

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. Due to the lack

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of information and resources provided by health professionals, along with the lack of understanding, people with rare diseases do not receive adequate support due to the lack of information and resources.

PROBLEM: There are many studies that deal with common diseases which hence help create 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.

- Possibly discuss how there are many studies that deal with common diseases which helps create awareness to provide them information and support whereas rare disease do not receive the same attention that is necessary to create awareness.
- Numerous research has been done in efforts to provide support in online health communities, It is difficult but essential that we expand this research to the rare disease population without manufacturing feelings of seclusion or invaded privacy.

OBSTACLE: A lot of research has been done in efforts to provide support in online health communities, but It is necessary that we expand this research to the rare disease population without manufacturing feelings of seclusion or invaded privacy.

- Since rare diseases are rare it may be hard to avoid making an individual with a rare disease feel uncomfortable or as if their privacy is being exploited but that is why we will make efforts to prevent this from happening with security measures.
- The already enforced Facebook terms and conditions still apply to our application along with further granted permissions from Facebook. [Provided by Facebook justifications]

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

- 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 order to identify what this population would like to see in a web-based application
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- 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 &Dc.

SOLUTION: 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. By creating an application which uses a matching algorithm based on user profile information, we may in hopes create an application which hence constructs a supportive online health community for the rare disease population.

Contribution: Application to create a supportive online health community for the rare disease population where they may find information and resources from like individuals.

- This web based community may serve as a source of 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 provide the research community with the knowledge of what features or aspects are found to be the most effective in an online health community application.

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 [20] 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 [19]. 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, 18]. The authors conducted a series of interviews where they found that by going beyond simple similarity matching techniques, [18, 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 [18]. 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 MASTs 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

We concentrated on a scenario-based evaluation [2] in order to understand how an application could best elicit support in an online, rare disease community. Our method included providing participants with multiple scenarios in which they could respond whether or not an application would benefit them in those specific situations. Scenarios were based upon users' interactions with an application so that we could recognize what design methods would be necessary to facilitate sharing and support in a comfortable setting. Overall, 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 application.

We first had to acquire approval from Facebook to use Facebook Graph API data from users. In order to obtain approval, we provided justifications on why we needed access to specific user-data such as birthdays, tagged-places, and statuses. We also constructed a mock-up application to provide Facebook with a simple visual on how users would interact with the possible application. After getting approval from Facebook for Developers, we composed an online survey that featured multiple scenarios for participants to read and respond to. 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 our 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.

4. FINDINGS

5. ACKNOWLEDGMENTS

Later.

6. REFERENCES

- [1] J. R. Brubaker, C. Lustig, and G. R. Hayes. Patientslikeme: empowerment and representation in a patient-centered social network. In *CSCW'10; Workshop on Research in Healthcare: Past, Present, and Future*, 2010.
- [2] J. M. Carroll. Five reasons for scenario-based design. *Interacting with computers*, 13(1):43–60, 2000.
- [3] C. E. Cutrona and J. A. Suhr. Controllability of stressful events and satisfaction with spouse support behaviors. *Communication Research*, 19(2):154–174, 1992.
- [4] M. Doyle. Peer support and mentorship in a us rare disease community: Findings from the cystinosis in emerging adulthood study. *The Patient-Patient-Centered Outcomes Research*, 8(1):65–73, 2015.
- [5] A. T. Fiore and J. S. Donath. Homophily in online dating: When do you like someone like yourself? In *CHI '05 Extended Abstracts on Human Factors in Computing Systems*, CHI EA '05, pages 1371–1374, New York, NY, USA, 2005. ACM.
- [6] L. Gibson and V. L. Hanson. Digital motherhood: How does technology help new mothers? In *Proceedings of the sigchi conference on human factors in computing systems*, pages 313–322. ACM, 2013.
- [7] J. A. Greene, N. K. Choudhry, E. Kilabuk, and W. H. Shrank. Online social networking by patients with diabetes: a qualitative evaluation of communication with facebook. *Journal of general internal medicine*, 26(3):287–292, 2011.
- [8] H. Jung, V. Bellotti, A. Doryab, D. Leitersdorf, J. Chen, B. V. Hanrahan, S. Lee, D. Turner, A. K. Dey, and J. M. Carroll. Masterful matchmaking in service transactions: Inferred abilities, needs and interests versus activity histories. In *Proceedings of the 2016 CHI Conference on Human Factors in Computing Systems*, pages 1644–1655. ACM, 2016.
- [9] A. W. Knight and T. P. Senior. The common problem of rare disease in general practice. *Medical Journal of Australia*, 185(2):82, 2006.
- [10] J. Liang, N. M. Krause, and J. M. Bennett. Social exchange and well-being: is giving better than receiving? *Psychology and aging*, 16(3):511, 2001.
- [11] S. Litzkendorf, A. Babac, D. Rosenfeldt, F. Schauer, T. Hartz, et al. Information needs of people with rare diseases-what information do patients and their relatives require. *J Rare Dis Diagn Ther*, 2:2, 2016.
- [12] H. MacLeod, K. Oakes, D. Geisler, K. Connelly, and K. Siek. Rare world: Towards technology for rare diseases. In *Proceedings of the 33rd Annual ACM Conference on Human Factors in Computing Systems*, CHI '15, pages 1145–1154, New York, NY, USA, 2015. ACM.
- [13] P. V. Marsden. Homogeneity in confiding relations. *Social networks*, 10(1):57–76, 1988.
- [14] J. M. Mayer, S. R. Hiltz, L. Barkhuus, K. Väänänen, and Q. Jones. Supporting opportunities for

- context-aware social matching: An experience sampling study. *context (eg, starting a new job or university)*, 14:28, 2016.
- [15] J. M. Mayer, S. R. Hiltz, and Q. Jones. Making social matching context-aware: Design concepts and open challenges. In *Proceedings of the 33rd Annual ACM Conference on Human Factors in Computing Systems*, pages 545–554. ACM, 2015.
- [16] M. McPherson, L. Smith-Lovin, and J. M. Cook. Birds of a feather: Homophily in social networks. *Annual review of sociology*, pages 415–444, 2001.
- [17] E. C. PhD. Engagement of the elderly in time banking: The potential for social capital generation in an aging society. *Journal of Aging & Social Policy*, 20(4):414–436, 2008.
- [18] L. Terveen and D. W. McDonald. Social matching: A framework and research agenda. *ACM transactions on computer-human interaction (TOCHI)*, 12(3):401–434, 2005.
- [19] S. H. G. Therapies. Rare disease impact report: Insights from patients and the medical community. *Shire Human Genetic Therapies, Tech. Rep*, 2013.
- [20] P. Wicks, M. Massagli, J. Frost, C. Brownstein, S. Okun, T. Vaughan, R. Bradley, and J. Heywood. Sharing health data for better outcomes on patientslikeme. *Journal of medical Internet research*, 12(2):e19, 2010.