluated the quality of MASTs matches with time bankers as participants. Timebanking [24] 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. The authors collected data from the users profiles which was used to match them to 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. Hyunggu et al. also found that some participants mentioned how 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 if we were replicating the same type of work. Instead, since our efforts are to collect data from users to match them with other similar users who can provide support for each other, we believe that this filtering will not be a big issue. Also,

a user may not be matched to another user solely based on the fact that they have the same rare disease. Although symptoms may vary, two users with different diseases may still be lacking the same kind of support. Therefore, even if two people have different rare diseases, they can still provide help to one another. 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.

2.3.1 Using Similarities in Data

McPherson et al.'s study [22] 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 create 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 [19] 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. [23], 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. [6] 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 a web-based application. Each scenario demonstrated a mechanism of a web-based application. The three mechanisms mentioned were 1) Direct notification to user who could assist another user in need; 2) Suggesting other users to add as friends based on similar conditions or symptoms; and 3) Suggesting other users based on similar interests and Facebook likes.

The participants' evaluations will be used in the future as part of the development process when building the web-based application. In order to prepare for future application development, our first step was to obtain permission to use Facebook Graph API by providing citations to justify why we needed access to specific user-data. We also constructed a mock-up application to provide Facebook with a simple visual on how users would interact with the possible appli-

cation.

3.1 Scenario Based Design Method

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. The scenarios featured on the survey were used to determine what features participants deemed necessary and effective for promoting and facilitating support. In the scenarios, we also presented the idea of being matched to others in the online health community through a social matching algorithm. 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.

3.1.1 Scenario 1: Notification to User Based on Similar Posts

Michelle is a 28 year old woman that would like someone to help her make a decision regarding her current medication. She did a quick search and found the Rare Disease support group that is housed in the Rare Disease Application on Facebook. She creates a new post in the Rare Disease Extension application asking if anyone has ever tried Drug A or her current medication, Drug B, so that she can learn about people's past experiences with both of the drugs. Jane, another user of the application, had previously posted about Drug A and Drug B. The Rare Disease Extension application then notifies her that Michelle is seeking assistance for the two drugs. Jane replies to Michelle's post and explains that she switched to Drug A from Drug B because Drug A makes her feel drowsy, unlike Drug B. After consulting with Jane, Michelle decides to give Drug A a try. Michelle and Jane's exchange on their experiences with Drug A and Drug B in relation to Inclusion Body Myositis is indexed in the system and will continue to benefit others with similar conditions in the community.

3.1.2 Scenario 2: Suggesting other users to friend based on similar conditions or symptoms

Molly is a 42 year old with Hereditary Angioedema. Molly has to work from home due to recurrent episodes of swelling in her limbs. She feels isolated and that she doesn't have anyone to communicate with about her disease. While she talks to her husband about her conditions and that her husband tries to help her with daily chores such as washing the dishes and cleaning the home, she does not want to be a burden to him. To a certain extent, it can be difficult for him to 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 a web based application that can find those with similar conditions. Molly finds and joins the Rare Disease Facebook Community. The application recommends that Molly becomes friends with 3 other women who have previously posted similar concerns. 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.

3.1.3 Scenario 3: Suggesting other users based on similar interests/likes

Frank suffers from a 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 a 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.

3.2 Evaluation of Scenarios

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, multiple choice, or on a likert scale from 1-5. The survey took around [blank] minutes to complete. The survey was distributed among [this many] rare disease groups, including [insert names here]. Only those who actually had a rare disease took this survey in order to get a first-hand account of the challenges they face, especially regarding seeking information and support. 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 the interface if this application actually existed. 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.

4. FINDINGS

4.1 Survey Results

The survey included two parts. The first part involved questions based on current support and about the 3 listed scenarios. [Table ?] shows participant's responses to the scenario based evaluation. The second part of the survey gathered the demographics of our participants. [Table ?] shows the demographics of those who took the survey. Overall, participants seemed to think that *these features* would be most beneficial in providing support for the rare disease population. *Will expand on this once we get results this week* - state what participants found to be beneficial and why (will fill in after receiving data this week) - state what participants found to not be beneficial and why (will fill in

after receiving data this week) - state any interesting trends in the data

4.2 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 3 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 the 3 features chosen as beneficial by participants of the preliminary scenario based evaluation, 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.

4.2.1 Notification to Users Based on Similar Posts

4.2.2 Suggesting Friends Based on Similar Disease and Symptoms

4.2.3 Suggesting Other Users Based on Similar Likes/Interests

5. FUTURE WORK

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 a social-matching algorithm along with the features chosen by the participants into the design of a web-based application, we directly address the issue of those in the rare disease population not receiving enough support. Below, we articulate broader impacts of the proposed design of an online health community for the rare disease population. We discuss the challenges of building an online health community and address the ways a social-matching algorithm could potentially serve as a resource for those with rare diseases to be exposed to more support. Potentially, this could create protected, and more involved communities all across the internet. We begin by describing the direct impact of the detailed design mentioned in the previous section and then describe additional broader impacts of our 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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