

Rare Disease Facebook Extension Outline*

Fernando Maestre
The School of Informatics and
Computing
Indiana University
Bloomington, Indiana
jfmaestre@gmail.com

Grace Bastin
The School of Informatics and
Computing
Indiana University
Bloomington, Indiana
gkbastin@umail.iu.edu

Vanessa Pereira
The School of Informatics and
Computing
Indiana University
Bloomington, Indiana
vpereira@umail.iu.edu

Patrick C. Shih
The School of Informatics and
Computing
Indiana University
Bloomington, Indiana
patshih@indiana.edu

ABSTRACT

Abstract goes here - work on later.

CCS Concepts

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

Keywords

ACM proceedings; L^AT_EX; text tagging

1. INTRODUCTION

Introduction goes here - work on later.

2. RELATED WORK

As the use of the Internet soars, many groups have gone from meeting in support groups in-person 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

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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, and how we can form 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 [5] and PatientsLikeMe [19] 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, its 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. [6], 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 [11]. Because there is not a huge population of people that suffer from a rare disease, the information they are often given is scarce or completely obsolete [10].

- background info on rare disease community [18]
- what kind of challenges do they face? [8]
- what kinds of support would ease these challenges? [3]

2.1.2 Web-Based Support

- Different kinds of support [2]
- Giving and Receiving support [9]

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 systems context aware [13, 14, 17]. The authors conducted a series of interviews where they found that by going beyond simple similarity matching techniques [17, 13] they were able to present a framework of relational, social and personal context as a predictor for matching opportunities. Unlike traditional matching [4], 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, more valuable new connections can be made [17].

Matching individuals based on similar interest has always been a shared approach among many dating websites and services. In addition to traditional matching [4, 13], Hyunggu Jung et al. [7] found that taking into consideration the times that 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's matches with timebankers as participants. Timebanking 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 found that a network that assures benefits can contribute to creating a stronger, more supportive community.

2.2.1 Using Similarities in Data

- homophily theory - McPherson et al.'s [15] homophily principle, which states that similarity breeds connection. He goes on to mention how this principle structures every type of network ties, which creates homogenous personal networks with regard to many sociodemographic, behavioral, and intrapersonal characteristics. In his article, McPherson et al. discuss 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 [12] 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 the further away someone was in age, the less likely that they were someone with whom one "discussed important matters."
- Examples of where homophily theory has been applied [4]

3. METHODS AND PROCEDURE

Like those used by Greene et al. [6]. Initially we created a dummy simulation where we invited our friends to install our web-based Facebook application. During this simulating we provided post and sample questions which allowed us to evaluate how our algorithm matched users to promote communication and support.

Through surveys and interviews we were able to take into consideration the feedback received and make changes accordingly before recruitment of actual users who suffer from a rare disease.

3.0.1 Procedure

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. When granted permission, we then created an algorithm based on user profiles and group post patterns [13, 16] 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.

3.1 Justification for Accessing User-Data

3.2 Developing the Algorithm

3.3 Application Production

4. FINDINGS

5. ACKNOWLEDGMENTS

Later.

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