# PUBLIC HEALTH 2.0: HOW WEB 2.0 SITES ARE USED BY PATIENTS WITH TYPE 2 DIABETES

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# PUBLIC HEALTH 2.0: HOW WEB 2.0 SITES ARE USED BY PATIENTS WITH TYPE 2 DIABETES

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## Abstract

**Objective**: Given the dramatic increase of new interactive features on the Internet known as Web 2.0 sites, the objective of this study was to determine how features such as member profiles, personal blogs and online social networks were used in virtual communities related to type 2 diabetes and to describe the potential differences between the social ecology model of these virtual communities and traditional physical communities.

**Methods**: All original posts and replies in two diabetes discussion forums in web 2.0 enabled virtual communities were recorded for ninety days. Utilization of these features and content from publicly available components of profile pages were recorded from a purposive sample of 60 members. Content was analyzed using qualitative coding techniques. Utilization of other Web 2.0 features was recorded to determine frequency of use among sampled members.

**Results**: 272 original posts and 3605 replies were generated by the participants in the discussion threads. Discussion forum analysis revealed that food, medication and blood glucose levels were major themes for original posts. Replies usually included the empathic and personal experiences of other members. Group guidance emerged from the cumulative responses provided by the community and provided the individual with a sense of the normalized behaviors of the community.

Analysis of the utilization of various Web 2.0 features revealed that those who withheld gender information used the features less often than those identifying with a gender. Utilization also appeared to be dependent on the design attributes of the website. Analysis of 204 personal blog entries revealed the daily struggles of the members and rarely discussed diabetes. Replies to personal blogs were more likely to include religious guidance and expressions of empathy and love. Strong social ties were evident between individual blog entries and those providing the replies.

**Discussion and Public Health Significance**: Discussion forums provided members with the ability to gather disease specific information from a large network of individuals with salient experiences. Personal blogs and other features facilitated the formation of strong social ties to develop. The combination of these features online provides a unique opportunity for public health practitioners to develop comprehensive and multifaceted interventions.

## TABLE OF CONTENTS

# LIST OF TABLES

# ACKNOWLEDGEMENTS

The journey started with a request to sit in on an undersold event hosted by the now defunct Society for Prospective Medicine. Their annual conference was to be sparsely attended and they needed warm bodies to sit in on the keynote lecture by someone named James Prochasksa on something called the Stages of Change, neither of which meant anything to me before that morning. I walked out of the lecture afterwards with my head spinning with the potential implications of his model of behavior change on business, healthcare and life.

A decade later there would be several such seminal events in my life. I would meet and befriend Pat Cluss. Pat would help me learn the nuances of motivational interviewing to help people through those stages. Her mentorship has transformed my thinking from the problem solving mentality of a paramedic to someone who is still learning ways to help people solve their own problems. Later, Ed Ricci encouraged me to apply for the doctoral program in BCHS over lunch one day with a mutual friend. In addition to his outstanding teaching skills in the classroom he would later epitomize how to handle whatever life throws your way. Patricia Documét guided me through the doctoral journey once it began and without her support I would not have been successful in nearing its completion. Her instruction introduced me to the power and vital role of qualitative studies when science is taking its own first steps in exploring a new phenomenon like Web 2.0 technologies. Near the end of my didactic studies, John Marx put me through his crucible course and in the process put me through a mind-bending experience as

significant as Prochaska's introduction years before. As valuable as his mentorship has been, it's our friendship that I value most of all.

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# 1.0 THE EVOLUTION AND INTERACTION OF THE INTERNET AND TYPE 2 DIABETES

## 1.1 INTRODUCTION

A public health provider trying to provide psychosocial support for a chronic condition or mental illness would likely arrange to have a meeting in a particular building in a single community. They would have to hope that the relevance of the topic, the accessibility of the location and the day and time of the meeting would be sufficient to attract a sustainable and active group. The practitioner would also have to hope that the group would be sufficiently large to sustain interesting conversations, but not so large as to cause logistical issues or to act as a barrier to providing a personalized experience. Fifty participants in such a group would likely be a mixed blessing. Parking issues, room size and providing meaningful interpersonal exchanges would be incredibly challenging. One hundred participants would probably require the group to break into smaller sub-sections, doubling the amount of work required to coordinate the new groups. Insofar as meaningful interpersonal interactions are crucial for support groups, having one thousand participants would be unimaginable and unsustainable. To accommodate that that number of participants in the same intervention, planners would require more of a large conference setting than a psychosocial support group. Perhaps such a group could meet face-to-face once a year at some location large enough to handle the number of members eager to participate.

Yet there is a group of 3,300 diabetics who meet regularly, some of them participating in the group several times a day[1]. They interact with each other individually, providing a warm, empathic and very personal environment for each member. In another community more than 39,000 people meet every day, [2] to participate in as many of the 600 different chronic disease or lifestyle-oriented groups available to members of this particular community. The only difference between these two groups and those described in the paragraph above is that they are communities who have formed through the Internet.

The concept of communities forming through computer networks has existed since the 1960s, but at the time was limited to those involved in the military or academia. Today these communities are part of some of the most frequently visited sites on the Internet. Health-related communities are immensely popular with people who have Internet access, yet to date they have existed without the noticeable involvement of traditional public health practitioners.

This manuscript will explore the history of virtual communities and the related domain of computer mediated communications (CMC). The report will describe how those technologies have changed significantly in the past few years with the evolution of more social and interactive technologies collectively known as Web 2.0. Focusing specifically on the unique biomedical, psychosocial and lifestyle challenges of Type 2 Diabetes, this paper will discuss the individual and collective behaviors of diabetic members of these virtual communities, framing the discussions within the relevant theories and cognitive frameworks of both the public health and CMC domains. Next, we will observe these virtual communities through the perspective of select components of the traditional social ecology model. Finally, implications of these new technologies on future research for public health interventions will be briefly described as well as the potential impact on the biomedical model of healthcare in the United States today.

## 1.2 SELECT HISTORY OF COMPUTER MEDIATED COMMUNICATION

Before the worldwide web was navigatable by high speed Internet connections and even before web browsers like Internet Explorer existed, there were two related but distinct types of computer networks that date back to the 1970s. The first was known as ARPANET, a government-funded initiative to allow military researchers the ability to disseminate information among their colleagues. Shortly thereafter a second type of computer network evolved known as a Bulletin Board System (BBS). Unlike ARPANET, the evolution of the computer networks on the BBSs was more of a "grassroots" development, promulgated by networks of computer enthusiasts using their personal computers. [3]

Despite the original intent of the network as a better way for the military and academia to distribute information, the technology of both networks helped to create new social networks among the participants. Admission to the online communities required a high degree of understanding text-based computer codes and a relatively high investment in the computer and communication technology necessary to access the site. Despite the restrictions, enough participants found their way to each other to create vibrant interactions through the computer.

The phrase "virtual community" was first coined by Howard Rheingold in his book of the same name in 1993[3]. The book was an ethnographic account of one of the original bulletin board systems formed from a collection of "interesting people" in the San Francisco area. The system was known as "The Well," and had direct ties back to the popular communes of the

1960s. The founders of the Well were actively involved in one of the most successful communes known as the Hog Farm, and hoped to create a self- governing and profitable forum for people to participate in a community through their computer screens.

The founders of the Well succeeded in their attempt to form an online community, and Rheingold's text describes how the members interacted on the site. Interestingly, some of the earliest examples that show how coherent the Well community had become include cases related to healthcare issues with its members. Rheingold describes the community's empathic response to a member who had just learned his son had leukemia. Another Well participant needed financial support for an operation and the community responded by raising the needed money through the Well. Another example describes a member who was traveling in India, but still in touch with the Well. The member became very seriously ill while there and the community responded by lending its medical and travel expertise to send medical equipment overseas to the member while in India and, ultimately, repatriating the member back to the US for appropriate care. Rheingold's discussion provides evidence that while most of the interactions were simple forms of interpersonal interaction, health-related social support has been a part of the Internet since its beginning.

### 1.2.1 The World Wide Web

As the network of computers grew larger, faster and easier to access and to navigate, the Internet began to blossom into a much larger collection of web sites. Individuals and organizations rushed to publish content in this new media. Oftentimes administrators just transcribed the text from their physical media materials in the new electronic format. Those who learned the new unifying computer-programming language called Hypertext Markup Language (HTML) could design and publish websites.

The introduction of Internet Explorer and commercial applications like America Online helped more people access the Internet, improving the user experience by making it easier to navigate to the content and websites of interest. Features like chat rooms made it easy to communicate with other like-minded individuals who were online at the same time and in the same virtual space. The interfaces of bulletin board systems shifted from specific sequences of keystrokes and text commands to using a mouse to click on a "hyperlinked" section of text that would transport the individual to the desired discussion.

As the content online became easier to search, more people started researching answers to their health questions. Unfortunately the results from the first search engines were unreliable and often returned hundreds of pages of completely unrelated material. Nonetheless, those looking for information could find useful resource pages like www.insulin-pumpers.org that has been in existence since 1997. The website is a good example of traditional Internet pages (alternatively known as a Web 1.0 page).

The site contains the familiar blue underlined text indicating which text should be selected with the mouse to navigate to the desired section. An easy to find search feature allows the user to review WebPages filled with content from previous discussion threads or with content from other websites. Much of the content contains summaries of what the website administrator perceived to be relevant information. Exploring (surfing) the web became as easy as clicking on the blue hyperlinks, letting the author of the website determine which sites are relevant to the topic on the page and moving from topic to topic as the new pages offered new links to follow.

Searching for relevant information was very difficult until Google developed a more reliable way to search through the millions of websites being added to the Internet on a monthly basis. The websites returned after the search, however, were static. The pages looked exactly the same as they did when they were originally published or when they were last modified by the author of the website. Much like reviewing the pages of a textbook, the content may or may not be relevant to the reader's interests, and there was no easy way to determine who else has read the information or whether they found the information to be useful. There was no way to ask a question to other visitors on the website or to solicit the thoughts of anyone else on the topic. Only those who were technically proficient with HTML programming could produce or modify information on the website. While these sites provided a convenient way to research information, most did not allow any form of socialization within the website itself. Thanks to the evolution of software applications on the Internet, all of those features and more are now available in a new breed of websites collectively known as Web 2.0.

The Internet today has evolved into more than just electronic copies of physical media into a truly interactive, participatory tool. Technology and financial barriers to writing content to the Internet have been significantly reduced, allowing everyone with Internet access to create and distribute content as easily as using a word processor. The only cost is the cost to access the Internet itself. Rather than just visiting websites, users can write about their favorite topics, share videos and photographs, create a virtual identity, and interact with a network of friends while adding similar content to their websites as well. The user interfaces of today's websites eliminate the need to understand any computer programming languages, and high speed Internet transmissions mean that users can upload much larger files than was possible in the past. Much of the content on these new pages is not authored by the administrator of the website, but by the users themselves. The medium has changed from a model relying on a single publisher for content to reliance on User Generated Content (UGC). The result is a more dynamic, interesting and fresh website for new visitors to see whenever they return to the site.

To define the phrase "Web 2.0" we turn to a source identified as a Web 2.0 site in its own right, Wikipedia. Wikipedia is a free, online encyclopedia written entirely through a collaborative process using volunteers from all over the world. Over 683 million people a year read one or more of the 10 million articles that are available in 253 languages in the encyclopedia [4]. Previously the domain of writers and publishers, Wikipedia has nearly made stalwarts like Encyclopedia Britannica obsolete. By comparison, the 2007 version of Encyclopedia Britannica's micropedia had a mere 65,000 articles [5].

According to the consensus of people who created the entry on Wikipedia, there are many definitions of the phrase "Web 2.0". The phrase was popularized by O'Reilly Media and coined by Dale Dougherty while describing common features of a new breed of websites [6]. Table 1-1 below lists those characteristics that O'Reilly uses to differentiate Web 2.0 companies and their web sites from their predecessors [7].

**Table 1-1 Characteristics of Web 2.0 companies and websites according to O'Reilly Media**

**Core Competencies of Web 2.0 Companies**

- Services, not packaged software, with cost-effective scalability
- Control over unique, hard-to-recreate data sources that get richer as more people use them
- Trusting users as co-developers
- Harnessing collective intelligence
- Leveraging the long tail through customer self-service
- Software above the level of a single device
- Lightweight user interfaces, development models, AND business models

Below are three select characteristics from the list above that are particularly relevant to Web 2.0 sites that are used for healthcare related topics.

***Control over unique, hard-to-recreate data sources that get richer as more people use them.*** One of the overriding principles of Web 2.0 sites are that their value is directly tied to the number of users interacting with the site. Known as network effect in economic terms, the more people visit and contribute knowledge to the website, the more likely other visitors will find useful content on the site. The more expansive and useful the information, the more likely it is that the website will continue to grow its user base. As will be discussed in Chapter 4, while the interactive nature of the medium has changed dramatically, the revenue model for Web 2.0 sites is similar to traditional newspaper, radio and television advertising. Web site administrators sell advertising space on the website to vendors who wish to target that particular community of individuals. The more data that can be captured about individuals, and the larger the community from which the data can be captured, the more likely it is that the administrators will be able to sell the advertising space for a premium price. Not only do health-related Web 2.0 sites create communities well beyond the size and scope of traditional support groups, but they also are able to gather much more intimate detail about individuals through a behavior known as hyper personal activity, which will also be discussed in more detail later in this manuscript. The result is a large and rich source of data that can be used to tailor advertising messages to the specific individuals using the website, and creating a premium value and price for the advertising companies.

***Trusting users as co-developers.*** As was mentioned earlier, one of the characteristics of the early generation websites was that a single author was responsible for generating the content on the webpage. Individuals or companies controlled the material, and controlled all of the applications and features available to the users of the site. When users become not just co-authors, but co-develop the applications and features, the site is rewarded with more functionality and faster application development than the site would be capable of producing with just its own staff. While there are risks involved in letting users co-develop applications, websites such as MySpace and Facebook experienced a significant increase in visitors when they allowed outsiders the ability to write applications that would work within their pages. As the size of the community grows, the value of the company grows for the users, clients and investors of the website's company.

***Harnessing collective intelligence.*** The true power of Web 2.0 sites in regards to helping people manage their disease(s) comes from the ability to learn from and share their disease experiences. Prior to the Internet, doctors and healthcare providers were the most common source of information for patients. Social support groups, when they existed, were helpful in learning how to manage the disease. Unfortunately traditional support groups required members to be in a particular location at a particular time to meet with the others in the group. Scheduling conflicts and discomfort with meeting others face-to-face may have prevented people from participating in these groups. Web 2.0 sites now make it possible to establish a virtual presence that allows members to learn from the experiences of others and allows them to share their personal experiences and concerns. As the collective knowledge of the site grows the value of the site to new members increases. Members learn that they are not alone in their concerns and frustrations and they learn from the experiences and advice of others who have attempted to cope with similar issues. The ease with which Web 2.0 sites collect and distribute information about diseases may significantly shift the role of healthcare providers who previously held a monopoly on the information.

One of the most common concerns voiced by healthcare providers relates to the inaccurate and potentially dangerous information that can be found on these social sites. While inaccurate information is undeniably a concern on these sites, the recent literature about the impact of errors in medicine would indicate that the provider-centric model of health information distribution is also far from perfect at managing health information [6].

While dozens of studies regarding the accuracy and quality of health related information exist, a systematic review of the literature by Eysenbach found that the studies were difficult to assess, and the results varied greatly [8]. The lack of methodological rigor, standardized definitions and quality criteria make it very difficult to determine the effect of the Internet on consumer health decisions [9]. A recent article by Lau however, indicates that the Internet might help to improve the cognitive ability of patients to answer health related questions [10] . She found that the rate of correct answers increased by approximately 20% in a study using a pre-post test methodology for participants. Similar results have been demonstrated in clinicians [11]. Interestingly, Lau also found that participants were significantly more likely to have correct answers than incorrect answers when the individual had social feedback [10].

### 1.2.2 Social Networks: The foundation of Web 2.0 social support groups

Two commercially successful websites, MySpace and Facebook, are prime examples of Web 2.0, social networking sites on the Internet. Boyd [12] defines social network sites as "web-based services that allow individuals to (1) construct a public or semi-public profile within a bounded system, (2) articulate a list of other users with whom they share a connection, and (3) view and traverse their list of connections and those made by others within the system."

In other words, members of the social networking site can construct or contrive an identity on the website. This is commonly done by providing basic information about oneself when registering to join the community. Demographic information is collected along with whatever other information is relevant to the rest of the community. For example, a site targeted towards undergraduates might ask questions about the primary major, expected graduation year and hobbies, so that those with similar studies or interests can more easily find each other online. Health-related sites may prompt users to share their medical history, medications and non-biomedical therapies that have been used as part of the registration process for the site. Social networks may allow the user to upload a digital photograph to use as the visual representation of the member within the community. Cartoon characters, silhouettes and graphic art designs are all acceptable alternatives to a more traditional head and shoulders picture of the member. The process for building an online identity usually does not require any advanced programming skills, although programming skills may allow the user to create a unique and interesting profile that attracts others to their site.

Once the profile is created, social networking sites allow members to explicitly define a list of other profiles they want to connect with through a feature usually known as "friending". By establishing an online friendship with another user, updates to one person's webpage will automatically send an email communication to the friends letting them know of the change. Oftentimes visitors to the profile can leave a comment for the individual that are usually visible to the public. Once a visitor posts the text on the page, all of the friends attached to that profile receive a notice about the update as well. The links can provide a form of synchronous or asynchronous communication in the social network of friends. These friendships may or may not represent the traditional definition of friend as used in the physical world [13]. Dwyer described the interpersonal relationships that form as a function of the individual's attitude toward impression management and concern for privacy coupled with the features of the website controlling profile, visibility and identity management [14]. New relationships may develop or existing ones maintained depending on the factors above.

Regardless of whether the social network online is the same as the one in the physical world, social network sites have changed a fundamental attribute of the web. Rather than blindly following hypertext links that lead the user from topic to topic, surfing the Internet now consists of clicking on user profiles and following the leads from friend to friend. The Internet has evolved from a relatively complex technical and text based communication tool into a rich, socially immersive medium unlike anything in history.

Unfortunately, while Web 2.0 technology was evolving, another phenomenon was emerging in the United States at roughly the same time. An epidemic of obesity was spreading through the country, and with it, increasing incidence and prevalence of Type 2 Diabetes. In the next sections we will discuss the spread of diabetes throughout the country and then discuss the theoretical implications of online social support groups, before returning to discuss how the Internet might shape the future of diabetes treatment.

## 1.3 TYPE 2 DIABETES

### 1.3.1 Epidemiology of Type 2 Diabetes

Type 2 Diabetes is one of the most complex diseases to self-manage. Treating the disease requires constant vigilance, invasive monitoring and treatment, and drastic lifestyle changes.

Given the complexity involved, one could speculate that Type 2 diabetics would benefit from a strong peer network. Several studies have confirmed the positive benefits that strong social networks have on diabetics [15-19].

Type 2 Diabetes is also an emerging epidemic in the United States. According to the CDC, in 2006 approximately 5.6% of the adult population reported that they had diabetes [20]. The prevalence of diabetes has tripled between 1980 and 2005 [21], and the estimates are that between 90%-95% of all Diabetes diagnoses are Type 2 Diabetes. Not only has the prevalence of diabetes increased but the incidence of diabetes is also on the rise. The number of new cases of diabetes diagnosed increased 123% from a rate of 3.5 cases per 1000 in 1980 to an alarming 7.8 cases per 1000 in 2007 [22]. Left uncontrolled, diabetes can have severe consequences resulting in blindness, kidney failure, amputation and death [23].

### 1.3.2 Internet based interventions

According to a study by the Pew Internet and American Life Project, about 8 million users seek health information online on a typical day [24]. Eighty percent (80%) of all 113 million Internet users reported seeking health information online during the previous year for at least 1 of 17 health-related conditions [24]. These and other data seem to indicate that the Internet is a growing source of information for people with chronic conditions as well as those seeking to make a lifestyle change. While the digital divide still appears to be a significant issue for poor and rural populations, 73% of adults in the United States have Internet access, and almost half of the new Internet subscribers have broadband access to the Internet at home [25]. Recently some of the fastest recent adoption rates have occurred in low income households and with individuals with less than a high school education [24, 25].

To help address the public health consequences of the growing population of diabetics, public health practitioners are beginning to explore the Internet as a medium to deliver interventions [26-35]. For example, Bull et al conducted a review of 87 websites pertaining to diabetes [26]. They analyzed sites based on their user-friendliness, site accessibility (literacy level), interactivity, social support, ethical considerations and other criteria. Their study, conducted in 2005, reflects the state of diabetes information on the Internet prior to the emergence of Web 2.0 technology. Almost all of the sites reviewed were easy to navigate and were well-organized. Unfortunately, the average reading level of the site was a bit high, between the 10th and 11th grade reading level, with almost half of the sites written at the 12th grade reading level. Only a quarter of the sites at the time were considered to be interactive, which consisted mostly of self- assessment questionnaires and tailored feedback. Fifteen percent of the sites reviewed contained peer support threads and 14% offered an online journal, albeit mostly to store self- reported biometric data. The authors made several recommendations, including the need for sites to focus on "their effectiveness in other modalities includ(ing) collaborative goal-setting, problem-solving, and social and peer support. Most sites could also benefit from increased interactivity and deeper tailoring." These findings were similar to those reported by a more global review of diabetes sites by Thakuresai et al [33].

In another study, researchers compared the biological, behavioral and psychosocial outcomes of three online interventions [36]. In the first arm of the study, participants had access to the Internet to review online educational materials and self-assessment tools. Participants in the second arm were enrolled in a tailored self-management program which included use of an application that provided an online health coach complete with in-home training on the use of the application. The final arm consisted of access to a specially designed website that provided access to peer support. Among the main findings reported by the authors was that utilization of the online interventions was highest for the peer support group across the entire 10 months of the study, although all groups showed a decreasing utilization rate over the course of the study. While there were few incremental differences seen in either the peer support or health coached groups, the peer supported group did show a significant difference when compared to the control group in perception of social support and in their HbA1c levels. HbA1c levels in the control group increased, while those in the peer support group decreased slightly from baseline readings. Also interesting were the findings that attrition rates did not differ appreciably between the groups. As mentioned earlier, one of the main concerns of traditional healthcare providers is that peer support groups will frequently contain questionable, if not dangerous, advice. Despite their initial concerns, the investigator found no evidence of inaccurate medical information being posted in the lightly moderated peer support group.

Zrebiec and Jackobson from the Joslin Diabetes Center at Harvard University also studied the use of a custom built website for diabetics that originally offered two discussion groups moderated by certified diabetes educators. While tracking the topics on the sites, the investigators realized that the discussion groups, while focused on family support and motivation for better self-management of the disease, were spending a great deal of time discussing nutritional issues. A third discussion thread was introduced, which ultimately surpassed the utilization of the other two groups combined. Also of interest in the virtual community were the overall utilization patterns discovered by the researchers. Over the eight months of the study there were more than 47,000 user sessions, averaging 65 sessions per day. During the last eight months of the study, the most active time of day was between 9PM-10PM, and the average user stayed on the site for more than 26 minutes [35]. As discussed in the beginning of the chapter, Zrebiec and Jackobson's study seems to confirm the potential of the Internet to deliver interventions during times and for populations much larger than could be achieved in the physical world.

### 1.3.3 Psychosocial Support and Diabetes

Effective psychosocial adjustment to chronic illnesses like diabetes has been positively correlated with decreased health service utilization, decreased costs and better quality of life and other health outcomes [37-48]. Social support can help patients adjust to the diet, blood glucose and physical activity regimes required to maintain optimal metabolic control [49, 50]. Such support may also decrease the stress and perceived barriers to achieving ideal control [40, 46, 47, 51-53]. There is also some evidence that social capital, defined "by such factors as trust, reciprocity, and cooperation among members of a social network [52]", may offer some protection against obesity and diabetes. By comparing statewide data on social capital to statewide data from the Behavioral Risk Factor Surveillance System, Holtgrave found a statistically significant inverse correlation between social capital and obesity and diabetes [52].

van Dam conducted a systematic review of the literature on the impact of social support on diabetes [18]. In the six randomized trials reviewed, he found that both gender and the amount of intervention have an effect on the success of the programs. In general, group consultations, social support groups and both telephonic and Internet based intervention were tentatively supported as effective interventions, at least for women.

Traditional peer-based or group interventions for diabetes were formed around communities who were synchronized in time and space. Diabetics, such as those in the group sessions reviewed by van Dam, needed to rearrange their schedules to be physically present with the rest of the members of the group. Even then, the program should be specifically designed to be culturally sensitive to be effective in that particular community [54]. An important question remains, however: what will happen if the social phenomenon of Web 2.0 technologies were used to address the growing threat of diabetes? As websites adopt more social technologies, those designing interventions for diabetes or for other public health interventions would benefit from a better understanding of the social behavior observed on support group sites. In the next chapter we will review existing theories of public health and introduce theories from the domain of computer mediated communication to describe and predict how health practices and online behavior may be influenced by the new technology.

# 2.0 RELEVANT THEORIES AND IMPORTANT CONSTRUCTS

## 2.1 INTRODUCTION

This chapter explores how familiar public health frameworks such as social cognitive theory and social network theory may change when applied to interventions through the Internet. It also introduces social presence theory to describe and predict behaviors in online groups that may differ from those encountered in physical group settings. Finally, it introduces some key constructs that do not fit into any existing conceptual models, but that are relevant to the interpersonal behaviors observed in online social support groups (OSSGs). Public health practitioners designing OSSGs need to pay particular attention to forming online environments that facilitate feelings of trust among their members [55], as well as allow participants to take advantage of characteristics of computer mediated communications to maximize their benefit from the program. In the next chapter, we will expand interpersonal health theories to a broader ecological perspective in order to discuss potentially critical differences between an ecological model based on the physical world and one derived from a virtual world.

## 2.2 SOCIAL COGNITIVE THEORY

According to a recent article by Bandura, health behaviors are influenced by the following core determinants of this well-known interpersonal theory: 1) knowledge of health risks and benefits of different health practices; 2) perceived self-efficacy over the ability to control one's behaviors; 3) realistic outcome expectations; 4) goals to adhere to healthy behaviors and plans to realize those goals; and finally, 5) knowledge of the perceived facilitators and barriers to the changes they desire [56]. The potential ability of the Internet and OSSGs to influence the core determinants is described briefly below.

Health advocates trying to design a mechanism to provide knowledge of health risks and benefits should be aware that seeking health information is one of the most common activities on the Internet today. According to the Pew Internet and American Life Project, over 80 million people searched for health information on the Internet in 2006 [57]. In addition to finding health information about a specific condition, a very recent study from Canada also described other reasons that people are turning to the Internet. Respondents also mentioned the desire to adopt a healthier lifestyle and looking for an alternative point of view as common reasons to search the Internet [58]. The study also referenced the lack of physician availability to provide information as a potential reason people are searching the Internet for health information.

The remaining four determinants, perceived self-efficacy over the ability to control one's behaviors, realistic outcome expectations, goals to adhere to healthy behaviors, and knowledge of the perceived facilitators and barriers to change, may all be influenced by providing an online venue for participants to communicate directly with others who share a diagnosis, healthy behavior goal or other common characteristic. For example, shared success stories regarding personal experiences in the treatment of a disease or difficulties encountered in adhering to lifestyle changes may help improve the perceived self-efficacy of other participants while setting realistic expectations about the outcome and defining achievable goals. Those lessons may also help provide concrete examples of the facilitators and barriers to the desired changes. A recent qualitative study discovered that potential stakeholders, commenting on a proposed diabetes site, desired a site that was both personalized and that allowed user to communicate with their peers on the site [58]. Both features are common features of Web 2.0 enabled OSSGs, and could influence Bandura's core constructs.

The Internet and OSSGs also provide other features that may not exist in the physical world. One of the most important characteristics is the ability to provide a program addressing stigmatized or isolated populations who may not be willing or able to participate in traditional physical interventions. One of the features of web-enabled interventions and OSSGs is the ability to provide an asynchronous and anonymous environment for its participants. Such programs may also be ideal venues for people who cannot participate in the intervention during traditional hours or who are physically or socially isolated from other program participants.

## 2.3 SOCIAL NETWORKS, HEALTH AND THE INTERNET

Sheldon Cohen, whose landmark experiment [59] described the affects of social networks on physical health, recently summarized the mechanisms and affects of social support on health. As defined by Cohen, "social support refers to a social network's provision of psychological and material resources intended to benefit an individual's ability to cope with stress,"(original emphasis) [60]. Social support, as defined by Cohen, may come in one of three forms as described in Table 2-1below.

**Table 2-1 Types of social support, modified from Cohen, 2004**

| **Type of Social Support** | **Description** |
|---|---|
| Instrumental | Material aid such as financial assistance, transportation, or other tangible products or services. |
| Informational | Cognitive assistance such as advice giving or teaching. |
| Emotional | Affective assistance such as empathy, caring and reassurance. |

Related to social support is the concept of social integration, defined by Brissette et al as "participation in a broad range of social relationships."[61] The size, reciprocity and availability of the social networks into which the individual is integrated can affect the perceived social support of the individual. Mounting evidence supports the hypotheses that social support influences health through stress buffering, increased self-efficacy and other psychological pathways [56, 59, 62-64]. However, social support also appears to work through "main effects" pathways directly influencing health behaviors such as smoking and exercise behaviors as well as psycho-physiological responses such as cardiovascular reactivity and immunological responses.[65]

Given the asynchronous and global reach of the Internet, OSSGs may be a legitimate supplement to traditional forms of social networks. Barrera et al conducted the only randomized controlled trial of online social support participants for Type 2 diabetics published to date [15]. The investigators studied mature (>40 years old) computer novices who were randomized into one of four interventions (information only, information plus online peer support group, information plus online health coach, or information plus both online peer support group and online health coach). Of the four treatment conditions, those randomized into the information plus peer support group showed the greatest improvement in the psychosocial measures pertaining to diabetes. The Barrera study and another review by Eysenbach [8] provide some evidence as to the effectiveness of online social support in the psychosocial management of type 2 diabetes.

## 2.4 SOCIAL PRESENCE THEORY

An obvious, but important difference between traditional, face-to-face interventions and those delivered through the Internet is the ability to determine whether a person is physically present within the group. Less obvious, but still measurable through a variety of observations, is whether a participant is focused on the information being discussed or appears distracted. A participant who falls asleep during a meeting would be an example of someone who was physically present, but not attentive. Put another way, the sleeping participant was not socially present. Other more subtle signs of social presence would include eye contact with others, smiling, body position, nodding and other non-verbal cues that indicate whether the person is mentally engaged with the others in the group. Facilitators who are particularly adept at leading these sessions will be sensitive to these cues and may adapt their presentation styles to engage as many participants as possible during the group sessions.

The challenge for health program planners who intend to provide programs that are mediated through telecommunications equipment (such as telephones or television screens) or through the Internet, is that those media strip away the cues that we use to determine whether a participant is physically and socially present within the group. While both forms of presence are important attributes to consider, this section will focus mainly on the concepts and constructs of Social Presence Theory. The section will not only describe the theory, but also related concepts and web-based system design features that influence participants' perspectives of social presence.

### 2.4.1 Concept and constructs

Social Presence Theory was developed by Short, Williams and Christie in their seminal piece The Social Psychology of Telecommunications [66]. Their theory builds on earlier work that described interactions between two people as a balance between their performance in certain roles or completion of certain tasks (intraparty exchanges) and their personal relationships (intrapersonal exchanges). While later work would demonstrate the effect of the medium on particular types of exchanges, Short, Williams and Christie hypothesized that "the degree of salience of the other person in the interaction and the consequent salience of the interpersonal relationships is an important theoretical construct...”. They coined the term social presence to describe the salience of the person and the prominence of the interpersonal relationship exchange.

Subsequent interpretations [67] would expand the definition to include social presence as the sense of being with others. However, the authors originally limited the definition of social presence to describing the presence of the actor as an attribute of the medium itself. Rather than rate the quality of the interactions with others, Short, Williams and Christie developed measures that were designed to measure the social presence of the medium. Using scales such as impersonal-personal, unsociable-sociable, insensitive- sensitive and cold-warm, the authors were able to discern the differences between the perceived social presence of different media.

Although not originally identified as constructs of social presence per se, Short et al did relate the concept to the sociological principles of intimacy and immediacy. Intimacy is defined as "marked by very close association, contact or familiarity"[68]. Immediacy, described by Wiener and Mehrabian and referenced by Short et al, is "a measure of the psychological distance which a communicator puts between himself and the object of his communication, his addressee or his communication." (Short et al, pg 72) The authors then describe how social presence would likely affect both attributes of interpersonal exchanges. At the time, Short and his colleagues estimated that because of the number of social cues filtered out by text-based interactions, face-to-face communications would have allowed for the highest degree of intimacy and immediacy between participants. However, the Internet has introduced new features that have dramatically impacted the way people interact.

### 2.4.2 Social Presence and the Internet

In the more than 30 years since the original theory was promulgated, advances in technology have significantly changed interpersonal exchanges. As Biocca et al describe in their more recent call for a more robust theory of social presence, "social interaction is increasingly mediated social interaction." In their proposed criteria they call for a new theory that will help determine not only what media to choose, but also a description of what features of the different media facilitate social presence [67]. Presence is no longer believed to be mediated solely by the medium used, but by the ability of participants to interact within the given medium. Now that broadband Internet access is more widely available, the single medium of the Internet can accommodate interactions as simple as text-based discussion threads to real-time, full screen video conferencing capabilities. One could argue that manipulating the features of the site will have a significant effect on the nature of the interpersonal interactions.

## 2.5 SOCIAL INFORMATION PROCESSING MODEL

Early studies of computer mediated communication demonstrated Short's et al paradigm of the affect of reduced cues on interpersonal exchanges[69]. While there were certain benefits to email use for task-oriented exchanges, face-to-face exchanges were considered to be the gold standard for interpersonal interactions. Walther challenged the premise by pointing to a growing body of literature that contradicted the effect of the reduced cues, including Rheingold's description of the formation of virtual communities [3]. To explain the discrepancy between the accounts, Walther speculated that participants inherently desire interpersonal exchanges despite the medium used to interact with the other participant. Initially individuals will use the textual information available to them through the medium to form simple impressions of the other participant, thereby increasing the other's social presence. He also hypothesized that participants would refine their impression over time, by testing their assumptions and learning more about the individuals through repeated interactions. CMC, Walther asserted, could be effective for interpersonal exchanges. However those exchanges would require more time in which to develop rapport because of the limited social cues. He later named that concept as the Social Information Processing Model (SIP Model). Sequential studies helped Walther refine the SIP Model to demonstrate that time was not the only important construct, but rather the anticipation of future interactions played a significant role in the development of more interpersonal communications [70]. The relevance of this finding will be discussed later.

Walther believed that CMC could play a role in settings where there was little time or expectation of future interactions as well as in settings where the participants were likely to interact with each other for longer durations. Other evidence in group decision support systems demonstrated that communications relying on equal participation, open criticism and brainstorming could be enhanced by creating a time-bound and anonymous environment [71]. The effects of anonymity are believed to have a profound effect on the exchanges occurring in OSSGs and will be discussed in more below.

### 2.5.1 Hyperpersonal behavior:

One of the surprising findings from Walther's original work was evidence that groups who interacted through CMC rated their interactions "significantly more positive than their FtF (face-to-face) counterparts on several dimensions of intimacy as well as on social (vs. task) orientation; the CMC groups outperformed, interpersonally speaking, the FtF groups."[70] No prior theoretical work could account for the level of hyper-personal behavior observed in the groups.

By focusing on the roles and contexts of various communication models, Walther constructed a unifying model to explain why this behavior may be occurring. The first role described by Walther was that of the receiver of the message. According to the social identity deindividuation theory based largely on the work of Lea and Spears [72], when receivers lack information about the individual involved in the exchange, the receiver tends to place great value on whatever cues do emerge from the interaction. During exchanges that occur in the context of group membership, such as those in OSSGs, the receiver also tends to adopt the behaviors of the group norms during their interactions, and attributes greater similarity and attraction to other members when they adopt the (para) linguistic style of the group. For example, if a new member of the community posted a message containing different colored fonts or WORDS WHOSE LETTERS WERE ALL CAPITALIZED, the person might be perceived as positive if those were the typical styles used in the group (i.e. on a MySpace page), or negatively if those paralinguistic attributes were not the norm for the group.

On the other end of the exchange, CMC allows senders of messages the opportunity to selectively represent aspects of their identity to other members of the OSSG. As Goffman described in 1959, "the performance of an individual accentuates certain matters and conceals others." [73] This allows the sender of the identity signals and message to have greater control over the interaction between the two parties and over the perception of the other participant. Since the senders' cognitive resources do not have to be on their physical presence during the interaction and since the dialog is not completely synchronous while they are communicating in OSSGs, senders have the ability to be more thoughtful about the content and subtle cues in their exchanges. Walther [70] noted the affect CMC had on the participants: "*They were better able to plan, and had increased opportunity to self-censor. With more time for message construction and less stress of ongoing interaction, users may have taken the opportunity for objective self-awareness, reflection, selection and transmission of preferable cues.*" This "cognitive reallocation" from the physical appearance allows the sender to focus on the presentation of the idea and on the effect the message will have on the interpersonal relationship between the participants [70].

Influencing the relationship between the sender and the receiver are the group norms and cultural attributes of the online setting. One of the most interesting attributes of OSSGs is the degree of self disclosure between participants. Self-disclosure and altruism are common behavioral norms for online support groups [74]. Several studies have analyzed self-disclosure in these groups and the effect such behavior has on the other participants [75-77]. Self disclosure may be influenced by a variety of factors. Some speculate that the Internet allows disinhibited behavior because of the "anonymity, invisibility, neutralization of status, and lack of eye contact."[76] Others suggest that the Internet also helps to mitigate the risks of self-disclosure such as indifference, rejection, loss of control and betrayal [77]. In all likelihood all of these characteristics make people feel more comfortable disclosing personal histories, thoughts and feelings than they would in a face-to-face environment in what has been described as hyperpersonal behavior.

What Walther suggests is that in addition to providing a safe environment for self-disclosure, participants in virtual groups reveal even more intimate details of themselves over time, due largely to the effects of the norms of reciprocity. Once personal information is disclosed, experiments have demonstrated that the recipient will feel obligated to reciprocate with their own self-disclosure [75]. Given the minimal social cues present in the text-only exchange between participants, the receivers of those disclosures tend to focus on the revelations more so than they would in face-to-face settings when they would be distracted by their own physical appearance and that of the other participant. The lack of other social cues may increase the need to reciprocate with even more disclosure in what becomes, as Walther describes, "an intensification loop." [70] As time continues, the hyperpersonal interactions in discussions become the culturally acceptable and normal behavior for the group, further incentivizing members to share their most intimate stories and conveying the group as a safe place for such interactions. Anonymity then, appears to be one of the key benefits of online activity, promoting more group unanimity through greater group salience and by providing a safe environment for mutual self-disclosure.

### 2.5.2 Trust

The increasing ability and desire of people to socialize on the Internet means that in addition to building a functional website, those designing the site play the dual roles of both software engineers and social engineers [78]. The user interface and features of the site will likely determine what people are able to do and prescribe how they can interact. Those social exchanges will likely only occur if the participants believe that the site is a safe venue for sharing their most intimate aspects of the health. Inherent in the decision whether to participate in the new community is whether the participants trust the site and the other members of the community.

Riegelsberger et al define trust as "an attitude of positive expectation that one's vulnerabilities will not be exploited". (Riegelsberger, pg 386). While the motivations to participate in an OSSG may vary, the interpersonal exchanges that occur in these virtual communities provide the opportunity to relate intimate stories of the trials and tribulations of coping with their chronic illness in exchange for empathy and psychosocial support. For the person providing the informational or emotional social support, they trust that there will be a reciprocal opportunity to share their concerns while receiving the same empathic response they provided the other participants. These exchanges involve a fair amount of risk-taking behavior for the participants. They may incur the systemic risk that the website is not secure and their online profile might be publicly tied back to their personal life. They also may be at risk of providing their information to a deceitful company that is really just seeking to share or sell the personal health information of its participants. Even if they decide to trust the site administrators with their personal information, participants incur the social risk that the other participants will criticize their concerns or ostracize them from the community if they reveal too much information or fail to adhere to some unknown community standards.

Riegelsberger *et al* further describe trust as a function of the context and intrinsic characteristics of the interaction between two actors. The context of the interaction in OSSGs is the virtual environment where the interpersonal exchanges occur. According to the authors, the factors affecting the contextual environment include the temporal, social and institutional embeddedness of the participants to the site. The temporal embeddedness of the site pertains to the likelihood that the members will interact again in the future. By creating an interesting site with new and engaging content, users are more likely to return and to interact with each other.

To decrease the amount of malicious activity or inappropriate content that could discourage visitors from returning, many Web 2.0 communities also require potential participants to register with their real email addresses and names before they are allowed to fully interact with others on the site. The registration process also decreases the chances of spam-bots (automated programs designed to mimic humans who populate sites with unwelcomed advertising) and increases the accountability of the individual members.

This "gated-community" approach to participation also helps increase the social and temporal embeddedness of the site. When coupled with reputation management systems that allow users to rate each other's behavior on the site and to report malicious activities, users feel more comfortable that their individual vulnerabilities will be protected. By actively censoring hostile or demeaning discussions, administrators for the OSSGs can also play an active role in the institutional embeddedness of the community. Institutional embeddedness refers to the credibility of the site itself among its users, including potential, active and former users. By requiring members to electronically consent to an agreement specifying the expected behavior and by deleting archival discussions that do not adhere to the desired norms of the administrators and community members, the site can effectively manage its reputation for providing a safe and empathic community of support and engender trust in future participants.

## 2.6 THE ONLINE SOCIAL SUPPORT MODEL

To help public health specialists interested in designing Web 2.0 sites to provide social support, a model of how the social theories described by Short et al [66] and Walthers [70] influence the more familiar constructs of Cohen's and Bandura's theories may be useful [56, 60]. The following model is proposed to help designers of online social support groups determine which aspects of website design are most relevant to their intended goals, based on the type of support they wish the community to provide.

### 2.6.1 Providing Instrumental Aid

To start, we will compare Cohen's schema for social support to the constructs of Bandura's social cognitive theory. Providing participants access to instrumental goods, such as financial assistance and transportation, was detailed in Rheingold's early accounts of The Well in the stories mentioned earlier. The effect on the participant's health is quite clear, in that it provided access to financial and transportation services that allowed the ill individuals to change their goals and behaviors in ways that they would not have been able to do on their own. While it may require a bit of reconceptualizing Bandura's constructs, the effect of the community on the individual's health in these regards was quite tangible.

The support described in "The Well" was largely motivated by the interpersonal rapport the community had within its community members. However, the actual exchange of goods was mostly what Douglas, Short et al would describe as an intraparty exchange. In other words, one did not have to feel any intimacy or immediacy with the affected individuals in order to donate their money. Conceivably, OSSGs using Web 2.0 technologies could provide mechanisms for fundraising campaigns for needy members or worthy causes where money, goods and services are exchanged between the members. Activities such as these are common among social movements, where money is raised for everything from the provision of free care to funding more research on a particular topic.

To enable instrumental aid, designers of the site would likely have to assure donors that the aid received would reach the intended beneficiaries. Such an exchange, particularly those involving the transmission of financial information, would require a high degree of trust, one of the constructs discussed earlier as a mediator of interpersonal exchanges. New users who viewed the solicitation for support would be asked to make an immediate judgment as to whether the site was a trustworthy environment to conduct the exchange. Their cues would be limited in large part to the design of the user interface, the perceived security of the transactional application (credit card or other online financial application used to exchange the monies), and the history of the interactions on the site. Reputation management systems such as user ratings, tallies of the number of other members who have donated to the cause and testimonies of the experiences of others in the donation process would be expected to affect the probability that the new member will donate. Should the member participate over a longer period of time, the likelihood of responding to future requests will be directly affected by their growing familiarity with the site.

Another construct that could predict the likelihood of donating instrumental aid would be the level of intimacy shared between the affected individual(s) and the potential donor. If the dyad mutually engaged in hyperpersonal behavior, particularly for an extended period of time, the probability that the donation would occur seems likely to increase. Sharing personal stories beyond those predicted in a face-to-face setting would likely establish a strong tie between the two individuals. Certainly issues such as the potential risk of deception and the trustworthiness of the site itself could negatively affect the potential exchange. However, all other variables being equal, one would expect a direct correlation between the intimacy of the individuals and the likelihood of exchange.

It is also conceivable that members will be willing to donate to individuals with whom they have no real level of intimacy but have a high degree of immediacy. Influential stories, reciprocal cues and other factors may influence whether an individual donates aid, not because they possess personal knowledge of the affected individual(s), but they likely possess some social presence with the individuals. Donations to disaster relief funds for the victims of the 9/11 attacks indicated that even when intimate familiarity with victims did not exist, if the potential donor was constantly thinking of the victim's plight (as was common given the incessant media coverage and subsequent emotional impact of the event), he or she could be said to possess some level of immediacy with the strangers. If true, designing sites that share vivid and memorable descriptions detailing the situation of the affected individuals through their personal stories would be predicted to increase the amount of instrumental aid provided.

### 2.6.2 Providing Informational Support:

Seeking information about health care issues has already been identified as a common activity on the Internet and is likely the reason that individuals find a virtual community in the morass of sites on the Internet. Given the algorithms used to direct search engines, one might predict that the greater the amount of information available on the site, particularly if it is relevant to the person conducting the search, the more that visitors will be directed and attracted to the site. To maximize the number of visitors, web designers need to find ways to encourage both visitors and members to add content to the site.

By looking at informational support through the perspective of SCT, receiving informational support would be expected to have a positive influence on health behaviors. The following constructs from social cognitive theory could be derived from having members exchange information.

- Knowledge of risks and benefits of certain behaviors
- Realistic outcome expectations
- Knowledge of barriers and facilitators
- Goals to adhere to healthy behaviors and plans to realize those goals

Informational support can come either as interparty or interpersonal exchanges. Questions pertaining to medical terminology, appropriate doses of medications and information on alternative therapies could conceivably be done with a simple exchange of information from the one party to the other without any intimacy or immediacy with the other individual. In fact, one could argue that the traditional patient-doctor exchanges largely involve an intraparty exchange, with physicians trained to provide the information with "clinical detachment". In other words, the physician is encouraged to avoid interpersonal exchanges, as they could interfere with the traditional role of the provider.

However, oftentimes people are seeking information that is beyond that which they can find through the existing biomedical healthcare system. They seek answers not only on how to clinically manage their disease, but also how to adjust their lifestyle to accommodate the changes. Anecdotal observations of discussion threads on diabetes communities seems to indicate that questions are often generated from a sense of frustration that the individual has not previously been able to resolve questions on their own, and they have finally come to the community for answers. Other questions seem to reflect individuals attempting to determine whether they are somehow outside of the norm in their thoughts, concerns or actions. In other words, participants are wondering whether it is normal to be thinking and acting as they have been about their disease.

Responses to these questions begin to transition from intraparty exchanges to interpersonal exchanges. Knowing the statistical prevalence of depression as comorbidity of diabetes may be helpful for the person with diabetes. Far more helpful however, might be responses from members of the community indicating that they too are depressed, and explanations of how they have coped with both diseases. This is most evident in the disparate answers from clinicians and patients about weight control as a realistic outcome for Type 2 Diabetes. Hearing a provider give detached discourse on the benefits of weight loss would likely be much less influential than hearing from those who have tried and finally succeeded in controlling their weight. Such differences are akin to knowing the right thing to do versus knowing how to actually do the right thing.

If interpersonal exchanges are more likely to affect the constructs described above, then by definition more intimacy and immediacy between the actors would increase the effectiveness as well. Features which increase the social presence between the members, be they synchronous communication tools, journal entries, descriptive profiles or active discussion threads would all likely improve the probability that members get useful information.

The constructs of time and trust are also likely to be positively correlated with the community's willingness to provide informational support. The more embedded the members are in the community, the higher the probability that they will receive support from the other members. If true, this model would predict that replies to questions from newbies would receive fewer replies than questions from celebrities and elders (which are roles engaged by individuals in virtual communities and described in detail in Chapter 3).

Intimacy and immediacy do have a cost however, even if the risk of providing the advice is less than the risk involved with the instrumental aid. Deceptive practices used to obtain either scarce intraparty information or emotionally charged information can have a significant detrimental effect on the community if the deceptive behaviors are left unchecked. This type of behavior is one typically used by "trolls" in communities, who will be discussed in more detail in Chapter 3. To mitigate the risk of trolling behavior and its effect on the trustworthiness of the site, OSSG administrators should actively censor detrimental conversations and provide members a system to individually censor and/or report malicious behavior to others in the community.

### 2.6.3 Providing emotional support

One of the hallmark characteristics seen consistently in the testimonials provided by participants in online communities is the positive and warm regard members receive and provide to other members. In fact, empathy has been described by Preece [76, 77] as one of the essential characteristics online health communities need to survive. Returning to the perspective of SCT, one could posit that receiving emotional support for health behaviors would have a positive effect on self-efficacy. Being able to communicate with others who can truly understand the nuances of living with a chronic condition is something that even our most intimate physical world network may not be able to understand. Receiving support from the virtual community about one’s goals and receiving feedback on the plans to achieve those goals would be expected to increase the confidence the member has in actually being able to accomplish those goals. By sharing stories of personal triumphs and failures of managing their own disease, members can help others set realistic outcome expectations and identify barriers and facilitators while providing the member the support and encouragement they seek for themselves.

These types of exchanges would primarily be categorized as interpersonal exchanges, as they require some level of disclosure by both the original author of the post and by those who reply. Those replying to the post would likely need to be engaged enough by the material to motivate them to write a reply. Responses that simply say "good luck" or "me too" in response to a request for emotional assistance would be classified as an intraparty response to the request, and would not be predicted to be as helpful to the individual as more thoughtful replies that included the responders’ own experiences.

It should come as no surprise that the benefit of the emotional assistance would be expected to be positively correlated to the intimacy and immediacy between members and also to have a positive correlation with the amount of emotional support provided. Increased time spent together and increased trust established between the two friends would also be predicted to increase the likelihood that emotional support was provided. In short, the deeper the intrapersonal relationship between the individuals, the more likely it is that emotional support will be provided.

The risk of deceptive practices in obtaining emotional support have been described earlier. Community members who have been tricked into providing unwarranted emotional support, such as the trolls who will be described in Chapter 3, will likely be ostracized from the community if the administrators don't terminate their access privileges beforehand.

## 2.7 SUMMARY

Developing online social support groups for public health interventions will require familiarity with both traditional public health theories and those pertaining to computer mediated communication. Significant differences exist between online and physical communities, and public health practitioners need to know what types of social exchanges occur, theories as to why they occur, and how they can be modified to affect positive health behavior change. This chapter introduced a model explaining how different types of social support could be affected, how they pertain to the social cognitive theory, and how certain features and design layouts can be introduced to allow for the positive exchanges. In the next chapter we will look beyond the social interactions of the OSSGs, to explore the broader ecological model that may also influence behavior.

# 3.0 SOCIAL ECOLOGY IN OSSGS

## 3.1 INTRODUCTION

The previous chapter described theories relevant to the interpersonal interactions occurring online and described how those constructs may integrate with traditional public health theories. Now we will take a step back to view OSSGs in a broader context of the social ecology model. This chapter will describe how the impact of traditional individual level characteristics can be managed in the online environment. Next, we will discuss various roles enacted by members of the online community, and the terminology commonly used to describe the behaviors of members online. Finally, we will conceptually describe two determinants (technical and cultural determinants) that are not part of the traditional ecological model in the physical world, but that may have a profound influence over behaviors in the online world.

## 3.2 A SOCIAL ECOLOGICAL PERSPECTIVE OF ONLINE SOCIAL SUPPORT GROUPS

The social ecology model is a useful conceptual framework for public health practitioners. Historically, American public health researchers have tended to focus on individual attributes or risk-factors relating to health and illness. Our genetic makeup and our health choices and behaviors have been seen as having a predominant role in our health status. However, the social ecology model is helpful in developing a more comprehensive framework by conceptualizing the determinants of health beyond the individual level to include those influences that arise from interpersonal and group dynamics, organizational and community characteristics as well as the regulations and policies that affect our health at multiple levels[79].

However, the social ecological model has been traditionally used to describe interactions occurring in a physically or geographically defined area. While many of the determinants are still applicable, different characteristics of each determinant, as well as the model itself may change when describing the ecology of “virtual communities” like those that exist in online social support groups.

## 3.3 INDIVIDUALS AND IDENTITY ON THE INTERNET

### 3.3.1 Profiles and the Presentation of Self in Cyberspace

In the physical world, social constructs such as race, gender and age are largely based on our physical features. However, in the digital world, participants have to "write themselves into being"[80]. How others perceive an individual will be based almost exclusively on the information the individual has chosen to use to define his or her identity. Participants of online social support groups can choose descriptions that are close to their true physical attributes, they can choose to withhold that information or even choose attributes that redefine themselves in a different age, sex or racial category. In fact it is possible to use any graphic image in the formation of an online identity. Members may use images of themselves or loved ones as a representation of their identity, but they may also use cartoon characters, flowers or other non-human images.

Impression management online is considered to be much more malleable than in the physical world. Goffman, in his seminal work The Presentation of Self in Everyday Life, describes the "front" as "that part of the individual's performance which regularly functions in a general and fixed fashion to define the situation for those who observe the performance." [73] Our personal front usually includes aspects of our physical features such as our age, race, gestures and clothes. Some of these characteristics are changed frequently, while others remain stable over time and between "performances." Through an evaluation of personal fronts, we as the audience can usually quickly and subtly assess our commonalities with the actor by evaluating their age, race, gender as well as other attributes.

As can be seen above in the images above however, the usual cues for defining physical attributes are often missing. One cannot determine the gender, age and race of SockFuzz by simply looking at his or her photo. Even in photos with people, it is impossible to tell at first glance whether the photo is that of the member, a loved one or someone unrelated.

Having unprecedented control over one's identity can be disconcerting for both the participant and the other members. As Wallace aptly describes, "...managing your own impression on the Internet is like navigating white water with two-by-fours for oars. Your impression management toolkit is strangely devoid of the tools most familiar to you, and new ones appear that you may not know how to use."[74] The same is true when trying to determine the common cues of the identity of others. Even in the early days of Internet socialization, Wallace described an early and common process that newcomers to the chat room could expect, called "MORFing". Apparently new participants in chat rooms or virtual communities would be asked early in their participation whether they were Male OR Female, and were also asked their age. The inquiries came through either direct or more subtle questioning [77] , which would be uncommon in face to face settings in the US, if not considered socially taboo.

To provide members easy access to these important social cues, contemporary websites using Web 2.0 features usually prompt participants to display their gender and age as part of writing their online profile, and it appears that most do. A demographic analysis by the author of the profiles of participants of one Web 2.0 online social support group for Type 2 diabetes revealed that less than 1% of the 910 profiles studied withheld gender identification, while approximately 11% of the profiles studied lacked any disclosure of age on the profile itself. In this particular community, the profile did not prompt participants to reveal their race or ethnicity. One of the difficulties of Internet based studies is that it is impossible to verify the age or gender of the participants. The rate of gender swapping or revealing an age different from their physical age is not known. Given the history of health disparities based on these cues, health promotion advocates need to determine what role these characteristics play, if any, in Internet-based interventions.

### 3.3.2 The Digital Divide: Unequal but Growing Access

A common concern regarding disparities on the Internet pertains to whether all populations have equal access to the Internet. In their most recent national random digit dial survey, the Pew Internet and American Life Project reported that as of April 2008, 55% of adult Americans now have broadband access at home, nearly double the rate just four years ago. An additional l0% of US residents have dial-up access at home and 73% report having some kind of Internet access [81]. While the majority of adults have access, a number of the individual characteristics associated with health disparities appear to correlate with Internet access as well. The largest difference in access, not surprisingly, appears to be with age, household income and with geographical access to the Internet.

The lowest broadband adoption rates in the US are found in those over the age of 65. Only 19% reported having broadband access to the Internet at home, compared to the 70% broadband adoption rate of those between the ages of 18-29 and 69% for those between the ages of 30-49 [81]. Not surprisingly, the next lowest penetration rates of broadband appear to be tied to income and education. Significantly higher rates of adoption existed between those with an annual income of $20,000-$30,000 compared those making less than $20,000, and for those who had completed high school compared to those who had not. The final major barrier to broadband adoption appears to be a geographic barrier, with rural access to broadband services lagging well behind both urban and suburban areas. [81]

Race and gender are also correlated with broadband adoption, but it less so than income, education or geography. Forty-three percent of non-Hispanic blacks have broadband access in the home, up a staggering amount from the 14% reported in 2005. There does not appear to be a significant correlation between Hispanic ethnicity and broadband access, as 56% of Hispanics report access, compared to 57% of non-Hispanic whites. Finally, there does seem to be a small gender gap in home broadband access. Fifty-three percent of women report having broadband access at home compared to 58% of men. [81]

Although access to the Internet is a significant variable, the proportion of American adults and adults from other countries who have broadband access already makes this medium too important to ignore as a viable tool for public health initiatives. Some estimates indicate that there are more than 1.4 billion Internet users in the world [82]. Although there are clear indications that adoption of broadband access is not equitable across all populations, solving access problems is not the focus of this monograph. Health advocates need to be aware of the disparities in access to online support and that the Internet may be a poor medium for interventions designed to reach certain populations. If the Internet is an appropriate medium, program planners need to also to consider how individual variables present themselves on the Internet, and whether to expect issues of prejudice or discrimination between those who are participating in online support groups.

### 3.3.3 Antisocial Behavior on the Internet

Early views of the Internet hoped that the new medium was a new tool for social justice in healthcare. The ability to shield the identity of individuals belonging to groups who have traditionally been targets of discriminatory behavior was hypothesized to provide equal access to health information and to homogenize the standard of care. One could hide one's race, ethnicity, income, gender and/or education from the other participants [83]. In the absence of traditional social cues, information could be obtained without the discriminatory behaviors that have been seen in traditional biomedical interventions. In short, anonymity was to be the "great equalizer"[83]. However, determining these social cues through voluntary or inadvertent disclosure, or by the conjecture of the other participant (s) may still be possible.

Anonymity has been previously framed as a benefit of online activity, promoting more group unanimity through greater group salience and mutual self-disclosure. However, the disinhibiting effect of anonymity can also result in an increase in anti-social behavior. Studies have shown that people are more likely to reveal racially-biased sentiments during surveys when they are in the privacy of their own home, the same setting as most online activity [83].

Anonymity can also encourage others who agree with the prejudicial statement to express their affirmation when their expression would normally be constrained by group norms [84]. To moderate the potentially devastating effects of antisocial behavior, online communities must maintain tight control over the content of the online discussion forums. By deleting racist, sexist and other vitriolic posts and by censuring individuals who violate the norms of empathy and support desired in such communities, social support group administrators can establish compassionate behavior as the dominate group norm for others to follow. Fortunately technology is now available on many Web 2.0 sites that allow each participant to create a personal censure shield, so that remarks from an offensive member will be invisible to the offended individual, even if the offender is not censured from the rest of the group.

### 3.3.4 Online social roles: from newbie to elder

Similar to labels used in the physical world, virtual communities have created roles for members to identify individuals as belonging to a particular group. Jocks, geeks, princesses and delinquents are common phrases used to identify individuals in the physical world as behaving like, or belonging to a particular social set. Public health providers who intend to administer an OSSG need to be aware of the terms commonly used, and what characteristics or behaviors are associated with the group names in the digital environment. As will be described, not all of the behaviors will have a positive impact on the community. Below is list of some of the more common names for social groups across all virtual communities. Golder prepared a useful typology for describing the social roles performed in online communities [84]. Relevant aspects of Golder's typology are provided below.

**Lurker**: Most participation in communities starts as a result of the individual searching for information on the Internet. Lurkers are those who observe the dialog occurring in discussion threads, but do not participate in the exchange. Preece et al described that the reason for lurking as opposed to participating had to do with the perceived benefit of lurking [85]. Those who were identified as lurkers claimed that they were just looking for information (53.9%), were still learning about the group (29.7%), were shy about posting (28.3%) and perceived that they had nothing to offer (22.8%). Interestingly there were no demographic differences between those who lurk and those who participate in the discussions found [85]. The proportion of those who engage solely in lurking behavior has been difficult to quantify, as their presence usually cannot be determined retrospectively.

**Newbie**: Once a member decides to participate in the online community, he or she may lack a solid understanding of the culture of the virtual community they wish to join and they generally lack any social capital in the group. Golder posits that newbies typically begin their participation by asking a question and acknowledging their relatively low status in the group through some form of supplication [85]. However, his thesis was completed in 2003, long before Web 2.0 features were commonly available on the Internet. Given the ease with which members can reply to other posts, it is not clear that Golder's assessment of the initial participation of newbies remains true today. Regardless, until the member consistently and frequently participates in the online forum, he or she will likely not gain the recognition that would be necessary to elevate him or her to a higher social status in the group.

**Regular**: Although Golder's typology did not include an intermediate status between newbie and celebrity, it appears likely that the ascension of the newbie into a higher social status will require regular participation that has not been deemed as special as those with higher levels of recognition. Regulars may reply to select individuals only (i.e. their online friends) or may not reply consistently or frequently enough to be widely recognized in the community.

**Celebrity**: According to Golder, celebrities are a vital part of any virtual community. They are frequent posters whose performances are usually consistent with the behavioral norms of the community. Their celebrity status is recognized because of the exponentially larger quantity of posts from these individuals compared to other members and by nature of the posts provided. Celebrities provide role model examples of the type of social exchange valued by the online group, and they do so very frequently.

**Elder**: Elders also enjoy some celebrity status, although the status is afforded to them based on the longevity of their participation in the group. Elders provide the much needed historical perspective of the community usually only obtained by having lived in a physical community for decades. Elders on social networking sites are not necessarily chronologically older than the other participants, but they usually do have to have a more active and respected membership than others in the group, including those recognized as celebrities. Interestingly, elders may revert to simply lurking on the site to ensure that the messages are still consistent with the historical perspective of the community and may not be as active in posting as celebrities.

**Flamer**: Unlike the roles above, flamers are not usually interested in participating in the virtual community in a manner consistent with the culture of the group. Rather, flamers seem to enjoy raising controversial topics, name calling and other activities that demean the other participants. Left unchecked, flamers can destroy the empathic and supportive nature of online communities by undermining the trust of the site. Fortunately new participant-level features allow other members to protect the community from such disruptive behavior by using the reputation management tools described in the first two chapters.

We should distinguish between flamers, who frequently engage in the disruptive activities and "flaming" which is the heated interpersonal exchange itself. Any participant may engage in a brief and highly confrontational dialog with other members, but they would not be expected to engage in those activities as frequently as a true flamer. Prolonged argumentative posts are referred to as "flame wars" and need to be monitored. An emotionally charged debate may be a harmless activity for the group so long as it does not corrupt the community or prove to be too divisive for the members.

**Trolls**: Where flamers are not usually interested in being recognized by the group, a troll, according to Golder, "makes others believe he is something he is not." Trolls (named after the fishing practice of putting out bait and waiting for fish to bite) will post a comment or question on the site that appears to be consistent with the cultural norms of the group. Based on the responses and replies, the troll then begins to manipulate the conversation by replying in ways that emotionally influence the other participants, getting them more emotionally charged, often in anger or confusion.

This activity is especially worrisome in online health communities where empathy and support are often the cultural norms for the group. As participants with more experience begin to suspect the suspicious communiqués as being trolling activity and

> raise the alarm, newer participants may actually defend the activity as being symptomatic of other mental health issues, but still warranting supportive behavior as observed by the author in other online community settings.
>
> In a variant of trolling behavior that has ties to the physical world, trolls may engage in a practice known as Munchausen's by Internet, named after the physical world's diagnosis of Munchausen's Disease (aka fictional disease disorder). In this variant, the troll creates a false report of an illness or injury in order to garner the typical support from the community. More extreme versions are usually easy to detect, but if the troll's story is plausible within the experiences of the group, he or she will usually receive the empathy of the community, only to later manipulate the members as described above.

Once revealed, trolls are typically ostracized by others in the community who feel that their empathy and emotional support were misplaced and their trust betrayed by dishonest accounts which detract attention from community members in real need. Administrators need to consider their policies for deleting the user privileges of those who engaged in the trolling activity as these activities can adversely affect participation in the group.

Antisocial behavior such as flaming and trolling would theoretically be more common in online support groups rather than face-to-face meetings, where their identity is immediately known and the norms of social interactions would serve as a significant deterrent to such activity. Behind the shield of anonymity, these behaviors are frequently observed on sites that do not hold the members accountable through a registration process that ties their online pseudonym to a valid email address.

Those interested in designing support groups for public health interventions may want to consider these roles and any associated dangerous activities as they build the features of the site and develop accountability controls, user agreements and peer-based reputation management systems to help mitigate the risks of such behaviors. They need also be prepared to expunge the archival history of these activities so as not to scare off lurkers and newbies who are trying to determine whether they want to participate in the groups.

## 3.4 FAMILY VERSUS FRIENDS: DIFFERENCES IN SOCIAL INTERACTIONS BETWEEN PHYSICAL AND VIRTUAL SOCIAL NETWORKS

In the hierarchy of the traditional social ecology model, the influence of family and peers is often perceived to be second only to individual level factors in the adoption of healthy behaviors. An individual's behaviors and unique personality are shaped through the observation of and reactions to those who are most intimate and immediate to the individual in their social and physical presence.

The evolution of the online identity, however, may not occur in the same way, particularly in online support groups. The most glaring omission in support groups is the influence of family in the virtual community. Even if members join the online support communities because of their caretaking roles for their loved ones, those same loved ones rarely seem to coexist in the same online community. This does not appear to be the case with teen oriented social networking sites like MySpace or Facebook. In fact those social networking sites are often used as surrogate meeting areas for the youth's physical network of friends. In adult online support sites, the opposite seems to be true. Adults develop a social network de novo on the online site, complete with the characteristics described in the previous chapters, with people they would consider to be complete strangers in the physical world.

Unlike physical world social networks, which are largely based on the physical proximity of the individual to others, virtual communities are formed solely on the basis of some common experience or interest. Many participants share MLL's sentiments on the role of the other members of her online communities:

> *One thing this site has done has filled a void that I would have filled with food. Fortunately my husband and children are supportive, but sadly (long story), my mom and sister don't even know that I have made this commitment to myself. I have come to rely on kind folks like you, who I have never met and probably won't, to feel support and care. Wow...shows you how things are what they appear to be.*

Another interesting difference between the social ecology models of online environments and their physical counterparts is the formation of "friends" in the social networking sites online. Unlike the physical world, accepting an offer to "friend" someone online results in a visible and consistent link between online identities (profiles). On most Web 2.0 sites, friends are often visible through a reciprocal link on both parties' online profiles. Updates on one site will be automatically sent to the other individual. These friendship links help maintain the social presence between the individuals and often result in more frequent communication between the two members. Despite the fact that they may not know the physical identity of their online friend, they often exhibit hyperpersonal behavior, revealing intimate details beyond anything comparable in the physical world.

The ease with which friendships can be requested, and the social awkwardness of denying a request for friendship can be somewhat troublesome for members just joining a community. As Donath and boyd have demonstrated, accepting online friendships is not without some cost and some risk [13]. As mutual friendships link together, participants may change the motivation for surfing through the site from an information-seeking behavior to a social-seeking behavior. In fact this new form of browsing the Internet is very common on social networking sites such as MySpace and Facebook, where the individual is the focus of the virtual community. While participants maintain a great deal of control over their personal identities online, they do not have that same control over the profiles of their online friends. Having friends who exhibit online behavior that is considered deviant from the standards of one virtual community may have an adverse impact on the reputation of the participant in that community for associating with the deviant profile. In other words, members are judged by the virtual friends they keep. If a virtual friend exhibits deviant behavior, the rest of their explicit social network may be viewed negatively as well.

Many social network sites do not allow the user to be explicit about the nature of the online friendship. There is no way to differentiate between a lifelong family friend and a casual acquaintance only recently introduced. The friend feature usually only displays the presence of the friendship without providing an opportunity to explain its nature. Another missing feature is the ability to contextualize the visibility of the friendship. Most sites show the visitors to your home page all of the individuals you have identified as friends. Unlike the physical world where we only reveal certain "facets" of our identity to others, here our entire social network is on permanent display.

These limitations are more significant when we are threatened with the exposure of our online identities to our physical social networks. While participants may be willing to engage in hyperpersonal behavior with complete strangers about the complications of a shared disease, they would not likely be interested in having colleagues from work read about their medical history. If others are able to deduce the identity of the participant from their online activity, the anonymity on which much hyperpersonal behavior is possible would be lost potentially having a negative effect on the value and trustworthiness of the site.

## 3.5 TECHNICAL AND CULTURAL INFLUENCES: NEW DETERMINANTS OF HEALTH IN THE ONLINE SOCIAL ECOLOGY?

As has been described above, there are significant differences between individual identity formation and online behaviors and those in the physical world. And, as previously demonstrated, online and offline social determinants of health also vary considerably from the apparent absence of family in the virtual community, to the nuances and different definition of "friend" in the online environment.

Online social ecologies highlight two components not traditionally described for physical social ecologies even though they are present in different forms. Both the technical features of the website and the scripted culture of the virtual community have a significant influence on the structure and functioning of the community as well as on the psychosocial and even biological health of the members.

Physical social support groups are restricted by the laws of physics. They need to meet in the same time and space to conduct a meeting where all the members can interact simultaneously. They are constrained to use existing buildings with existing physical resources and barriers. The groups all meet in a social setting that has customs in place to regulate behavior in the physical world. Social influences over conduct in physical support groups are now intentionally addressed to make the planned intervention "culturally sensitive."

Members of virtual communities are, however, bound by a different set of constraints. Unlike the physical world, the technical features which influence the interactions on the site are all created by the team that developed the website. The ability to form an identity, the format for presenting that identity, the ability to add graphics or to write an online journal and even the ability to socialize with others in the community all have to be written in computer languages by the site administrators before the members can engage in those activities. Those who are running the site have to write computer code in order to allow every function and every interaction to occur. If the feature is not coded into the computer, or if the code "breaks" because of some other technical interruption, the members of the community will not be able to perform the affected tasks. Should the site experience a malfunction affecting the ability of members to communicate with one another, then the entire community would be made mute. Every interaction, every feature, every event on the website has to be created and executed on the site before anyone on the site can participate in the community. Technology mediates every activity on the site, from the member's access to the Internet at home to the ease of search and navigation through the site itself. In addition to addressing the essential components of the intervention, those designing the programs to be delivered through a virtual community will have to give much more thought to the technology required to enable the intervention to occur.

Another unique, but related feature, is the ability of those administering the site to affect the culture of the online community. Unlike the physical world, rewriting the history of the online community is a relatively simple feat. If a prolonged and antagonistic communication occurs between the members of the community, others in the community can report the unacceptable behavior and discussion thread to the administrators for their review. Should the administrators decide that the dialog does not reflect the culture of the community they are trying to maintain, they can modify or delete the dialog completely, effectively erasing it from the history of the site. No existing or new members will find evidence of the dialog occurring in the archives of the site. The same can be done with members who deviate from the expected behavior on the community. If the administrator decides, either arbitrarily or through some prescribed or democratic process, the member will be banned from the site. The individual and their respective threads can easily be erased from the community completely at the whim of the administrator of the site.

Such power would be considered god-like in the physical world, but is commonplace in the virtual world. The individuals developing the website are therefore not just software engineers, but are in fact social engineers. Cultural cues such as the language, graphics and customs can all be manipulated in unprecedented ways in virtual communities. The features made available and the relative ease of finding and using the features will all help influence the customs and normative behavior of the group. While traditional public health practitioners and programs may have an influence on the cultural practices of their community, they often have to design programs that are sensitive to the existing or predominant norms of their target populations. In virtual communities, practitioners get to establish the culture of the population *de novo*; they need only put up signposts to help the billions of online users who would be interested in such a place find their way to the site.

## 3.6 BRIDGING ECOLOGIES: WHEN ONLINE NETWORKS MEET IN PERSON

The previous sections have highlighted ways that the ecology varies between computer mediated social networks and those in the physical world. One question remains however. How do participants integrate the two ecologies, particularly with respect to their disease self-management practices? Numerous questions exist about how the two domains can interact, if at all.

Public health practitioners should consider whether the outcomes desired by their interventions would be better served by computer mediated interactions, physical world interactions or a combination of both. Both modalities have their benefits and drawbacks when it comes to providing psychosocial support. Before designing interventions that use a mixed method approach, where part of the interaction between the participants is in a physical setting and part delivered through the Internet, program planners would be cautioned to take into account a recent report on the effects of modality switching.

Ramirez and Zhang [86] conducted a quasi-experimental study to determine whether modality switching [moving computer mediated relationships (CMC) to a face to face (F2F) setting or vice versa] resulted in any different perceptions of social interaction. Participants were randomly placed into dyads who had no previous acquaintance with their partner, and were randomly selected to participate in variants of modality switching including face-to-face only or CMC only or who were switched either early in the study their interactions or late in the study into the other mode of interaction (F2F to CMC or CMC to F2F). Participants were given a series of social interaction assessment tools to determine their perspective of their partners before and after the modality switching occurred.

Their findings provided support for Walther's Social Information Processing Model as the better predictive tool for online interactions. Those who remained in a strict CMC-based relationship demonstrated the highest levels of intimacy and social attraction. Switching from a CMC to F2F modality slightly enhanced the perceived relationship when done early in the interaction, but significantly decreased the perception when done later in the interaction. Those who started in F2F settings did not seem to vary much from their original impressions after switching modalities. Apparently CMC only dyads were more likely to engage in hyperpersonal behaviors, beyond those expected in a F2F setting. If the relationship had progressed for the longer time frame, the cognitive image of their unseen partner would likely be perceived as similar to an existing acquaintance or stereotype based on their online behaviors [87]. Once the dyad met in the physical world, the (usually positive) preconceived image was rarely confirmed by the physical attributes of the partner, which dampened the subsequent relationship. If prolonged CMC interactions are expected or have led to high levels of disclosure between participants, program designers should be very cautious about the effects of modality switching. If such switching is necessary, program designers should anticipate a decline in hyperpersonal behavior in any subsequent CMC interactions between individuals.

Unlike Facebook and MySpace, which are virtual environments usually supplementing social networks first established in the physical world, OSSGs are typically built and exist only on the Internet. An ethnography of participants in an OSSG designed for patients suffering or recovering from ACL injuries helps further understand how the physical and virtual social networks interact. Maloney-Kirchmar [90] reports that participants that she interviewed felt the online community played a significant role in their physical world. Members felt they were better prepared when visiting doctors and were able to compare their care to others who have experienced a similar injury. They also felt that the group helped them deal with their injury in ways the medical community did not have time to address and that friends and family had no idea about.

Participation also seemed to help alleviate the depression, anxiety and isolation that occurred when patients lost their mobility from the injury. By participating in the discussions and sharing ideas, members could feel better emotionally and feel as if they were contributing despite their real-world limitations. However, when discussing how the online network in the ACL OSSG would translate into their physical network, the interviewees did not feel that such a modality switch would be beneficial. Apparently, in this particular group, there was little in common between the participants aside from their ACL injury. One participant described a physical meeting with other participants as "interesting, and that's all." [88]

Maloney-Kirchmar's account of an ACL-oriented OSSG provides useful insights and a conceptual framework for future research. However, the study was conducted prior to the introduction of Web 2.0 features to the Internet. Interactions between the participants lacked the graphical cues, journal entries and other attributes now available through current Internet technologies. The next chapter will discuss additional future opportunities for research from a public health perspective and the potential of more modern technologies to shape OSSGs in the future.

# 4.0 SUMMARY AND IMPLICATIONS OF THEORETICAL RESEARCH

## 4.1 SUMMARY

The evolution of the Internet from a publication (one to many) to a social (many to many) medium has the potential to significantly change the nature of healthcare in the US. Much like the site Wikipedia has democratized the production of encyclopedic knowledge, Web 2.0 enabled health care sites have the potential to democratize medical knowledge. The impact of that change is little understood or appreciated given its nascent state.

To better understand this emerging phenomenon, public health researchers and practitioners need to study how traditional public health models and theories of computer mediated communication are affected by the new medium. Existing public health interventions, particularly those addressing psychosocial support, were designed in an era when physical presence and social presence were nearly always experienced together. Usenet sites, BBS sites and today's Web 2.0 sites now allow for physical reality and social reality to exist separately. While the social interactions on these sites involve no traditional face-to-face interactions, they are nonetheless very "real." These interactions generate the same cognitive and affective reactions as physical interactions and often surpass intimate interactions in the physical world in what is described as hyperpersonal behavior. In addition to discovering how these new features of online social behavior affect our interparty (task-oriented) and interpersonal (social) exchanges, we also need to explore how ecological models differ between physical and virtual communities. When the functions of software engineers merge with public health and virtual community development, our roles and responsibilities become that of social engineers. In these communities we have unprecedented abilities to create and shape many of the significant determinants of health as well as to mold the culture of the community to reflect the ideals--typically of trust, empathy and altruism-- that will provide the type of community we desire for its members. However, those roles will require a significant paradigm shift for public health practitioners and researchers alike. In Web 2.0 communities, the administrators are charged not only with setting the culture, but enforcing it among its members. Flamers, trolls, and other individuals whose deviant behavior could jeopardize the community should to be monitored and expelled from the community and reinforcements used to ensure that members can safely engage in their discussions and interactions. While the role of policing these communities connotes a totalitarian state, it is more likely that sites that employ such safeguards will obtain and maintain the critical mass of participants necessary to generate a thriving community.

Based on the empirical and theoretical literature, significant differences exist between a person's behavior in a face-to-face environment and behavior in a virtual community. Given the existing prevalence and growing use of online social networks, public health practitioners need to consider these differences while trying to design and study effective interventions through the use of online social support groups. The following sections discuss some of the implications such technology introduces to the design of future public health research and interventions.

## 4.2 IMPLICATIONS

### 4.2.1 Theoretical issues

As was discussed in Chapter 1, developing public health interventions will require the evolution of public health theories to explore how people interact when the intervention occurs primarily through computer mediated communication. This paper outlined an online social support model that combined elements from the social cognitive theory with social presence theory to predict how the different constructs would impact behavior online. Other theories will need to be developed to provide predictive or descriptive models for interactions occurring through Web 2.0 enabled interventions.

### 4.2.2 Methodological issues

Qualitative research will be useful in the near term, to explore the use of existing OSSGs with Web 2.0 features. Exploring how people are using the features of the sites and what benefits they perceive to participation will be critical in the design of future research and interventions. Once we have a more robust description of current utilization, public health advocates will be able to development measurement tools to determine whether correlations between online utilization exist with other predictors of healthcare behaviors.

Despite the ease and temptation to inquire about the physical world implications of OSSG participation, Paccagnella cautions us against placing too much value on the information if it is obtained through CMC interviews. He states:

> *"obtaining information about someone's off-line life through on-line means of communication- although seemingly easy and convenient- is always a hazardous, uncertain procedure not simply because of the risk of being deliberately deceived but also because in such cases the medium itself increases the lack of* ***ethnographic context****... and may also produce misunderstandings due to different communication codes." (Original emphasis). [89]*

Another methodological issue to be considered is the inherent biases of conducting research through the Internet. As mentioned in Chapter 3, Internet access still maintains a disparity based on many SES variables. Internet users tend to be younger, better educated and more affluent than non-users and care must be exercised not to generalize the results of the study beyond the population of Internet users.

### 4.2.3 Analytical considerations

In addition to drawing on theories from other intellectual domains, public health researchers will have to draw on the analytical tools from other domains as well. For example, network analysis, a common analytical tool used in sociology and economics, will be essential in future studies of OSSGs. Understanding the nature of network relationships, the strength of ties between participants and the variability in the cohesion of networks in different virtual communities will help researchers develop more robust applications for the online environment. For example, these tools may help researchers monitor the impact of their interventions on network relationships to determine whether the experimental procedure changes the density and/ or size of the network.

### 4.2.4 Ethical considerations

Given the hyperpersonal behavior of OSSG participants, researchers have debated whether the information provided in online forums are public or private data. It seems, given the sensitive nature of the medical information discussed in these forums, that the information would be considered confidential and private data in most other venues. Certainly mere knowledge that one is participating in communities oriented to socially taboo subjects could negatively affect the person's employment, their social networks and family relations.

However the anonymity afforded to the participants through their pseudonym may alter the nature of the research by significantly reducing or eliminating the risk of exposure. In fact, if individuals cannot be identified directly or indirectly during the observation, the research itself would be exempt from the federal regulations protecting human subjects. Given the level of control over the visibility of their discussion threads and personal journals on many Web 2.0 sites, it is also not clear that the participants had any reasonable expectation of privacy. In that case, the text collected by researchers would be considered observation of publicly available records.

Because of the ability of many of today's search engines to find samples of text and the potential for someone to conduct a search based on the pseudonyms or phrases used in the report, researchers should avoid using direct quotes and are advised to change the pseudonyms used in publications. This protection of research participants was promulgated by the American Psychological Association's Scientific Advisory Group on the Conduct of Research on the Internet [90]. By adhering to these techniques, qualitative analysis of the discussion threads and profiles of the participants should be considered exempt from IRB review.

Researchers should also be careful to differentiate between simply collecting extant text from an OSSG, which is commonly considered to be a review of existing public records, and active participant observation in an OSSG. If the investigators are active participants in the virtual community, they introduce potential risk, not just to individual participants, but to the community itself. Reasonable safeguards should be used to protect the members and the integrity of the community, as mentioned above.

Extending the research to include the use of interview techniques with individual participants, according to the APA's Advisory Group referenced above, should include the provision of an electronically signed informed consent, even if that consent is only obtained by clicking a button at the end of the consent text agreeing to participate [90]. Although not specifically mentioned in the Advisory Group's recommendations, interviews conducted through instant messaging or text functions should include the informed consent language at the beginning of the interviews and transcripts of the interview be kept to verify that the participant affirmed their consent.

### 4.2.5 Scope and Sustainability

Current community based interventions are typically limited in their scope. Interventions involving community members are necessarily geographically and temporally bound to the same space and time of the research team. However, the global reach and asynchronous nature of OSSGs will significantly change the nature of Web 2.0 based interventions. Experimental designs will either have to limit the scope of the involvement to ISP addresses listed in a specific location or be prepared to have a community that potentially operates 24 hours a day and on a global scale. Unless otherwise designed into the experimental process, the only adoption-limiting factor will be the participants' ability to communicate in the predominant language of the site and their access to the Internet.

Concurrent with managing the larger scope of the interventions will be concerns over finding new ways to keep the programs sustainable after the initial research funding is exhausted. While the costs for operating servers and providing broadband access are lower than ever, the research communities will still require technical assistance to ensure that users have reliable access to the group. The most important feature of any online community is that the technology works consistently. Frequent outages of services or access will limit the interest in participating in the site.

Operational costs associated with managing the site will have to be included in the initial program budgets. Equally important is maintaining ongoing financial support to sustain interventions that are successful in building a thriving online support group. The consequences of ending a physical support group model is generally limited to the geographic area involved and to the limited number of participants affected by the change. In the online environment, it is possible that tens of thousands of participants could be adversely affected by the termination of a successful community. Fallout from the affected community will have consequences far beyond the research facility, and may call public health research practices into question on a national or international scale.

Most of the current commercially funded OSSGs rely on a variant of the traditional publication/ advertising revenue model. Site administrators sell "screen real-estate" to advertisers who are promoting their goods and services. The benefit of online advertising to marketers is the amount of detail available to companies compared to radio, television or print media. Marketers can get granular data, such as who clicked on certain types of advertising, how long did they stay on the company's site, what activities did they engage in while there, did they make a purchase and, if so, for what amount? With this information, companies can tailor their advertising campaign to focus their limited dollars on those processes which have proven to be the most profitable.

This funding model raises obvious ethical and practical concerns for the research team. Researchers will be wrestling with the dilemma of whether protecting the rights of the research participants as individuals exceeds the rights of the subsequent community that is formed to sustain itself financially. If successful communities and interventions are formed, research facilities and lawyers will be wrestling with questions over ownership of intellectual property rights. Who owns the content in a community when the majority of the content is provided by the participants in the interventions, but the site is maintained by the research team? Suffice it to say, public health investigators will be dealing with many unexplored areas as more interventions are provided through the Internet.

## 4.3 CONCLUSION

As public health researchers begin to explore and experiment with the effects of online virtual communities, they will need to reconsider the effects of computer mediated communication on their research designs. A few methodological, analytical and ethical tools were introduced to describe just a few of the differences investigators can expect to encounter as the entire institution of public health research becomes more familiar with online communities. Issues such as sustainability, which receives little attention in most physical world research efforts, become more paramount. Successful interventions may become so large that tens of thousands of individuals could be impacted if interventions ended prematurely due to the end of research funding.

The popularity of sites like MySpace and Facebook mean that millions of people in the US have grown up with and have created part of their identity on computer mediated social networks. While most of these networks are extensions of their physical world social network, as they get older and face more health issues, this generation will likely turn to extended online networks to help manage their diseases. This phenomenon is particularly likely with diseases such as Type 2 Diabetes, which are increasing at epidemic rates in both incidence and prevalence. As diabetics struggle to manage the medications, lifestyle changes, and comorbid conditions associated with diabetes, they are likely to increasingly turn to a virtual network to supplement their physical network for managing their disease. Public health advocates need to consider the most effective ways to create and maintain online social support groups that will make participation in these communities an effective tool in diabetes management.

# 5.0 GENERAL METHODOLOGY

## 5.1 RATIONALE FOR USING QUALITATIVE METHODOLOGY

From a public health perspective, the unprecedented level of social interaction made available by recent innovations on the Internet creates new opportunities and new challenges. The Internet has included interactive elements since its inception, but only recently have the technical and financial constraints associated with early Internet experiences been almost entirely negated. In recent years the US has experienced the emergence of broadband Internet access, low cost computers and new Internet applications that no longer require computer coding skills to create web-based content. These technological feats mean that for the first time in human history, nearly everyone has the ability to communicate with nearly everyone else, most notably those in their social networks.

Web 2.0 features, such as those described in Table 5-1 on page 70, are recent inventions on the Internet that have significantly enhanced interpersonal exchanges through computer mediated communications. The very recent introduction of these tools and their impact on existing public health theoretical models and conceptual frameworks needs to be better understood. Will prominent explanatory models like the social cognitive theory and the social ecology model still be useful in describing or predicting health behavior change when mediated with Web 2.0 interactions? Important questions to be answered are: what, if any, changes need to be made to more accurately describe what is occurring on social networking enabled sites; and how can we best leverage the potential of these new features to affect the collective health of its users?

While quantitative studies will be essential in describing and monitoring the growth and effects of Web 2.0 interactions, qualitative studies are uniquely positioned to help develop new cognitive frameworks and theoretical models to explain their current use and to provide guidance to public health practitioners who are considering adding these features to their armamentarium of interventions.

According to Ulin, Robinson and Tulley [91], qualitative research is unique in its "theoretical and methodological focus on complex relations between (1) personal and social meanings, (2) individual and cultural practices, and (3) the material environment or context." Qualitative methods are ideal for our efforts to gain the deepest possible understanding of the current practices of members using Web 2.0 enabled support groups and to develop better insight into the relationship between the online environment and the interactions of the members.

Conducting a qualitative analysis of these virtual communities is facilitated by the text based nature of the interactions between the individuals. The written record of the discussion threads, personal blogs and other features provides an authentic and complete transcript of the social exchanges, leaving them unaltered by the researcher's presence as is common with many other types of qualitative research. Part content analysis and part observations of public behavior, this study allowed the researcher to "lurk" in the community without interacting directly with the members. The research also benefited from not having to rely on hastily scribbled research notes to capture the observations. Data containing the social exchanges were downloaded regularly, and research notes were reserved for the perspective and insights of the investigator.

## 5.2 CONTEXT OF STUDY

Two online support communities for type 2 diabetics were selected that included the Web 2.0 features listed in Table 5-1. Site 1 is a community that was created by a Type 1 diabetic using a publicly available online community hosting service. The site is dedicated to diabetes in general and has a discussion forum focusing on Type 2 diabetes. Members can participate in a variety of different groups and discussion forums, regardless of their primary diagnosis. As part of the registration process, all members create an online profile, a website with their personal information dedicated solely to them. Site 1 profiles could be customized extensively. In addition to the features listed in Table 5-1, the background image could be modified on the page, and music added if desired.

**Table 5-1 Select Web 2.0 features**

| **Web 2.0 Features** |
|---|
| Ability to create and modify an online profile |
| Ability to explicitly create a “friend” within the community |
| Ability to upload and share photographs and video |
| Ability to create a personal blog |
| Majority of content in discussion forums provided by community members |

Site 2 was founded by a private commercial entity, and has communities for more than 600 different disease and lifestyle concerns. It has a discussion forum focusing on type 2 diabetes, but many members simultaneously belonged to several different communities.

Members on this site also had a profile webpage, but the customization was limited to those features listed in Table 5-1.

Only members of the communities were allowed to interact with the community members in the discussion forums. While membership required only a valid email address and minimal information, the investigator did not join either community, focusing only on that information that was publicly available. This allowed the investigator to observe the natural communications and interactions occurring on the sites without altering the exchanges because of the research process.

The study consisted of a content analysis for the discussion forums and online profiles of selected members participating in each site. One analysis focused on the content of the discussion forums for type 2 diabetes in the community. The other arm analyzed a convenience sample of the profiles created by the members to determine what features were being used, and what information was being conveyed through the profile pages. Both methodologies are described in more detail below.

## 5.3 METHODOLOGY FOR DATA COLLECTION AND ANALYSIS: DISCUSSION FORUMS

This study was approved by the University of Pittsburgh's Institutional Review Board as observations of public behavior and therefore exempt from obtaining informed consent from the participants. However, to protect the confidentiality that may be presumed by the participants and to maintain the trust inherent within the participants in revealing potentially sensitive information about their health, individual user names (which were often pseudonyms themselves) and the names of the communities will be referred to only by a alphanumeric code (S1- site one, S2- site two, S1Ux- user x on site one, S2Ux- user x on site two).

The discussion forums of the two independent online communities were observed daily for ninety days beginning in February 2009; all new discussion threads and replies were recorded during that timeframe. The investigator visited the websites daily, typically at the same timeframe between 5AM-7AM ET. Each site was reviewed for new topics or activity posted within a discussion thread within the previous 24 hours. On Site 1 members were free to reply directly back to any prior reply or the original post in the discussion thread. Since replies were not added in a direct sequential fashion, each page of the thread was reviewed to determine where updates may have occurred. On site 2, all replies were added sequentially; therefore the investigator simply had to go to the page containing the most recent updates to capture replies that had been generated in the previous 24 hours.

One hundred thirty-eight discussion threads were collected from Site 1, and 134 discussion threads were collected from Site 2. The combined 272 threads generated 3605 replies between them. Both discussion forums were labeled as Type 2 diabetes discussion forums although members from any other community within the broader virtual communities on the two websites could participate regardless of their diagnosis. Since membership was not required to read the discussion forums for either community, the investigator did not interact with either community, other than to view and download the content under study. This allowed us to capture the authentic communication process between participants without influence from the research process or the presence of the researchers themselves.

Data were downloaded from the websites into a word processing document. Unlike other qualitative studies where data are coded as they are collected, data from this study were collected first then imported *in toto* to the qualitative data software program for coding and analysis. Because of the nature of the online forums, new replies could easily be added to prior discussion threads regardless of the time that had elapsed since the previous entry. This feature required the investigator to wait until all of the discussion forums and replies were posted before coding could begin. Otherwise, coding might begin on a primary document, only to be discarded or modified later once subsequent comments had been added.

Once the study period ended, the documents were imported as primary documents into Atlas.ti® (version 5.59) for qualitative analysis. Once the data were captured in the word processing document, all 272 documents were read and analyzed for recurrent themes. Both the original discussion posts and their subsequent replies were categorized based on those initial themes. Once categories were established that were believed to capture the majority of interactions on the sites, those categories were refined in discussions among the research team to reduce ambiguity about the definitions and appropriate use of the codes. All coding was conducted by the primary investigator (DRS).

Codes for the original posts were developed to be mutually exclusive. The original posts were coded to identify the website and the predominant theme for the inquiry or statement. Multiple coding iterations were conducted until the majority of topics could be described in a relatively small number of descriptive categories. The codes for the original posts are listed in Appendix A. In total, seven codes were developed to categorize the content and one of two codes were used to capture the site where the discussion occurred.

Codes for replies were originally developed based on a modified version of Barrera’s social support model [92]. However, the investigator soon realized that not all of the social exchanges occurring on the discussion threads could be classified as a form of social support.

Additional categories were added to accommodate other types of social exchanges and the original definitions were modified to better capture the nature of the interactions on the Internet. The codebook used to describe the data is included in Appendix A.

Codes for replies were applied to the entire response as the unit of analysis, rather than to more granular levels such as paragraphs or sentences within the reply. Because each reply was typically multifaceted in the types of social support and exchanges it included, the codes for the replies were not mutually exclusive. While some replies were succinct, others included several forms of information and support. Rather than trying to determine the predominant intent of the reply, all applicable codes were used to categorize the reply.

An *in vivo* coding process was used to capture two aspects of the discussion forum that were not captured through the other coding schema. Whenever a participant referenced the virtual community, the quote was captured in Atlas Ti as a free quotation to capture the exact words used to describe the member's perception of the community. The same was true for passages that the investigator considered to be examples of "folk wisdom." These passages could include motivational statements, examples of community-specific jargon, or interesting insights or perspectives offered in one of the replies. In total 7,333 codes were used to describe the original threads and subsequent replies.

To complete the discussion thread analysis, the primary investigator logged all of the members who either authored one of the original posts or one of the subsequent replies. The logs were created in a Microsoft Excel Spreadsheet, noting the total number of times the author posted a reply within each discussion thread. Basic demographic information on each author included their gender. Age, if revealed, was calculated to provide a demographic analysis of the participants in the discussion forum.

## 5.4 METHODOLOGY FOR DATA COLLECTION AND ANALYSIS: ONLINE PROFILES OF DIABETIC PARTICIPANTS

Online profile data were collected from a purposive sample of 30 participants from each site. Ten participants were chosen who identified themselves as male, ten who self-identified as female and ten who chose not to state their gender explicitly. Because of differences in the search parameters available on each site, the method for selecting these individuals varied slightly between the two sites. On Site 1, members of the community who revealed in their profile that they were a Type 2 diabetic were chosen by searching for “Type 2 Diabetes” and selecting the gender from the advanced search on the members page. Gender-undisclosed members were chosen by only selecting on “Type 2 Diabetes” and manually searching through the search pages for members who had not disclosed their gender. On Site 2 members of the “Diabetes Type 2 Support Group” were filtered based on their gender. To identify gender-undisclosed members, the investigator also manually searched through member profiles to find those who did not explicitly state their gender. On Site 2, that required viewing 582 individual profiles to find ten who had not disclosed their gender. Identifying gender-undisclosed members on Site 1 involved searching fewer than 100 individual profiles to find the desired 10 profiles.

Once gender identification was determined, each profile was reviewed and publicly available and relevant data from the profile captured in a Microsoft Excel Spreadsheet. Because of the different features of the two websites, slightly different information was captured from the two sites, as detailed in Table 5-2.

**Table 5-2 Select elements captured from profiles of members**

| Site 1 Profile Fields Captured | Site 2 Profile Fields Captured |
|---|---|
| Pseudonym<br>Profile URL<br>Code for photo used for profile site<br>Gender<br>Age (if disclosed)<br>Response to "Do you have diabetes?"<br>Type of Diabetes<br>Date diagnosed<br>Type of treatments<br>Response for "How did you find the site?"<br>What do you do for a living | Pseudonym<br>Profile URL<br>Code used for profile site<br>Gender<br>Age<br>Date Joined<br>Emotional State<br>Text from "About Me" section |

In addition to the fields listed in Table 3.2, the use of other features was recorded from each profile webpage. Every two weeks during the study period a list of all the friends and the number of photos listed for each profile was observed for additions and deletions. Group memberships for each member were recorded every six weeks for changes in participation. While both sites had groups created by the members, Site 2 also provided the option of joining over 600 different disease and lifestyle related groups developed by the site administrators. Membership in each of those groups was recorded and changes such as joining a new group or leaving a group were noted. Descriptive statistics were calculated to provide a picture of those profiles being observed; these statistics are not likely to be representative of all the members of the sites or online social support group members in general.

The personal blogs of the participants were recorded twice during the study period. Originally the investigator planned to download only those blogs posted during the study period. However, there was insufficient activity on the sites during the study period to provide any valuable data. At the end of the study period the investigator downloaded the blogs from all the members in the sample starting from February 2008. Both sites allowed the member to keep the blog private among only their friends, or to make the contents publicly available. Only those left publicly available were recorded. The expanded timeframe allowed the investigator to record and analyze slightly more data and to draw comparisons between the types of posts and replies on the discussion threads and those occurring on the personal blogs.

Another feature unique to Site 2 was the availability of virtual social interactions (VSIs), which allowed the members to exchange graphic emoticons that represented several types of social interactions. Along with the graphic, members could send the recipient a message. At the end of the study period, the number of VSIs given by the recipient and the number and types of VSIs received were tallied for each profile being studied and recorded in an Excel spreadsheet for quantitative analysis. The messages received by the participant were also recorded and the investigator performed a content analysis using a coding schema similar to that used for the discussion threads. Since the topics of the personal blogs and VSIs were often about issues other than diabetes management, new codes were developed to describe the new exchanges. The conversations in the VSIs were similar to recording one side of a telephone conversation, as the only communication available for observation were those received by the profiles under study. Nonetheless, these communications provided valuable insight on the use of this feature from the members of the community.

Chapter 6 will discuss the results of the analysis of discussion threads, describing the types of interactions observed and common characteristics of the participants of those discussions and will attempt to describe the potential role such discussions can have on influencing diabetes management. Chapter 7 will discuss the results of the online profile analysis, describing the use of the various features available to the members and the types of social exchanges occurring in the more personal context of the profile page and will hypothesize about the meaning of such interactions to the members using the sites. Chapter 8 will describe the differences between the two sites and will proffer a model to describe the differences between the social cognitive theory and the social ecology conceptual model in physical environments and those observed in these computer mediated environments.

# 6.0 WHAT ARE THEY TALKING ABOUT? A QUALITATIVE ANALYSIS OF TWO ONLINE DISCUSSION FORUMS FOR TYPE 2 DIABETES.

## 6.1 INTRODUCTION

According to the Pew Internet and American Life study, 61% of American adults search online for health information. The majority of those surveyed still relied heavily on health professionals when dealing with medical issues; however, 41% of those who searched online also read about someone else's experience with disease [93]. The ability of members of online communities to add their own content to the sites is easier and less costly than ever before.

The benefits of a strong social support system in the management of diabetes are well documented. Decreased health service utilization, decreased costs and better quality of life have all been associated with higher levels of psychosocial support [36-42, 44-48]. van Dam's systemic review of the randomized-controlled trials of psychosocial support and diabetes and found evidence that gender and the amount of intervention is associated with an effect on the success of the programs [18]. In general, group consultations, social support groups and both telephonic and Internet based interventions were tentatively supported as effective interventions, at least for females.

Online discussion groups have been shown as effective way to deliver psychosocial support for diabetes to a large population of patients. In 2004 Zrebic surveyed visitors to a diabetes discussion board and found that 71% rated participation in the board "as helping them to feel more hopeful"  [94]. Barrera et al found in their randomized controlled trial that participants in a monitored, but peer-directed, online group reported significantly more perceived social support than groups that received information only [15]. An interesting, although not statistically significant finding was that those participating in the peer-directed only group also reported more social support than two models that included interaction with a health coach.

In addition to being scalable to large populations of patients, online support communities also allow members to communicate in an asynchronous format. In 2001 Zrebiec and Jackobson monitored the use of the Joslin Diabetes Center's website that included two discussion groups. Over the 21 months of the study, the website logged more than 47,000 user sessions, averaging about 65 sessions per day. During the last and busiest months of the 72 month study the most active time of day for the website was between 9PM-10PM, later than traditional support groups would normally meet. The average user was logged on to the site for approximately 26 minutes. The site was also redesigned during the course of the study, based on the observations of the researchers that a significant portion of the discussions related to nutrition. Once a third discussion group was created to address nutrition specifically,  the activity in that group quickly surpassed the traffic on the other two sites [35].

In the years since these studies were conducted, the financial and technical costs to creating online support groups have decreased significantly while participation in social networking sites like Facebook and MySpace have increased dramatically. On September 15, 2009, Facebook CEO Mark Zuckerberg announced that Facebook now serves over 300 million people [95],  an incredible adoption rate considering that the application was first made available to Harvard students in February 2004. The widespread adoption of computer mediated social networking may represent a significant opportunity for health care providers, educators and public health practitioners to use the new technologies to engage diabetics in new forms of online social support as well as other interventions. However, before creating a virtual community for their diabetic patients, programs may benefit from a deeper understanding of how the members of established communities are using the existing features. The analysis reported in this manuscript will describe what members from two virtual communities for patients with type 2 diabetes are asking in disease-centric online communities and what type of responses members from the communities are providing.

## 6.2 RESEARCH DESIGN AND METHODS

The investigator monitored the discussion forums of two independent online communities focusing on type 2 diabetes for 90 days beginning in February 2009, recording all new discussion threads and replies. Both sites produced roughly the same number of discussion threads during the study period: 138 from Site 1 and 134 from Site 2. Both sites labeled the discussion thread feature as “Type 2 diabetes discussion forums,” although members from any other group within the broader virtual communities on the two websites could participate in the discussion threads, regardless of their diagnosis.

Membership was not required to read the discussion forums for either community. The investigator did not interact with either community, other than to view and download the content under study. This allowed the research to capture the authentic communication process between participants without influence from the research process. The methodology used to capture data for the discussion threads was explained in Chapter 5.

## 6.3 RESULTS

### 6.3.1 Who's Asking? Demographics of the authors of the original posts

On site 1, 89 unique users generated 138 original messages during the 90 day study (range = 1 to 8 original messages per unique user). Fifty-five percent of the original post authors were women, 37% were men and 7% of the users did not disclose their gender explicitly (the profiles for the remaining 1% were unable to be located at the time the analysis was completed). The mean age for women was 35.3 years and 47.7 was the mean age for men. All of those who withheld their gender also concealed their age.

On site 2, 79 unique users generated 134 original messages during the study period (range = 1 to 11 original messages per user). Women initiated 84% of the discussions, men started 12% and members who did not disclose their gender started 1.5%. Profiles for the remaining 2.5% were unable to be located at the time the analysis was completed. The mean age for women originating the discussions on site 2 was 48 years, and 53.8 was the mean age for men. Only one participant who did not identify with a particular gender chose to reveal his or her age.

### 6.3.2 What are they asking? Common topics for starting a discussion thread

Despite the highly individualistic nature of the original posts, several common themes emerged from the type of questions or statements made by the authors. The most common questions pertained to diabetes medications, blood glucose levels, interactions between diabetes and other health concerns, food, and sharing recent research or media coverage pertaining to diabetes. The proportions of threads containing these themes are listed in Table 6-1.

**Table 6-1 Common themes and relative proportions of original topics in type 2 diabetes discussion forums**

| **Proportion of Discussion Topics** | **Site 1** | **Site 2** |
|---|---|---|
| Medication related | 30% | 25% |
| Blood glucose levels | 20% | 13% |
| Diabetes and other health issues | 11% | 13% |
| Food | 9% | 19% |
| Sharing articles and research | 8% | 1% |
| Diabetes- general | 6% | 4% |
| New member introducing themselves | 1% | 7% |
| Other | 15% | 16% |

The quotes below are examples from the most common categories.

### 6.3.2.1 Questions about Medication

*Hi -*
*Sorry if this is a question that's already been answered! I've researched it quite a bit and I'm seeing a lot of different views. I was just put on 50 mg of Januvia (in addition to my 1000 mg/day of Metformin, low carb and exercise). My question is does Januvia cause beta cell exhaustion?*
*I've seen no, I've seen yes and I've seen that it actually stimulates and improves beta cell function.*
*Anyone have any insight?*
*Thanks!* ***(S1U68)***

*I know the question about side affects from Metformin have been on here before. But I was wondering does anyone get heartburn from it? I've been on it since July of last year. Since then I've gotten heartburn from time to time. Now I'm getting heartburn at least 2 to3 times a week. Could it be the Metformin? Or something else? I have a doctors appointment today (5-15). But I was wondering if anyone else gets it? Thanks for the responce.* ***(S2U121) [SIC]***

### 6.3.2.2 Questions about Blood glucose

*Glucose #'s*

*What should your glucose #'s be after eating? One hour after. Two hours after. I have read two different things and confused. Sounds like I should not follow ADA rules..........someone please correct me or tell me what guidelines to look for?  Thank you!!  (S1U79)*

### 6.3.2.3 Questions about Food

*Anyhow, my question is does anyone out there know of any breakfast cereals that don't spike BS levels too high? So far I have been very unsuccessful in finding one that doesn't. I know cereals are all full of carbs and all, but I love cereal in the morning and was hoping someone might know of one that maybe doesn't shoot it up as high. I have tried the [name redacted] brand cereal and it tastes like I am chewing on cardboard strips. IT'S AWFUL!*

*Any suggestions??? (S2U101)*

### 6.3.2.4 Questions about other health concerns

*Women Only! Do you find that diabetes makes your libido almost non- existent? Thanks gals...... (S2U104)*

Of interest in the first two threads are the authors' acknowledgements that similar topics may have been discussed by the group in the past, but there were still unique issues that the author wanted to address pertaining to their circumstance. Participants also often seemed to be looking for individuals who share their experiences with diabetes to provide some guidance or assurances that their situation is not completely unique and that they are not alone. As demonstrated in the questions above, the topics usually pertained to issues about their individual concerns about diabetes. From the perspective of the authors, seeking knowledge about my unique situation and other aspects of my diabetes, asking questions that may not be appropriate or possible in other venues and seeking kinship with others who share similar experiences often emerged as possible motives for posting a question to the forum. Replies from the community in return provided some reassurance that the questions were valid enough to warrant a response. The combined responses also established the normative parameters with which the member could compare their own behavior. In effect, the responses both established the group norms for the behavior and addressed the unique situation of the member who created the post.

The vast majority of posts shared this self-centric trait. However, not all posts were focused on the author's concerns about his or her own case of diabetes. Posts in the forums also included: questions from people who had not been diagnosed, but were concerned about whether they were at risk for diabetes; questions from those who were concerned about the health of other individuals; and questions from those who were making statements or asking questions about diabetes in general, but that did not pertain to their particular situation.

Despite the relatively broad selection of codes, the investigator was unable to code a significant portion of the original discussion threads into a single, mutually exclusive heading. These posts were either multifaceted in nature and would have been inadequately described by a single category or were single topics that were infrequently addressed. Below are examples of those topics that could not be combined into a more discrete category.

*I recently started insulin as part of my diabetes management routine.*
*My question is... Do I notify my employer and client of this?*
*On one hand, it isn't really any of their business how I manage the diabetes.*
*On the other hand, I feel it good to inform those who I spend quite a bit of time around. If I experience a bad low, it would be good for them to be aware of what may be going on.*
*What would you do?*
*What have you done?*
*What are your fears of doing either?* ***(S1U35)***

*Hey everyone!! So I dont know about you but i hate wearing my medical id tag. Which i know if i ever get hurt and cant tell the parametics i would be in huge trouble. I was thinking about tattooing my id tag on my wrist so that everyone will always know and kinda a reminder to my self to be proud not ashamed of my disease. I was wondering if anyone has had problems with tattoos or what i should watch for when getting mine. Plus i would love any ideas or suggestion on what it should look like or what i should include with my tattoo!!*
*Thanks* ***(S1U16)***

Topics in the *other* category covered a wide variety of subjects, from concern over pre-diabetic symptoms to a solicitation that resulted in hundred of responses from others about the perceived discrimination against type 2 diabetics from those who had Type 1. That particular debate centered largely around the role personal behaviors played in the plight of Type 2s, and whether individual choices were largely responsible for their diabetes, as opposed to the predominantly genetic determination experienced by Type 1s. Other posts made announcements of upcoming dates or other groups of interest, some asked questions about technology issues pertaining to glucose meters and still others just seemed to provide an opportunity for the author to vent their frustrations to the group, or to gloat about their accomplishments in controlling their diabetes.

While the sites were similar in the proportion of topics relating to blood glucose levels, medications and other health issues, the sites were very different in the proportions of discussions pertaining to food (S1-9%, S2-19%) and sharing information, research and media articles (S1-8%, S2-1%). These differences may reflect the different cultures of the two virtual communities, or may reflect previous discussions that were written before the study period began, but that prompted the community to continue the conversation. For example, several of the food related questions on Site 2 discussed the various brands of pasta available that could be eaten without immediately affecting blood glucose readings. On Site 1, the founder of the site shared several hyperlinks to media coverage and research related to diabetes. While others contributed similar content, they may have done so in part because of the precedence set by the founder.

### 6.3.3 Nature of replies

#### 6.3.3.1 Who is answering? Demographics of respondents

Three hundred eighty-two unique users participated in the Site 1 (S1) discussions during the study period. One hundred thirty-eight original discussion threads produced 2298 replies in the forum during the observation period. Participants in these discussions had a mean age of 38.4. Fifty-five percent of the respondents identified themselves as women, while 33% of the respondents were men. Nine percent of the respondents did not explicitly disclose their gender. The mean age for women was 35.2 while the mean age of men was 44.6 years. Whether these ages represent the true mean age of the group is unknown, however, because only 28% of women and 25% of men chose to reveal any age information on their profiles.

Unlike S1, only 163 unique user IDs participated in the Site 2 (S2) discussions. One hundred thirty-four original discussion threads produced 1,307 replies during the study period. Participants in these discussions tended to be older than the S1 participants, with the average mean age calculated at 49.9 years. While the gender difference was greater in S1 participants (72% female, 18% male and 9% undisclosed), the difference between the mean age of the genders was smaller than in the S1 community. The mean age for women was 49.5, while the mean age for S1 men was 51.5. Also unlike the S1 community, 95% of women and 97% of men disclosed their age.

#### 6.3.3.2 What are they saying? A typology of replies

The replies from both sites were reviewed multiple times for themes that could be used to categorize the myriad responses provided to the original posts. After several iterations, a list of nine distinct themes emerged that seemed to capture the majority of the replies. The codes and their definitions are detailed in Appendix A.

Below is an example of an original post and a sample of the replies that followed.

*Carb counting?*

*Posted by S1U28 on March 7, 2009 at 11:23pm in Type 2 Diabetes Forum*

*Hey,*

*I have just started the carb counting. How many carbs do you have in a meal?*

*Reply by S1U281 on March 7, 2009 at 11:32pm*

*Hi there, I try to have no more then 50carbs per meal.. the less the better of course ! no more the 150 for the day. But I use this as a guide.. sometime I stick to it well and sometime I just doesn't happen..*

*everyone is different.*

*Cheers*

*S1U281*

*Reply by S1U282 on March 9, 2009 at 6:07am*

*I think it really depends on what type of diabetic you are and what meds you take - or wish to take - and whether you are on a basal-bolus routine or are only managing with diet/excercise - so there are a lot of variables.*

*I'm a type 2 and I adhere to Dr. Bernstein's diabetic guidelines - 6 breakfast, 12 lunch, 12 dinner. I take only metformin and Lantus. I could eat more carbs if I wanted to take more medicine.*

*Reply by S1U283 on March 7, 2009 at 11:35pm*

*I do about 60 a meal with a bunch of 15ers in between. But like she said everyones different*

This example highlights a fairly typical exchange on both forums. The author of the original post prefaces her question about how many carbs to ingest during a meal with a description that she is just starting to count the carbohydrates in her meal. The subsequent replies don’t just provide an answer, but they demonstrate a common experience by sharing their personal histories.  Taken together, the collective history of the members of the community provides a sense of “experienced empathy” from the respondents in both communities. The authors can see that others too have struggled or are presently wrestling with similar issues, reinforcing to the member that the question was a valid concern and that they are not alone in trying to manage that aspect of their diabetes.

#### 6.3.3.3 Establishing normative behavior

In one of the longer discussion threads on Site 1, a member started a discussion thread about an article he encountered that described various dangers associated with a commonly prescribed medication for type 2 diabetes. In describing the side effects, he related his story of how he adopted a diet consisting of only natural foods and a fairly demanding exercise regime. The thread elicited a number of responses from individuals who had also experienced side effects from the medications. The discussion evolved into various members hypothesizing about the pathogenesis of their disease. Later in the replies, however, the thread elicited concern from some members that the discussion should not dissuade those with type 2 diabetes from using their medications. Later comments generated pro-medication conversations and elicited feedback from others who did not feel confident that they could adopt the drastic lifestyle changes touted by the original author.

This particular thread demonstrated that discussions occurring in the online forums were more than a series of individual replies to the original author. Later replies often sought or provided clarifying statements to earlier comments in the thread. Individual pieces of advice often built on previous replies, generating a multifaceted knowledge base that contained the collective wisdom of the community. Members searching for information about a particular topic and finding prior discussion threads would read the "group guidance" created from the collected experience and cumulative advice on that topic. Members could, and often did, continue the conversation even if the topic had not been active for months. Threads tended to remain active long after the author of the original post made her last comments, shifting the focus of the responses to whomever appeared most in need of the information at the time.

### 6.3.4 Specific Types of Replies

#### 6.3.4.1 Talk to your doctor

One recurring concern over participation in online communities seems to be the potential for the participant to receive bad or dangerous information [96]. As such, one particular interest in the present study was to explore the groups' discussions about their interactions with physicians. Specifically, the analysis coded all recommendations to speak to a healthcare provider, be it an internist, endocrinologist, certified diabetes educator, dietician or any other health professional.

Both communities seem to approach their interactions with healthcare providers from the same perspectives. The most frequent recommendations came when discussing changes in medications. Whether discussing the effectiveness (or lack thereof) of their current treatment or recommending adjustments to the doses or types of medications the participant was currently taking, the group often reiterated that the participant should not make changes in their medication regime based solely on the advice of the community. Replies frequently reinforced the idea that those decisions were between the patient and his or her physician to work out together. The same recommendations seemed to be true when the discussing various symptoms the member was experiencing. Symptom discussions ranged from uncontrollable blood glucose readings to chest pain to tingling and numbness in the extremities. In those cases the group reiterated the need to seek medical consultation as quickly as possible.

That is not to say that all mention of physicians were positive. The communities, particularly site 1 members, often expressed concern over the ability of primary care physicians and internists to treat diabetes adequately. Several members expressed frustration over the number of new participants who explained that they had just been diagnosed with the disease, yet did not understand how to use their meters, what their ideal blood glucose levels were, or what to expect from their medication regimes. These threads often included a recommendation to see a diabetes educator or an endocrinologist for further care. Other concerns were voiced about physicians who appeared to be unresponsive to the patient's interests. In those cases the recommendation was for the patient to find another provider. However, the overall perception gleaned from the discussion was that the community viewed itself as a complement to traditional medical care, rather than as a replacement for it.

#### 6.3.4.2 Influence of group on member behavior:

Another legitimate concern over participation on the websites is whether the members actually change their behavior as a result of their interactions. To determine how often members signaled that they intended to or had already changed their behavior, the investigator coded all responses that indicated that the member had made some change based on the information they received on the site.

The most frequent changes mentioned were intentions to try a new recipe or to modify their diet and to speak with their healthcare provider. Many of the recipes shared and adopted by the community involved low carbohydrate or low glycemic index foods. Not unlike the findings in Zrebiec's and Jackobson's study [35], food was a frequent discussion topic and replies often shared recipes and the members' attempts to prepare the various dishes.

When an intention to discuss information with their healthcare provider was expressed by the member, the most frequently stated intentions described that the member planned to follow up with his or her physician to discuss medications and blood glucose levels. Another topic mentioned multiple times on Site 1 was an interest in discussing various diagnostic tests with their physicians to determine whether members had been diagnosed correctly. C-peptide tests and antibody tests were frequently mentioned as being of interest to the members on the site, although there did not appear to be any mention of the tests on Site 2.

### 6.3.4.3 Perceptions of the community by the members

*Good Luck and stay close with (Site 2). This is a wonderful support group. There is a wealth of information that gets communicated in the discussions. It also makes you feel less alone with this disease. We are all in this together!!- S2U102*

Direct quotes aided in determining what the members thought of the community and provided some insight as to why members participate. The investigator captured those sentiments by using the *in vivo* references about the group made by its members. The reply above to a post from a new user succinctly expresses the recurring themes from that analysis. The vast majority of references to the community were positive expressions of the community's attributes. Feeling supported, less isolated, learning new information about their disease and feeling optimistic and more confident about their future were common expressions from the members when they were describing the community to others in the discussion.

These perceptions seemed to be shared with many participants, regardless of how long they had been diagnosed with diabetes. One member expressed how she had learned more in her brief time on the site than she had in the nine years that had passed since she was first diagnosed. Another participant shared this perspective with another new member,

> *Welcome S2U89, I know it is a lonely and horrible disease, but dont ever feel alone. I have been type 2 since 1998 but just lately by coming on this place do I feel I am NOt (sic) alone. You will learn so many things on here, no matter how long you have had diatetes, a week or years. It is a great group and has helped me out alot. Ask anyone whatever you want on here, and you will always get help. Good luck and again welcome!-* ***S2U891***

Whether the group was providing information that explained things in a language that newcomers could understand or sharing their own personal experiences, members reiterated the themes of *salient information* and *shared experiences*. Members seemed to be able to discuss and learn about their diabetes in ways that they were not able to accomplish in their existing social networks or physical environments. Below are examples of social and environment barriers encountered by members that demonstrate the unique ways online social support groups seem to facilitate diabetes self-management. In one post, a new member explained "I really look forward to being a part of this community. Right now I feel the only person in the world with diabetes! :-)" She goes on to clarify what her current social interactions are like,

> *Whenever I talk to someone who is not a diabetic ...I get the impression the person thinks I am whining. So, now I just don't bring it up anymore. When people comment that I am losing weight I no longer tell them I found out I have type 2 diabetes and had to change my life style - I just tell them I went back to exercising! -**S2U894***

The replies go on to provide her guidance and share the respondents' own experiences, reiterating the fact that they too had often felt alone, and had found in this community a place where they knew they could discuss their concerns. One member included an invitation to email her directly whenever she needed to talk.

From perceived social isolation to extreme geographic isolation, the following discussion demonstrates the unparalleled scope and scale of online communities. In this example, a member describes the particular geographical constraints he and his wife encounter, followed by two of the replies from the community as to how they might be able to help.

*…Please understand that we live in Saudi Arabia. Our doctor is actually 500 kilometers (over 200 miles away). We visit him sometimes but we usually communicate with him via emails and faxes. Like all foreign doctors in the Kingdom, he is extremely busy so we don't waste his time with perhaps simplistic questions. Any advice any can give us is greatly appreciated.**S1U131***

*Reply from S1U1313…I can't imagine how hard management of diabetes could be when your doctor is 500 km away! While we shouldn't be giving direct medical advice if we're not medical people, there are lots of people here with many years of experience. Don't hesitate to ask.* ***S1U1313***

*Reply from S1U1314…Wow, I thought I had it hard living in Guatemala...at least my endo is only an hour away! Best of luck to you and there are a lot of knowledgeable people on here to help; you might encourage your wife to post herself as she will enjoy connecting with everyone.* ***S1U1314***

The replies reinforce the perception that not only do they share common experiences with their diabetes, but that there are members who share similar access constraints. While the first reply acknowledges that the information they offer online is no substitute for professional medical advice, both replies acknowledge that the group can offer valuable and relevant support. In this particular case, the author was asking about his wife's insulin injection practices and whether she should leave the needle inserted after releasing the folded skin. The majority of other replies shared their personal practices and providing advice, reinforcing the idea that this topic merited discussion. While he was worried that the topic was too “simplistic” to bother their physician, the community reinforced the perception that this was an appropriate place to ask for such advice.

## 6.4 CONCLUSIONS

Discussion forum threads often began with topics that one would predict would be of interest to people with type 2 diabetes. Questions about medications, blood glucose control, interactions between diabetes and other comorbidities and food were among the most popular concerns. However, the overarching theme arising from the discussion thread analysis was that participants in both virtual communities used the discussion forum for more than just an opportunity to find an answer to a question about diabetes, but rather used the discussion threads as opportunities to have *my questions* answered about *my diabetes*. In other words, participants often described their personal experience with an aspect of diabetes and asked the group to answer questions or share experiences that were similar to their specific circumstances. Unlike the type of information that one would expect from a site with content generated from traditional expert sources, the replies from these communities usually framed their advice within the context of their personal experiences with the issue. Once started, those discussions evolved into a community-centric knowledge base of information on that reflected the “experienced empathy” and “group guidance” of the members.

The phenomenal growth of individuals using the Internet to research health-related conditions and the unprecedented access to the experiences of others who are at various stages of managing similar conditions signifies a new dimension of healthcare exchange that can no longer be ignored. Providers, educators, advocates and researchers should understand these online behaviors more deeply to determine how best to leverage this new source of information for their patients or clients. In the two groups analyzed during this study, members who posted a question or statement to the group received “experienced empathy” from other members and “group guidance” from the community as a whole. The information that evolved from the original discussion thread was usually directly relevant to the member based on the experience of the other members, but was made even more salient by the clarifying interactions that helped the community garner a more comprehensive picture of the conditions that could affect their response. The information not only gave the community a better perspective, it helped members think about their own responses in more depth and continue to share their conversation with a community that welcomed their dialog. Rather than viewing the discussion as “whining” about their disease to those who did not share the same experience, participants found others who shared much in common.

While the results of this study may not be generalizable to other conditions or websites, from these data it appears that concern over the potential for Internet users to hear and adopt potentially unhealthy advice from these communities may be exaggerated. In general, the community recommended that the member posting a question consult their healthcare provider before changing medications or adopting more stringent lifestyle changes. As part of the cumulative wisdom demonstrated in the discussions, those who espoused drastic changes in lifestyles or treatment regimes were generally met with healthy skepticism from those who had unsuccessfully attempted the changes themselves. A recurrent theme, as explicitly stated on Site 1 quite frequently, was the disclaimer that “your mileage may vary” with whatever changes the community offered.

Just as the community was critical of questionable advice from its members, it was also critical of what it collectively perceived to be inadequate medical management of a member’s diabetes. The community frequently advised its members to seek care from an endocrinologist or find a certified diabetes educator when it perceived that the care provided by the current internist or PCP was inadequate. Likewise, members of the community often chastised physicians who appeared to have adopted a pedagogical relationship with their patient and who were unwilling to discuss alternatives of interest to the member. Community members questioned their motives and challenged their clinical competency while espousing the role of the clinician as a consultant.

Advising patients to avoid Internet discussion groups may socially isolate individuals who do not have an existing social network that they can rely on to ask questions that may not be suitable in other settings. Given the limited time available to discuss a patient’s concerns during an office visit or session with an educator or dietician, online discussion forums may be the only safe place to discuss issues such as tattoos, the pros and cons of revealing their disease to their employer, or other important questions about the implications of diabetes on their lifestyle and not just their health. In addition, people living with the disease may actually be a more appropriate resource for information on topics such as these than a diabetes educator or physician.

The qualitative methodology used in this analysis allowed the investigator to explore the content and use of these sites more deeply than would have been possible with a quantitative study and was an appropriate methodology to use to help determine how the social ecology of online communities may vary from physical communities. However, the methodology employed in this study also has two significant limitations. The first is that the results found from these two websites are unlikely to be generalizable to other virtual communities discussing type 2 diabetes, or to other types of chronic disease. In fact, even within the two sites there were differences in the proportions of the topics that were discussed. The nature of the communications within the online groups is likely to vary significantly reflecting both the culture and technology that shapes the communication in these venues. The second significant limitation is that without direct interaction with the community, there was no way to verify constituent validity, wherein the members of the community under observation have an opportunity to review the findings of the research team and provide their feedback on the findings. The methodology did afford the team the complete and total transcripts of the interactions between the members, which were not influenced by the presence of the investigator. Relying on these unaltered and complete communications should provide a solid foundation upon which to base the conclusions that have been drawn.

The technology enabling unprecedented use of the Internet as an interactive communication medium is still in its infancy. Its extraordinary adoption rate, however, is unlike anything seen in history and will undoubtedly shape the future provision of medical care delivery, patient education and social support. This research is among the first to study these virtual communities among diabetic patients, and provides some insight into how the technology is currently being used. Future research will help determine how the support provided in online communities compares to physical support networks, and what effect participation has on healthcare utilization, perceived quality of life, patient-physician communications and adoption of health behaviors. Given the Internet’s widespread adoption and the astonishing rate of technical innovation, it seems certain that the future of diabetes care will be shaped by the ability of diabetics to share their experience and advice with each other through online support groups such as these.

# **7.0 DIGITAL DIABETICS:** A DESCRIPTIVE AND QUALITATIVE ANALYSIS OF THE WEB 2.0 PROFILES OF MEMBERS OF ONLINE SUPPORT GROUPS FOR TYPE 2 DIABETES

## 7.1 INTRODUCTION

The unprecedented growth of social networking sites such as Facebook are fundamentally changing the way people socialize with each other. While most of the use of social networking sites today involves (re)connecting with acquaintances and engaging in entertainment, this new medium also holds the potential to provide new ways for patients to provide support to each other. Only four years after its initial launch, Facebook has more than 300 million members [95]. The adoption of this technology has occurred faster than any other technology in history. Given its prevalent use in today's society and its relatively recent introduction in computer-mediated communications, social networking and other sites with interactive features known as "Web 2.0" [6]sites are fertile grounds for public health exploration.

The building blocks of these massive online communities are individual profiles [80]. These member-centric websites are built initially by the completion of an online form requesting information about the new member. Participants are free to describe or contrive identity signals such as age, gender and self-portraits in response to the form. Once completed, the member can then utilize or ignore various features of the website that allow them to share an online photo album, link their page to other friends in the virtual community, post content to personal blogs and even send virtual representations of social interactions like hugs, pats on the back or a virtual flower bouquet to other members of the community. In addition to being the building blocks of the online community, the members also choose the other blocks to which they want to associate.

They then add the mortar connecting them through their mutual and reciprocal use of the communication features enabling socialization on the site.

According to Amy Jo Kim [97], member profiles are necessary to provide context for other members considering joining the site, showcasing members, and building trust between the members of the community. In addition to the benefits to the community, the profile page can be the hub of socialization for the member [98]. Allowing the member to ask questions and interact with those who share a similar experience with their disease could help not only increase their knowledge of health risks or benefits but could also provide them real-life examples of members who have successfully managed their disease. These are all important constructs for those seeking to build a thriving online community and could be particularly useful for those focusing on health issues. For example, showcasing certain members could help increase self-efficacy and provide a role model for new members, elements that could both lead to successful health behavior change according to Bandura [56].

An increasing number of people are searching the Internet to find medical information [93]. Before the World Wide Web existed in its present form however, Granovetter in 1973 described the potential benefits of using weak ties in one's social network to acquire new knowledge. He defined the strength of the social ties as "a combination of the amount of time, the emotional intensity, the intimacy (mutual confiding), and the reciprocal services which characterize the tie."[99] His theory was that weak social ties, rather than strong ones, would expose the member to new information. The theory predicted that two individuals with strong social ties would likely already know much of the same information based on the frequency of their interactions. The strongly tied relations would have shared experiences and would likely know the same group of individuals. Individuals to whom we are weakly tied offer greater potential to introduce new knowledge, as they have different experiences and likely have acquaintances with whom we are not familiar. Since Granovetter's original work, the emergence of Web 2.0 sites have significantly improved access to a broad variety of experiences and the potential to establish many more weak ties through participation in online support communities. The information (experienced empathy and group guidance) shared through the online discussion forum reported in Chapter 4 could be considered an example of weakly tied individuals sharing information with each other.

While access to new information is an attribute of weak ties within a social network, others have described the benefits of strong ties. In particular Lin, Woelfel and Light described their empirical study showing that strong ties, rather than weak ties, demonstrated a buffering effect against depression when the individual was faced with an important, but undesirable, life event [62]. If there are potential health benefits to both strong and weak ties in ones social network, a relevant question may be to determine whether other features such as the ability to write a personal blog, establish friends online or to send virtual social interactions provide an opportunity for strong ties to develop among members of the community.

A recent meta-analysis of 28 studies by Rains and Young provides evidence that participation in computer-mediated support groups can influence health outcomes [100]. The team reviewed the literature reporting the effects of formal online interventions. Unlike the sites being studied in this monograph, their research focused exclusively on sites that provided a formal educational component, had a closed membership and had a defined participation period with beginning and ending points of participation. Similar to the sites analyzed here, however, the meta-analysis included studies that involved an online support group with a focus on a particular health condition and one where computer-mediated interaction between the participants occurred.  The authors concluded that participation in online social support groups led to significant increases in quality of life, perceived social support and self-efficacy, while significantly decreasing the likelihood of depression.

Given the potential for these virtual communities to help people manage their disease, the present study examined two online communities focused on type 2 diabetes. Type 2 diabetes was chosen because of the increasing incidence and prevalence of the disease in the US and the complex lifestyle changes, medication regimens and invasive and frequent monitoring it requires to be successfully managed. According to the CDC, the prevalence of diabetes has risen from 3.5% of the US population in 1980 to 7.8% in 2007.  In 2007, approximately 1.6 million new cases of diabetes were diagnosed in adults. Approximately 90%-95% of those new cases were type 2 diabetes. [101]

## 7.2 METHODOLOGY

The investigator chose two online social support sites with Web 2.0 features that addressed type 2 diabetes and collected publicly available profile data from a purposive sample of 30 participants from each site. The investigator then chose ten participants who identified themselves as male, ten who self-identified as female and ten who chose not to state their gender explicitly. Because of differences in the search parameters available on each site, the method for selecting these individuals varied slightly between the two sites. On Site 1, members of the community who revealed in their profile that they were a person with type 2 diabetes were chosen by searching for “Type 2 Diabetes” and selecting the gender from the advanced search on the “members” page. Gender-undisclosed members were chosen by only selecting on “Type 2

Diabetes" and manually searching through the search pages for members who had not disclosed their gender. On Site 2 members of the "Diabetes Type 2 Support Group" were filtered based on their gender. To identify gender-undisclosed members, the investigator also manually searched through member profiles to find those who did not explicitly state their gender. On Site 2, that required viewing 582 individual profiles to find ten who had not disclosed their gender. Identifying gender-undisclosed members on Site 1 involved searching fewer than 100 individual profiles to find the desired 10 profiles.

Once gender identification was determined, the investigator reviewed each profile. Publicly available and relevant data from the profile was captured in a Microsoft Excel spreadsheet. Because of the different features of the two websites, slightly different information was captured from the two sites, as detailed in Table 7-1.

**Table 7-1 Select elements captured from profiles of members**

| Site 1 Profile Fields Captured | Site 2 Profile Fields Captured |
|---|---|
| Pseudonym<br>Profile URL<br>Type of photo used for profile site<br>Gender<br>Age (if disclosed)<br>Response to "Do you have diabetes?"<br>Date diagnosed<br>Type of treatments<br>Response for "How did you find the site?"<br>What do you do for a living | Pseudonym<br>Profile URL<br>Type of photo used for profile site<br>Date Joined<br>Text from "About Me" section |

In addition to the fields listed in Table 7-1, the use of other features was recorded from each profile webpage. Every two weeks during the study period a list of all the friends and the number of photos listed for each profile was observed for additions and deletions. The investigator recorded group memberships for each member every six weeks, looking for changes in participation in the groups. While both sites had groups created by the members, Site 2 also provided the option of joining over 600 different disease and lifestyle related groups developed by the site administrators. The investigator recorded membership in each of those groups and changes such as joining a new group or leaving a group were noted. Descriptive statistics are presented to provide a picture of those profiles being observed and are not likely to be representative of all the members of the sites or online social support group members in general.

The personal blogs of the participants were recorded twice during the study period. Originally the investigator planned to download only those blogs posted during the study period, however, there was insufficient activity on the sites to provide any valuable data. Instead, I downloaded all of the blogs from all the members in the sample beginning with the year prior to the study. Both sites allowed the member to keep the blog private among their friends or publicly available, and I recorded only those left publicly available. The expanded timeframe allowed the investigator to record and analyze slightly more data and to draw comparisons between the types of posts and replies on the discussion threads and those occurring on the personal blogs.

Another feature unique to Site 2 was the ability to exchange graphics and text representing virtual social interactions (VSIs). This feature allowed members to exchange graphic “emoticons” that represented several types of social interactions such as hugs, pats on the back and gifting flowers. Along with the graphic, members could send the recipient a message. At the end of the study period, the investigator tallied the number of VSIs given by the recipient and the number and types of VSIs received for each profile being studied and recorded the results in an Excel spreadsheet for quantitative analysis. The investigator also recorded the messages received by the participant and performed a content analysis on the text. Since the topics of the personal blogs and VSIs were often about issues other than diabetes management, codes were modified to describe the new exchanges. The conversations in the VSIs were similar to recording one-side of a telephone conversation. The only available text to record was that received by the members in the sample. Nonetheless, the communications provide valuable insight on the use of this feature from the members of the community.

To report the analysis, we will first look at the attributes described and the features utilized by the members to complete their online profile. The responses to the registration questions are described beginning with traditional demographic information. From there we will review the use of the photo sharing feature of both sites to determine what pictorial representations the members chose to share with others in the community. We will then also look at the ability to define individual goals for the members, a feature that was unique to Site 2 but that may be of interest to public health practitioners.

Following the profile analyses, we will review profile features that facilitate member interaction and that begin to form the links between profiles.  I will first analyze their participation in the various member initiated groups available on both sites.  Site 2 also had other health communities available for members to join and the sample's participation in those communities will be reported as well. Following that discussion, I will report the use of features that could potentially support strong ties between the members. The first was the use of the "friend" feature on the sites, which linked profile pages and alerted members to online activity from each of the friends in their network. Next, we will report the use of personal blogs, the use of which varied greatly between the two communities, likely due to the title used to describe the feature. While clearly a way for the individual to further define their online identity, the ability to respond to journals resulted in social exchanges that were similar in intent to the online discussion forums, but unique in the content shared between the members. Finally, the ability to share virtual social exchanges between the participants is discussed, another feature that was unique to Site 2.

## 7.3 RESULTS

### 7.3.1 Demographics of the sampled profiles

#### 7.3.1.1 Female Participants

In completing the member registration form, none of the 10 women in the sample from Site 1 disclosed their age. If age can be inferred from the mean age of participants of the Site 1 discussion forum on type 2 diabetes, the mean age for women on Site 1 was approximately 35.3 as described in Chapter 4. Similarly, the investigator was unable to determine the length of membership of the members, as that information was not publicly available. Conversely, all women in the sample for Site 2 disclosed their age, with a mean age of 43.0 (range 25 to 57). The sample was slightly younger than the average age of the women participating in the Site 2 discussion thread, who had a mean age of 48.0 years. Women in the Site 2 sample had been members of the community for an average of 409.3 days (range 22-756 days).

#### 7.3.1.2 Male Participants

Only two of the 10 men on Site 1 disclosed their age. The inferred mean age, if similar to the participants of the discussion forum on type 2 diabetes on the site, was approximately 47.7 years. As above, no information was available regarding the length of their membership in the

Site 1 community. Similar to the female profiles sampled, all male members of the Site 2 sample disclosed their age, with a mean age of 45.8 (range 23-73 years). This result appeared again to be slightly younger that the male participants in the Site 2 discussion forum studied, which had a mean age of 53.8. Men in the Site 2 sample had been members of the community for an average of 294.8 days (range 12-684 days).

#### 7.3.1.3 Members withholding gender information

Similar to the participants above, those who chose to withhold their gender identification on Site 1 also withheld information about their age. No mean age could be calculated for those who participated in the type 2 discussion forum on the site, as only one individual from that cohort who participated in the discussion forum chose to reveal his or her age. The mean age for the 10 individuals who withheld gender identification on Site 2 also could not be estimated, as only 2 of the 10 individuals disclosed their age. The group withholding their gender on Site 2 had been members of the Site 2 community for a mean period of 286 days (range 26-480 days).

### 7.3.2 Use and types of self-photographs on profile pages

Earlier in this monograph I hypothesized that the decision to remain anonymous in the virtual community could afford some benefits to the member, including their ability to ask questions that may be socially taboo and the ability to withhold identity cues that could be used in a physical setting as a basis for discrimination. Given the ability to control identity cues in the virtual world, this study sought to determine how members would represent themselves with a feature that allowed members to upload a photograph that would be used to represent the member in the virtual community.

Both sites offered members the ability to upload a personal photo to use on their profile page. The types of photographs used by members in the sample are summarized in Table 7-2. On Site 1, the majority of men and women used what the investigator believed to be a picture of the member based on the accompanying text description or other clues on their personal profile page. That result differed from the photos on Site 2, where 40% of the women used a picture falling into the "other graphic" category, followed by 20% each either using photos of animals (usually appearing to be pets) or using the default graphic of a silhouette. On Site 2, three men appeared to use a photo of themselves and two members each used a cartoon character, default graphic and "other graphic." Those who withheld their gender predominately used the default

**Table 7-2 Type of Photos Used on Profile Pages to Represent Member by Gender Cohort**

| **Type of photo used** | **Site 1** | **Site 2** |
|---|---|---|
| **Women** | | |
| Self | 7 | 1 |
| Other Graphic | 0 | 4 |
| Animal(s) | 1 | 2 |
| Default Graphic (Silhouette) | 1 | 2 |
| Cartoon Character | 1 | 0 |
| Person | 0 | 1 |
| | | |
| **Men** | | |
| Self | 6 | 3 |
| Default Graphic (Silhouette) | 2 | 2 |
| Other graphic | 1 | 2 |
| Cartoon Character | 1 | 2 |
| Place/ Scenery | 0 | 1 |
| | | |
| **Undisclosed-gender** | | |
| Default Graphic (Silhouette) | 6 | 7 |
| Animal(s) | 3 | 0 |
| Other Graphic | 0 | 3 |
| Cartoon Character | 1 | 0 |

graphic for each site (Site 1: 6/10, Site 2: 7/10). Three members on Site 1 used a photo of an animal and three members on Site 2 using an “other graphic”.

### 7.3.3 Site 1 responses to other registration questions

Both sites allowed members to present certain information about themselves on their profile page, but the approach between the two sites was very different. Site 1 members completed a structured questionnaire pertaining to specific aspects of their life and their diabetes history. The information gathered from the questionnaire was placed on their profile page. Conversely, Site 2 members could complete an open-ended field entitled “About Me” where they were free to write whatever text they thought relevant.

In response to the question “How did you find Site 1?”, 23/30 respondents said that they found the site while searching for information on diabetes on the Internet, or found the community while on another website, including blogs, a popular photo-sharing site and other discussion forums not related to diabetes. Others found the site after having “friends” refer them to the site. Two members used this section as a way to promote their personal or commercial activity. One member’s response solicited support to restore land to convert it to a diabetic camp for children. The other member discussed the origins of his commercial bakery operation which sells muffins which he claims positively affect blood glucose levels. The owner described the origins of his journey and how he donates a portion of the proceeds to a researcher searching for a cure for Type 1 diabetes.

Members on Site 1 also described their treatments for diabetes. The majority of the members indicated that they used a combination of oral medications, diet and exercise. Eleven of thirty members used shots, 20 of 30 members used diet, 19 of 30 used oral medications and exercise, and 3 members reported using a pump in their treatment for type 2 diabetes.

Site 1 also asked members to provide the date they were initially diagnosed with diabetes. Six women responded with an average length of diabetes of 12.4 years. Similarly 6 out of 10 of the men responded with an average of 12.1 years. Half of the 10 members sampled who did not disclose their gender responded and that they had been living with their diabetes diagnoses for 9.3 years.

### 7.3.4 Other profile identity cues and participation options- Site 2

The profile sections for Site 2 contained a free-text based “About Me” section where the members could provide cues about their identities without being prompted for any specific information. Among the male and female members, only one woman chose not to reveal any information about herself. Conversely, among the gender-undisclosed cohort only one member in the sample chose to reveal anything. Three major themes emerged from the content of this section. The most prevalent self-description included the member’s medical history and the impact health concerns had on his or her life. Other content included information about their families and/or their occupations. Two members shared their general philosophy towards life, while two others (one man and one woman) used the section to describe their ideal mate.

In addition to the information above, all members on Site 2 had the option of changing a small graphic representing their emotional state as horrible, bad, ok, good or excellent. It appeared as though the default emotional setting for the members was set at “OK” and if the member did not actively change the setting, the default appeared on their profile page. Table 7-3 describes the self-reported emotional state by gender cohort and for the entire Site 2 sample. Interestingly, the profiles of those who listed their emotional state as “horrible” were featured in a special section of the global member directory known as the “Members in Need” section.

**Table 7-3 Self-reported Emotional State by Gender Cohort**

| | **Horrible** | **Bad** | **OK** | **Good** | **Excellent** |
|---|---|---|---|---|---|
| **Overall Percentage** | 13% | 7% | 43% | 33% | 3% |
| **Women** | 10% | 10% | 50% | 20% | 10% |
| **Men** | 10% | 10% | 40% | 40% | 0% |
| **Undisclosed** | 20% | 0% | 40% | 40% | 0% |

### 7.3.5 Use of photo sharing

One of the more prevalent features of Web 2.0 and social networking sites is the ability for members in the community to upload photographs to their profile page. The use of a photo sharing feature is logical in social networks where pre-existing friendship networks exist, given the potential for shared physical experiences. However, the investigator was interested in knowing how often members would use the feature and what type of photographs would be shared in a community that consists primarily of members who were strangers before joining the disease-related community. Both sites allowed the members to share photographs.

On Site 1, the vast majority of members in the sample had not uploaded any photographs. Only 6 of the 30 members uploaded a picture (2 women, 3 men, 1 gender-undisclosed member). The range of the number of photos uploaded varied from 1 to 32. Only two of the members showed any change in the numbers of photos between the beginning and end of the study period.

One member uploaded 11 additional photographs to her initial 21 in the first two weeks of the study period and one member added 14 additional photographs in the last week of the study period, having not uploaded any prior to that.

On Site 2, slightly more individuals added photos to their profile page, with 10 of the 30 members uploading a picture (5 women, 5 men). None in the undisclosed gender cohort uploaded a photo. The range in the number of photos was quite different, however. The minimum number of photos uploading in the sample was 5 and the maximum number of photos was 1230. Four members made changes to their photo albums between the first and last week of the study, ranging from withdrawing one photograph to adding 643 new photos.

The investigator was also interested in analyzing the type of photographs shared on the profile pages. Given the sensitive nature of the topics discussed in the sites and the potential benefits of concealing identity cues in discussing those topics, this study evaluated the types of cues that could be determined from the photo albums. Because of the unexpectedly large size of some of the photo albums, the investigator only codified the first 30 photos in the members' albums. The investigator developed a series of 9 codes to describe the contents of the photo albums in the sample, to describe the type of pictures members chose to share. The results are summarized in Table 7-4.

The three most common types of photos on Site 1 were: 1) pictures of the member (as determined by the text accompanying the photo by matching the physical description with the individual in the photo or by the subjective interpretation of the investigator); 2) pictures of family members (using a similar methodology) and; 3) "other graphics", which could include a variety of different graphic art. The most popular photos in the albums on Site 2 were: 1) "other graphics"; 2) pictures of family members and; 3) pictures of scenery or locations which were

**Table 7-4 Types of photos in sample photo albums for each community**

| Type of Photo in Album | Site 1 | Site 2 |
|---|---|---|
| Family Member | 20 | 31 |
| Place/ Scenery | 10 | 28 |
| Self | 22 | 23 |
| Animal(s) | 9 | 22 |
| Photos marked as private | 0 | 9 |
| Group | 3 | 7 |
| Person | 0 | 5 |
| Cartoon Character | 0 | 1 |
| Other graphic | 11 | 37 |

often vacation photos or photos of other favorite places of the member. Pictures of the member were not uncommon on Site 2, but were slightly less prevalent than those on Site 1 relative to the number of other photos.

### 7.3.6 Goals

One of the features that was unique to Site 2 that might be of particular interest to those interested in affecting health behavior change was the ability for members to publicly mention goals that they were interested in accomplishing to record progress towards their goals. The investigator was interested in how often this feature was used in the sample, what type of goals were recorded, and what type of progress was made towards those goals.

Out of the 10 members sampled in each cohort, 6 women, 5 men and 2 members with undisclosed gender cohort listed at least one goal on their profile. Four members of the 13 who used this feature listed 2 goals, with no apparent correlation by gender identification. Table 7-5 shows the various goals listed by the members.

Five of the members who listed a goal reported progress towards accomplishing the goal at some point during the study period. DS22 accomplished his goal of finding one good friend and was rewarded on the site by a virtual trophy appearing next to his accomplishment. DS20’s goal of “beat the nicotine habit” apparently started on his quit date, as the site informed those visiting of how many days he had been smoke free. DS 16 apparently withdrew the goal of “control my borderline PD,” as the goal was not visible on the final download during the study period.

**Table 7-5 Goals listed by members of Site 2 sample**

| Member | Goal 1 Description | Goal 2 Description |
|---|---|---|
| S2U1 | get off diabetes meds | |
| S2U4 | lose 20 pounds | |
| S2U6 | finish my college degree | |
| S2U7 | find a new partner | |
| S2U8 | make a new friend on Site 2 | to control diabetes |
| S2U10 | make a good friend | |
| S2U14 | improve Spanish | write a book/ metaphysics |
| S2U16 | manage my diabetes | control my borderline PD |
| S2U19 | help my brother/save his life | |
| S2U20 | beat this nicotine habit | |
| S2U21 | work thru hypothyroid | lose 10 pounds |
| S2U22 | find one good friend | no peeling of skin |

The most common goal was to find a new friend/partner through the site (n=4) followed by managing or controlling diabetes (n=3). Weight loss was also mentioned as a goal twice. Other goals seem to be related to other health concerns, self improvement or helping others.

When viewing the goal section of members’ profiles, the investigator observed that others could provide support for the member by clicking on a link to send the member a message. Out of the 12 members in the profile who listed a goal, only 3 members received a note of support from other members. The notes were usually expressions of support such as “you go gurl [sic]” or were encouragements to keep pursuing the goal despite some setback.

### 7.3.7 Participation in member-initiated groups

#### 7.3.7.1 Site 1

On both sites, members had the ability to create groups within the larger infrastructure of the websites. Participation in any of the groups was voluntary and could be easily discontinued if the member changed his or her mind. The investigator recorded group membership from the profiles at the beginning, middle and end of the study period to determine how dynamic group membership changed in both communities. On Site 1, 15 of 30 members participated in at least one member-initiated group. The mean number of group memberships for the members who participated in at least one group was 5.5 (range 1 to 12). The distribution of men and women participating in the groups seemed similar, with a mean number of group memberships of 2.4 for both genders. In the cohort of those who did not disclose their gender, 9 of 10 members did not participate in any groups and one member participated in four groups. Despite a few exceptions, membership appeared to be relatively stable during the study period. Site 1 members tended to belong to the same number of groups throughout the entire period, ranging from no change at all, to one member joining four additional groups.

Members in the sample tended to belong to groups discussing specific medications or treatment therapies (e.g. “Symlin user forum”, “pumping our insulin”). Other member created groups could be broadly classified as “diabetes and other health conditions” (e.g. “diabetes and disability”), geography-centric groups (e.g. “Canada Diabetics”) and special interest groups (e.g. “Geeks with diabetes”, “Diabetic Dancers!” and “Diabetic NASCAR Fans”). The investigator could not determine through the methodology employed for this research what, if any, moderation or editorial control was exercised to restrict the types of member initiated groups. While the topics of some of the communities were unexpected, none of the names of the communities seemed to be controversial or to fall significantly outside of social norms.

#### 7.3.7.2 Site 2

On Site 2, 17 of the 30 members sampled did not belong to any member-created groups. The mean number of group memberships for those participating in at least one group was 6.4 (range 1 to 17). Women seemed to participate in the member-initiated groups more often than men did, with a mean membership of 4.6 groups per participant for women and a mean of 2 groups for men. It should be noted, however, that only 3 of 10 men participated in a group, compared to 8 out of 10 females. For those withholding gender on their profile, 8 out of 10 members did not belong to any group. Of the two that did belong, one belonged to 2 groups and the other belonged to 15 groups. Site 2 membership was also mostly stable. The range for those who had some change varied from one member leaving all 7 of the groups he belonged to at the beginning of the study period, to one member joining 6 additional groups.

Site 2 had a much broader variety of member-created groups with much less focus on diabetes. This result was not unexpected, given the diversity of the overall site hosting more than 600 disease communities rather than having a predominant focus on diabetes. Common themes among the titles of the member-generated groups included groups addressing mental and physical health issues (e.g. “Chronic Pain Group”, “Fibromania”), marital and dating focused groups (e.g. “Divorce after twenty years together”, “Rebuilding Marriage After Infidelity”), humor and joke sharing groups (e.g. “fer the lov of laughter”, “Club Funny Bone”), positive thinking groups (e.g. “What I did right today”, “Daily Positive Thoughts”) and a wide variety of other special interest groups (e.g. “Obama Watch”, “Movies!Movies!Movies!!”). Some moderation may have existed on Site 2, as one group warned its members not to share foul jokes because such activity would be reported to the administrators.

#### 7.3.7.3 Site 2- Membership in administratively-created health communities

One feature that was different between the two sites was Site 1’s exclusive focus on diabetes compared to Site 2’s inclusion of a broad diversity of health related conditions. Site 2 provided over 600 communities to choose from and members could belong to as many communities as they desired. Since the sampling frame for the Site 2 profiles came from the Type 2 diabetes community, all the profiles sampled belong to that community. However, the investigator was interested in knowing what, if any, other groups were common among the sample. Most of the members in the sample belonged to more than just the type 2 diabetes community. Twenty-two of the 30 members belonged to other groups as well. Of the 8 who belonged only to the type 2 diabetes group, 5 were members in the cohort who chose not to reveal their gender.

Altogether, the members in the sample participated in a total of 69 unique health-related communities, not including the type 2 diabetes community. The mean number of non-type 2 diabetes community memberships for all participants sampled was 3.2, with a wide range for the means based on the gender cohort. Women belonged to an average of 5.9 other communities (range 0 to 15); men belonged to an average of 2.6 other communities (range 0 to 7); and the undisclosed gender cohort belonged to 1.1 other communities on average (range 0 to 3).

Not unlike the member-initiated groups, membership in these administratively-created groups appeared to be stable. During the study, 23 of the 30 participants made no changes to their memberships. Activity in the 7 members who did make a change ranged from 1 member dropping membership in 3 groups to 5 members joining 1 additional group. The most common co-occurring communities in the sample were as follows: 6 members belonged to the Depression community; 5 members belonged to the Chronic Pain community; 4 members belonged to the Anxiety community. Three members each belonged to the Site 2 Members community, the Diets and Weight Maintenance community and the Back Pain community. A total of 12 other communities shared two members with the Type 2 diabetes group.

### 7.3.8 Network of friends

Another popular feature on Web 2.0 sites, and the feature that social networking sites are best known for, is the ability to explicitly define friendships on the site. The feature allows two members to link their profile pages to each other and receive a notice whenever the friend’s page has been updated. Most Web 2.0 sites require both members to confirm the link, with one member initiating the link and the other member confirming the desire to have the two profiles linked. A section of the profile page titled “Friends” listed all of the friends of the members in the samples. To determine how often members used this feature the investigator reviewed the network of friends on a biweekly basis during the study period.

#### 7.3.8.1 Friends on Site 1

The analysis revealed that the site administrators for both sites appeared to be listed as friends by default. That setting aside, the ability to make connections with others on the site was one of the more popular features utilized. On Site 1, only 6 members had no friends listed and had apparently actively delisted the administrator as a friend. No members had just 1 friend, as would be expected if the member chose only to accept the default friend request from the administrator without adding others. While the average number of friends varied each week, the average number of friends listed within the sample on week 12 was 17.3 for all three cohorts combined (range was 0 to 123). Further analysis revealed that the means were quite different based on the gender identified by the member. Women had a mean of 21.5 friends; men had a mean of 25.7; those in the undisclosed gender cohort only averaged 4.2. In fact, of the 6 members identified with no friends, 5 were in the undisclosed gender cohort.

This study also monitored additions and deletions of friends from the social network of the members in the sample. Forty-seven percent (n=14) of the members sampled had a change in the total number of friends during the study period. The majority of the members had minor changes, adding or deleting 1 to 3 friends. There were, however, two notable exceptions. The total net change between the beginning and final week of the study for all of the friend networks was a cumulative increase of 82 friends. One female member in the sample accounted for 29 new friends and one man accounted for 60 new friends during the period. Minor changes resulted in a net decrease of 7 friends from 12 other members combined resulting in the final tally.

The combined network of friends on Site 1 included 307 unique members at some point during the study period. Not including the site administrator, 7 members of the sites appeared to be highly connected to others, as they were in the friend network of more than 30% of the members in the sample. Conversely, 250 members (80% of the unique members) in the combined network were listed as a friend only once in the sampled members.

#### 7.3.8.2 Friends on Site 2

Not unlike Site 1, the friend feature of Site 2 was also a popular feature. Only 3 members on the site had no friends, again actively delinking the default setting for the administrator. Five members listed only the site administrator as the friend by week 12. The mean number of friends for the entire sample on Site 2 was 16.4 (range: 0 to 91), similar to the 17.3 mean demonstrated in the sample on Site 1. Likewise, the mean number of friends for women on Site 2 was 27.9, slightly larger than the 21.5 friends averaged in Site 1. Those in the undisclosed-gender cohort had a mean of 4.2 friends, the same as the cohort of members on Site 1. Men on Site 2 appeared to have fewer friends on average than those on Site 1, with a mean of 17.2 friends on Site 2, compared to the 25.7 average observed on Site 1.

Fifty-three percent (n=16) of the members made some change to their number of friends during the study period, resulting in a net increase of 81 friends. Again, 3 members accounted for the majority of the increase, adding 73 friends between them. One interesting difference was that 11 of the additions were from a member in the undisclosed gender cohort. The largest single increase again came from a man who added 46 friends to his network during the study period.

Unlike Site 1, the network of friends on Site 2 appears much more diverse. The combined network of friends for all of the sampled members included 503 unique members. Outside of the administrator, no member appeared as a friend in more than 4 of the sampled members, and 480 members (95% of those listed in any friend network) were only listed as a friend once.

### 7.3.9 Personal Blogs

Both sites offered members the ability to add written content to their site easily in the form of a blog. Site 1 referred to the feature as a “blog”, while Site 2 referred to the feature as a “journal”. The investigator was interested in knowing how many members used the feature and, more importantly, what they were writing on the blog. To conduct the analysis, the investigator downloaded the contents of the blog section (when available) for everyone in the sample.

The vast majority of members in the sample from Site 1 did not use the blog feature at all. Twenty-six of the 30 profiles had not written an entry in the blog during the previous year.

The few that did use the blog used it mainly to make an announcement of some upcoming or recently transpired happening in their life and around their participation in some media-related events in particular. One pair of members used a blog to have a dialog about how to start a physical support group for people with diabetes.

The utilization on Site 2, however, was quite different. Apparently heeding the difference in the title of the feature as a “journal”, 17 members in the sample wrote something in their blog (range: 1 to 91 entries). While analyzing the entries, the investigator was reminded of his clinical experience in assessing patients. One of the key pieces of information to obtain from the patient is termed the “history of present illness” wherein the patient provides relevant information on the signs, symptoms and events leading up to the present interaction with the clinician. The content of the blog written by the members on Site 2 often appeared to be a brief “history of the present,” during which the member reflected upon the thoughts, feelings and events leading up to the current post. The most common description of the content from the investigator was a category called “reflections,” that typically involved the member waxing philosophically about life in general or particular recent events therein. Below is an example of a “reflection post”.

*Been Away* 😐
*Saturday, March 14, 2009*

*Hi everyone,*

*Thanks for all the messages checking in on me! What a nice thing to come back to. As you know, I've been away for awhile. Life has been pretty crazy hectic. Everyone has gone through illness it seems between the flu, strep, HCV issues, my uterus rebellion....it's been a bit overwhelming.*

*Consequently, hubby is on a downslide towards another depression. To be honest, I don't have the energy to deal with it. He's gonna have to ride this one out on his own. I'm going to go about my business and ignore his rants and mopes. Although I have to admit they grate on my nerves something fierce.*

*Today for example…*

This particular post goes on for two pages and discusses the member and her husband's recent interactions, her struggles between her desires and her Christian upbringing and her husband's recent Hepatitis C diagnosis. Journal posts in this category included multifaceted accounts of the member's recent history, wherein many issues, events and interactions were lumped into a stream of consciousness post that allowed the member to vent their frustration to the group and/or to seek support.

Table 7-6 is a summary of the codes for the topics of the journal entries. Of the 204 posts in the Journals of the sample, only 21 made any mention of the member's diabetes. Posts in that category could have included anything from issues with the healthcare team to concerns about maintaining healthy eating habits to technical issues with their glucometer. By comparison, the investigator labeled 107 posts as a "reflection" by the member and 33 posts specifically dealt solely with family issues.

**Table 7-6 Type of journal entries on Site 2**

| Type of Journal Entry | Number of Entries |
|---|---:|
| reflections | 107 |
| family | 33 |
| diabetes | 21 |
| goals | 14 |
| Report of poor health | 7 |
| Report of good health | 6 |
| poem | 3 |
| announcement | 3 |
| blank | 2 |
| complaint about site | 2 |
| announcement* | 1 |
| conversation | 1 |
| unemployment | 1 |
| sharing video | 1 |
| business | 1 |
| insurance costs | 1 |

#### 7.3.9.1 Replies to Journals

The 204 journal articles posted by the members of Site 2 elicited 452 responses. Friends in the members' profile during the study period provided one hundred seventy-seven of those responses. One hundred forty responses came from other members who were not identified explicitly as friends when the network was analyzed. Their behavior on the journals, however, often mimicked those of the friends, as many of them responded reliably whenever a member in the sample posted a journal entry. The journal authors wrote the remaining 135 replies to the journals, usually to clarify or update a statement made earlier or to socialize with the other respondents.

To capture the types of interactions occurring on the journals, the investigator used select codes from the schema describing the discussion forum conversations outlined in Chapter 4. The types of social support provided through the replies to the journal entries were very different from that provided in the discussion forums. Whereas providing “Guidance” and “Personal Experience” were the most frequent types of support provided in the discussion threads, “Pro-Social Statements” and “Feedback” were slightly more common in the responses to the journal entries. Unlike the types of statements made in the discussion forum, however, pro-social statements in the journals contained many more expressions of love for the member. Likewise, feedback provided in the journals tended to use more superlatives in describing the individual than in the discussion threads. Feedback in the journals also included the shared feelings between the respondent and the member, including deep sympathy for tragic events and great elation over happier news.

While “Guidance” was the third most frequent type of support given, the nature of that guidance was also very different. Rather than providing medical information or opinion, the guidance usually consisted of an attempt to normalize the feelings or thoughts of the member, provide more “common sense” or “folk wisdom” form of advice or, frequently, to relate some relevant biblical passage or encourage the member to rely on God to help them through their current situations.

Another significant difference between journals and the forums was in the explicit empathic responses contained within the replies in the journals. Members were much more likely to make statements such as “I know exactly how you feel” in the journals. As in the discussion forums, personal experiences were often provided to give evidence of how the respondent had gone through a similar circumstance. On several occasions however, the personal experiences described the interactions the respondent had in their relationship with the member writing the journal, as in the example below. This response was provided in response to a journal entry from a member after being fired from his work.

*OH JOHN!!! How horrible for you. I can attest through my own personal experience that you are NOTHING like the person that you described above. Your kindness to me in my time of need was so incredible - that you would reach out and help me, a complete stranger in another country…*

*Keep strong my friend. You have many who care.*

The reflections made by members in their journals and the responses they received often resembled a near-synchronous communication style which imbued the conversations with a sense of shared presence between the individuals. Replies often included language apologizing for not responding earlier to the journal entry. Some entries also included intimate details of the members’ recent concerns (e.g. sharing transcripts of discussions in couples therapy between a member and her spouse) and reciprocal details shared from a respondent (e.g. how she was envious of the member for actually getting to therapy and the lack of physical intimacy between the respondent and her husband). The interactions on the journals also provided evidence that, in some cases, the relationship between the members had evolved from online friends to meeting in the physical world, including a more extreme example of a friend becoming the godparent to one of the children of a member in the sample when their friendship appears to have started online.

### 7.3.10 Virtual Social Interactions

Another unique feature on Site 2 was the ability for members to exchange graphics representing various virtual social interactions (VSIs) (e.g. hugs, kisses, pats on the back, good luck wishes, etc.) along with a brief message. Profile pages contained tallies of the number and types of exchanges received from other members and the number of exchanges provided by the member. As with the others, the investigator was interested in the utilization of this feature by the members in the sample and the types of written messages conveyed with the graphic-based exchange. At the end of the study, the investigator downloaded all of the publicly available information about the VSIs from the sample members' profile pages. I then analyzed the VSI tallies and the accompanying messages to explore how often the features were used and what types of messages were conveyed.

Similar to the ability to friend other members, the ability to share VSIs appeared to be a commonly used feature. Only 9 members in the sample of 30 never gave another member a VSI and only 6 members in the sample never received a VSI from another member. Only 5 members neither gave nor received a VSI, 4 of whom were in the cohort that did not disclose their gender.

From the date they initially joined Site 2, members in the sample received more than 7795 VSIs in total (range 0 to 2244 VSIs received per member). Also, beginning with the date they joined, members gave a total 14290 VSIs to others in the community (range 0 to 6269 VSIs given per member), providing an overall ratio of 1.8 VSIs given for every one received by the members in the sample. As can be seen in Table 7-7, women appeared much more likely to give and receive VSIs than the other gender cohorts.

**Table 7-7 Utilization of VSI feature by gender cohort**

| | **VSIs Given** | | | |
|---|---|---|---|---|
| | Min | Max | Mean | Median |
| Females | 1 | 6269 | 1023.1 | 229.5 |
| Male | 0 | 3154 | 393.4 | 10.5 |
| Undisclosed | 0 | 112 | 12.5 | 0 |
| | | | | |
| | **VSIs Received** | | | |
| | Min | Max | Mean | Median |
| Females | 3 | 1866 | 461.7 | 139 |
| Male | 0 | 2244 | 308.9 | 11 |
| Undisclosed | 0 | 68 | 8.9 | 1 |

#### 7.3.10.1 VSI Message Content Analysis

In general, the nature of the messages reflected a more conversational tone than in the features described earlier. Unlike the discussion forums discussed in Chapter 4, social support and simple social exchanges were fairly evenly mixed. Messages often seemed to be prompted by exchanges on the member’s journal entries, in reciprocation for a VSI received, or in reply to a comment posted in a discussion thread. Some messages were succinct and self contained (e.g. “hi”) while other messages were part of a multiple part, VSI-based dialog between the members. In those cases the feature appeared to be used to enable synchronous communication between members on Site 2 including dialog that seemed to occur when the chat room feature was not working properly. Finally, holidays and other celebrations were often acknowledged by sending an appropriately themed VSI.

## 7.4 DISCUSSION

Table 7-8 summarizes and compares the results of the analysis of the Web 2.0 features on both sites reviewed in this study. While both communities address type 2 diabetes, the use of the features and the subsequent social interactions that occurred reflect some similarities and some differences between the two communities.

**Table 7-8 Comparison of Web 2.0 features on Site 1 and Site 2**

| **Feature** | **Site 1** | **Site 2** |
|---|---|---|
| Self-description | Generated by questionnaire | Generated by open-ended question |
| Age disclosure | 2 of 30 disclosed age | 22 of 30 disclosed age (including all 10 women and all 10 men in sample) |
| Self photo used on profile | 13 of 30 used a self-portrait | 4 of 30 used a self portrait |
| Emotional state of member | Not available | Displayed for all members<br>(default setting believed to be set to "OK") |
| Photo album use | 6 of 30 members uploaded photos | 10 of 30 members uploaded photos |
| Goals | Not available | 13 of 30 wrote at least one goal |
| Participation in member-initiated groups | 15 of 30 members joined at least one group | 17 of 30 members joined at least one group |
| Participation in administratively created health communities | Not available | 22 of 30 participated in one additional health community |
| Friends | 24 of 30 listed at least one friend | 27 of 30 listed at least one friend (including 5 who only had one friend, a site administrator listed by default) |
| Blog/ Journal | 4 of 30 wrote content in blog | 17 of 30 wrote content in journal |
| Virtual Social Interactions (VSIs) | Not available | 21 of 30 members exchanged at least one VSI |

To begin to understand the significance of the results described above, we will take the perspective of building a new online support group for a health-related issue. As we begin to construct the virtual community, we will first need to understand the effects of the registration process on creating a member profile, or more specifically the member’s online identity. Next I will discuss the potential benefits of members’ connections to other groups and communities within the sites based on our observations of the two sites and the potential implications of enabling similar features on new sites. Finally, we will consider the features that may allow members to do more than find information online, but also to build strong ties with other members of the community through the use of the “friend” feature and the online journals (blogs) on both sites and the virtual social exchanges (VSIs) possible on Site 2.

#### 7.4.1.1 Online Identities

Building a successful online support group for health conditions depends, in part, on members’ ability to create online profiles. Providing identity cues such as gender and age will be determined by both the member’s choice to reveal that information and on the member’s ability to provide the information. While both sites included in this study provided the ability for members to provide certain cues, the sites differed in the willingness to share that information and in the types of information that was revealed. Age, for example, was usually withheld from public view on Site 1 (only 2 out of 30 members revealed their age), but was usually provided on Site 2 (all men and women sampled revealed their age, but only 2 of 10 members in the undisclosed gender cohort did). Conversely, members on Site 1 appeared to be more willing to use a self-portrait to represent themselves on their profile page, as compared to those on Site 2, who used their own portrait infrequently. Both of these differences are likely due to the different registration forms for the different sites and to the culture of the site as reflected by the other profiles.

More concrete evidence of the influence over the registration process could be seen based on the information available on the member’s page and the variation that existed between the responses to a structured questionnaire on Site 1 and a single, open-ended question on Site 2. Those looking to build online health communities in the future should pay particular attention to the questions and formats asked when members join, as the culture of the final community will in large part reflect the information obtained during the registration process.

Of particular interest on Site 1 was the revelation that although the members had often found their way to the site while searching for information on the Internet, the group had been diagnosed with diabetes for a decade on average. This finding was somewhat surprising, as one could assume that the sample would have been weighted towards newly-diagnosed patients searching for information about diabetes. Apparently regardless of how long members had been living with the disease, finding new information on ways to manage the disease and finding new support from those who could truly empathize with the experience is helpful regardless of how long one has lived with the disease.

If the length of experience observed in the sample reflects the actual experience of the entire community, that understanding could provide a number of benefits to the community as a whole. The amount of experience that would be accumulated and shared among the members conceivably would be greater than that possible with those with less experience with diabetes. That experience could not only give members access to more knowledge than they may be able to receive through traditional channels (i.e. in their physical support network), but would also conceptually serve to improve or reinforce the credibility of the online community. Perhaps it is not the profile page itself, but the credibility of the members that helps establish the trust that Kim [97] describes as a benefit of member profiles.

Profile pages in both communities allowed the member an opportunity to do more to signal their identity than just providing the responses to the registration form and the ability to choose a self portrait. Members could provide more cues through the use of an online photo album. While the utilization of the photo sharing feature was relatively low in the sample, developing an online photo album has potential benefits in establishing an online identity as well. Not unlike physical photo albums, online albums allow the member to share photos of the people (or pets) and places that are significant to the member. A key difference is the presence of "other graphics" which included a wide variety of graphic art that one *might* hang on the walls at home, but are not likely kept in a photo album. Although it is not clear from the methodology employed in this study why the members chose to share the photos in their album, it seems likely that the graphics and pictures reflect some facet of the identity of the individual that they want to present to others in the community. By sharing photos of people and places that are important to the member, the member is also revealing more about what he or she considers to be important. A photo album full of pictures of the member herself would likely signal very different aspects of her identity than an album full of pictures of grandchildren and pets.

In addition to the ability to create a profile and share photographs, the ability to communicate and share personal goals represented an interesting feature of Site 2. At least half of the men and women studied chose to list at least one goal. Providing members the opportunity to set goals and make the goals public may help members adopt healthy behavior changes [102] in addition to rounding out their online identity. Developing communities with goal setting features provides public health practitioners with an interesting opportunity to guide the member in choosing goals that are appropriate for their desired behavior change and to facilitate feedback from other members of the community as they attempt to accomplish their goals. The information relayed through the goal setting feature appeared to be elicited from a form-based process which gathered specific information from certain types of goals (e.g. the number of days one of the members had quit smoking was likely due to the website eliciting not only the goal of quitting, but the date at which the member quit). By manipulating the information solicited and provided when the member defines a goal may ultimately help the member be successful in achieving it. Teaming those queries with positive reinforcement from the members' social networks may help them adopt and maintain healthy behaviors.

#### 7.4.1.2 Gender Non-disclosure

While eliciting feedback from the community around individual goals has the potential to provide social support, it is clear from the cohort of those who chose not to disclose their gender that some members want to withhold certain identity cues and may not want to participate in the more social exchanges occurring in the online communities. Despite providing the opportunity for members to interact in a somewhat disinhibited manner and be freed from potential sexist comments on the site, members who chose not to reveal their gender generally did not participate in the other features of the community as often as those who were identified with a gender. Across every profile-centric feature analyzed, those in the undisclosed gender cohort demonstrated significantly less utilization of the features than those identifying with a gender. The causal relationship between withhold gender and participation was not clear from this study. Withholding gender could be a signal that the member chooses not to interact with the community from the outset and may reflect her desire to maintain a higher level of anonymity from the group. Conversely, members in the community may have chosen not to interact with or trust those who did not reveal more details about their lives. The relationship between withholding identity cues and the level of participation in these communities requires more exploration to determine whether these patterns persist with a more representative sample.

### 7.4.1.3 Social Networks and Social Support in Online Support Groups

While the features studied in this analysis were all based on the profile pages of individual members, it is clear that some of the features did more than help form an online identity. Much of the social exchanges appearing in the communities occurred through the use of features on the profile page. In the broadest context, the profile pages allowed participants to participate in groups that were smaller and more focused than the context of the entire community itself. Both of the sites reviewed allowed members in the community to form their own smaller groups within the site. Approximately half of the members from each site participated in at least one of these groups and tended to continue participation for the duration of the study period. While some of the groups focused on health related topics, others reflected the diversity of interests in the two communities. It is unlikely that a traditional, expert-led, physical support group would be named “Diabetic Dancers!” or “fer the lov of laughter,” yet both groups had a respectable membership. At the time of this writing “Diabetic Dancers!” had 46 members on Site 1, while “fer the lov of laughter” had 93 members on Site 2. These smaller groups represent a way for members to connect with others in areas that may have nothing to do with their diabetes diagnosis or even their primary health concerns. This raises the question of what, if any, potential health benefits could be derived from such a feature. In his analysis of controlled intervention studies, van Dam found that perceived social support demonstrates a dose-response relationship with the length of the intervention [18]. Further research would be necessary to determine whether participants in these member initiated groups stayed online longer, or had a different perception of social support than non-participants before their potential to affect health behaviors can be fully understood.

Site 2 also offered the members the option of choosing from more than 600 online disease communities that the administrators of the website developed. As a result most members in the gender-specified cohorts belonged to more than one community with women joining at almost twice the rate of men in our sample. Depression, chronic back pain and the anxiety related groups were the most frequently co-occurring groups along with those in the diabetes community. The potential influence of these structured communities on health behaviors is conceptually easier to understand than the member-initiated groups. Rather than forcing the member to participate in multiple online communities and having to recreate identities for each, allowing members to participate in one comprehensive site with multiple communities seems to offer many benefits to the member and to those interested in exploring the potential implications of their participation.

Whether the groups were initiated by the members or the administrators, memberships in these other groups remind us of the multi-faceted nature of the individuals we serve in public health. While traditional interventions are usually focused on a single health topic or behavior (e.g. type 2 diabetes), our clients are rarely that one-dimensional in their concerns. Despite their comprehensive nature, even robust, social-ecological based interventions are usually only focused on one disease or health-related behavior. Allowing groups to emerge from the members or prompting membership by creating other communities ahead of time might provide a unique opportunity to develop interventions that address the complex and intertwining health issues that face many patients with diabetes and to study the interactions between the co-morbidities from a more well-rounded psychosocial perspective. An online support group offering membership to multiple disease-focused communities would allow health practitioners an opportunity to provide not only a comprehensive intervention, but a multi-faceted one as well.

### 7.4.2 Strong Tie Features

Even with multiple communities present for the member to choose from, the member would likely have only weak ties to the rest of the participants. While that would suffice to provide new information to the member, stronger ties might be helpful to mitigate the impact of negative life events. Online community developers should consider adding features like friends, personal blogs and virtual social exchanges to facilitate growing those stronger ties. Use of these features in our sample seemed to demonstrate the power of allowing members to develop deeper relationships with other selected members.

#### 7.4.2.1 Personal blogs and Friends

One of the features offering significant potential for delivering structured online interventions is the use of personal blogs, at least when they are perceived to be a journal for the members to use like a diary as opposed to a "blog." Writing itself has potential therapeutic benefits, although the specific therapeutic processes involved may still be unknown [103]. In the sample from Site 2 I observed members discussing their "history of the present," in an unstructured, stream of consciousness monologue where the member reflected on significant events leading up the post. The content included a myriad of issues ranging from their ongoing struggles with their families, their health, their economic situation and many other topics. Simply writing on the site may be of some benefit to the member, but by opening the prose to others in the community, members also frequently received expressions of love, personal feedback that likely reinforced the member’s self-esteem, and advice that included both folk wisdom and religious guidance.

Based on Granovetter’s definition of how the strength of social ties is measured, “a combination of the amount of time, the emotional intensity, the intimacy (mutual confiding), and the reciprocal services which characterize the tie,” [99] the investigator believes that the interactions on the journals represent a computer-mediated strong tie between the member and her network of friends and respondents. The computer-mediated nature of the communication between the respondents and the members did not seem to significantly deter the empathic concern expressed on the personal blogs or the relationships that developed as a result and may actually have been facilitated by the notification process believed to occur when a friend posts a journal entry online. The site appeared to deliver a message automatically that a friend has written an entry in their journal. That message would likely prompt their social network to reply, beginning a potentially empathic and reciprocal exchange of communications between the member and her network.

In face-to-face communications, verbal exchanges are temporary exchanges occurring between the two members that disappear as soon as the words are exchanged. In online communities however, the archived text of the dialog is available for the public to read which may also serve to define and reinforce the culture of the site. These communications evolve from providing temporary support for the affected member to a signal to future members as to the expected normative behavior from the members of the community.

Site 2 also provided the opportunity to develop strong ties through the interactions on the personal journals of its members. Members could choose to interact through the near-synchronous feature of the virtual social interactions (VSIs) enabled on the site. The features were used to share a virtual representation of some form of social interaction with the member, and were often accompanied by brief text from the sender. Such interactions could and often did provide social support. More often however the VSIs seemed to be indications of one member thinking of another member and using this feature to express those thoughts. Short, Williams and Christie and Walther described this interaction as an indication of *social presence* [66, 70] or the awareness of the other person in a computer-mediated communication. The number of VSIs exchanged between the two would likely increase the perceived "time" spent between the two members, strengthening the social ties between them. Likewise, the type of virtual exchange shared would be expected to influence the strength of the tie. Further research will be needed to determine whether a virtual pat on the back is perceived differently by the recipient than a virtual hug or kiss.

## 7.5 CONCLUSIONS

The popularity of social networking and Web 2.0 sites will require public health practitioners to reconsider the nature of their interventions to leverage the potential of these new features. My hope is that those designing online interventions will build robust sites based on the observations of these two mature communities. Several limitations of the study must be taken into consideration. The study used a purposive sampling technique specifically to explore the differences between gender cohorts in the community. The sampling technique was useful for the purposes of this study, but does not support generalizing the results to the entire populations of the websites. Future studies should use these results to develop a quantitative study randomly choosing the members to determine whether the utilization of the features accurately represents the entire population.

The results may also not be generalizable beyond communities for type 2 diabetes or these two websites in particular. Type 2 diabetes, while difficult to manage, does offer a variety of options to help control the disease. Online communities for those dealing with terminal or mental health diagnoses or many other health concerns may elicit very different responses from their members. Our findings demonstrate that different sites build profile information about their members differently, and that the features enabled on the sites have a significant impact on the social interactions possible in the community. Exploring more communities offering support for type 2 diabetes may reveal different findings than those discovered on these sites.

The features explored in this study have only been available in their present form and with their existing prevalence for approximately 4 to 5 years. As such, this exploratory study was necessary to help guide future research efforts. In addition to the quantitative studies described above, serious consideration should be given to measuring the delivery of traditional health interventions through these online communities. In particular, we must determine how traditional, expertly-moderated interventions can be delivered through online communities enabled with these interactive features. Could social support be provided to larger populations through *expertly designed* features on these sites that not only allow for weak and strong ties to develop between the members, but that help the members be even more helpful to each other? Given the rapid adoption of these technologies, a growing population of clients may demand that such interventions be available. One could argue that the thousands of people participating in the communities I studied have already demonstrated that they are unwilling to wait.

# 8.0 A THEORY OF ONLINE SOCIAL SUPPORT

## 8.1 INTRODUCTION

In Chapter 5, I discovered that members of the sites receive different types of social support depending on whether the interactions occurred in a community-based discussion forum or in the member-centric features associated with their online profile. Discussion forums provided members an opportunity to leverage what Granovetter described as the strength of weak ties, while personal blogs, friend networks and other unique features of one of the sites enabled the formation of strong social ties [99]. In this chapter, I will revisit the social cognitive theory and the social ecological model to determine how the behaviors on the Web 2.0 sites I observed fit within the existing models. I also describe how this new empirical evidence supports or modifies the Online Social Support Model (OSSM) introduced in Chapter 2. Important constructs are added at the end of the Chapter to help the OSSM evolve into a more useful Theory of Online Social Support (TOSS).

As mentioned earlier, public health practitioners who are interested in developing online communities could benefit from a conceptual framework that describes how the constructs from computer-mediated communication (CMC) theories could affect health behavior and predict or provide social support in a virtual setting.  In Chapter 2 I introduced OSSM to hypothesize how CMC theories could be integrated with well-known public health models such the social cognitive theory and the social ecology model. One of the specific aims of this research was to determine how these concepts presented themselves in a virtual community.

Research regarding the public health applications of these technologies is rather limited. Just as the new interactive features of the Internet known as Web 2.0 were beginning to be adopted, Wright attempted to relate the empirical research to that point regarding online social support with social support and CMC theories [104]. The results of this study support Wright's assertion that online support groups function as weak tie networks. Through their size and heterogeneity, these groups are able to provide a diverse set of information. Wright also notes that they provide the potential to reduce the stigma of illness by providing a safe meeting place for people with similar illnesses to share their information and receive empathic responses in return. He also noted the differences in supportive communication possible in online environments, describing Walther's work on hyperpersonal behavior, the asynchronous nature of communications and the potential therapeutic benefits of writing. Unfortunately these relatively recent findings, while still relevant to the discussion forums review in this study, do not address the effects of other interactive communication technologies that have emerged since then, including the impact of the various profile features described in Chapter 5.

A more recent publication by Ritterband, et al provides a more recent look at online health behavior models for online interventions [105]. Their model illustrates the complex nature of computer-mediated interventions. According to Ritterband, treatment maintenance, symptom improvements or behavior changes are all dependent on the interaction of the social ecology of the user in the physical world (described as the "environment" of the user), the type of support available to the user, several characteristics of the webpage itself and the specific "mechanisms for change" possible between the online and offline environment of the user. Intended specifically to help guide planned health behavior change interventions in the online environment, the model begins to illustrate the difference between the social ecology of the user in the physical and digital worlds and the influence of both environments on the ultimate success or failure of the intervention. The utility of the model to predict change or to be a useful guide for those designing online interventions may be somewhat limited, however, given the complexity of all the various interactions Ritterband tries to include.

The Internet itself is a relatively recent communication medium and the Web 2.0 features described previously are still in their infancy. Therefore, it is understandable that traditional public health educational institutions and researchers would not yet have addressed the differences between the physical and online worlds in their curricula or research agendas. This chapter is meant to begin the discussion for public health practitioners to better understand how traditional concepts such as social support, social cognitive theory and social ecology changed when they were empirically studied in an online environment.

## 8.2 TYPES OF SOCIAL SUPPORT ONLINE

A brief review of social support reminds us that Cohen [60, 106, 107] and others [28, 92, 108] have described the types of social support as falling into one of three categories. The first, *instrumental support*, is the provision of material aid such as financial assistance, transportation or other tangible goods and services. *Informational support* supplies cognitive assistance or giving advice. The last type of support described is *emotional support*, in which members provide affective assistance in the form of empathy, caring and reassurance. Below is a description of how these categories appeared in the online social support communities I observed.

### 8.2.1 Online Instrumental Support

While Rheingold [3] described the financial and transportation assistance members of the Well provided to one of its members in his work in the late 1970's, there was little evidence of such exchanges in the online discussion forums or the profiles in the sampled communities. This result was not particularly surprising given the geographic distribution of the members from across the world. However a new form of instrumental support can be argued to exist in the online communities. One of the most common types of "tangible" aid provided was what was coined "Navigational Aid", defined as "providing a hyperlink to a potentially useful or relevant website."

Navigational Aid can be considered a form of Instrumental Support if Instrumental Support is defined to be a "means to an end "(e.g. someone provides me money so I can pay my bills or someone gives me a ride so I can see my doctor). Instrumental aid assists the member in completing some task, in our case a task related to their health. However, instrumental aid does not necessarily represent the desired end in and of itself.

I observed evidence of this kind of support from two components of the study. The first was the revelation from the Site 1 member profile analysis that most members found their way to the website while searching for information about diabetes. Either the search engine they used or members of a different community provided the hyperlink for the member to find what they were seeking. The search engine or colleague did not provide them the information they sought, but rather provided them the means with which to find the information. This behavior was also observed in the online discussion forums. When a member solicited information about their diabetes, the respondents provided some combination of informational and emotional support that often included a hyperlink where they could find additional information. Again, respondents usually provided a direct answer to their questions about diabetes, however, some responses differed in that they provided the author the means to find that information elsewhere by providing the navigational link. Rather than providing them a ride to the doctor's office, the navigational aid put the member one click away from their desired destination.

In addition to members providing navigational aids to other members, online environments also offer the unique ability to have that form of assistance generated automatically. The most familiar examples of automatically-generated navigational aids are observed when a member enters a keyword into the search feature of the online site. The computers search their databases for relevant information and present the member with various links to the information it believes is salient to their search.

This study observed a more discrete, if much less specific, way for members to receive navigational aid through a unique feature on Site 2. Whenever members replied to an original post, the website analyzed the text of their response and automatically created a hyperlink within the text whenever a word matched an entry in their "treatment" database. The intent of the website administrators appeared to be to provide the members reading the discussion thread a convenient way to find more information on the therapeutic benefits of the medications or behaviors in the thread that may not be familiar to the reader. The largest flaw appeared to be the inability for the search protocols to determine the meaning of the word in the context it was used in the text. The result was that sometimes amusing hyperlinks to pages describing the therapeutic benefits of certain words appeared even though the word was used for an entirely different meaning in context (i.e. the word "heat" does not always refer to temperature or its potential therapeutic effects).

While the provision of URLs to salient websites containing more information is not necessarily limited to the online world (e.g. you can provide someone a written hyperlink on a piece of paper), what does make the online environment unique is the ability to navigate directly to the site. The ability to provide websites with relevant information and supplying the mechanism to navigate directly to the site is a form of instrumental support unique to the online environment.

### 8.2.2 Online Informational Support

The explosive growth of using the Internet to find information about a particular health topic [93] likely reflects many factors, including the convenience of typing phrases into a search engine and receiving a series of hyperlinks directing you to the desired information. The difference between Web 1.0 and Web 2.0 sites is that the information retrieved from the search is more likely to include content generated from the users of the website, as opposed to content published solely by the site's administrator.

In this study, the questions posed in the discussion forums often included very specific questions that relayed the unique and personal context of the author asking the question. Rather than trying to guess appropriate keywords for search engines or searching through dozens of irrelevant websites looking for information, members in the discussion forums simply asked questions and provided information they believed was relevant to their particular situation. I defined the search behavior witnessed in the communities in the study as "asking my questions about my diabetes." This process appeared to generate more relevant information than was possible from more traditional presentations of the information such as an online medical encyclopedia or an expert-run site would provide.

Prior to the Internet members may have had to rely on a network of weakly tied individuals to find relevant information, as Granovetter described [99]. His premise was that individuals would gain more information from the experiences of those in a weakly tied social network because the individual would likely already know much of the information available from those with whom she maintained a stronger social tie. The use of discussion forums allows individuals to quickly access weak social ties with a population of individuals who have salient information. In the communities this study observed, the weakly tied network had the additional benefit of having a common experience with type 2 diabetes. The responses to questions in the discussion forum allowed the member to receive a form of advice described as "experienced empathy." The community provided their answers or advice and, as importantly, conveyed a sense that the member was not alone in her concern through stories of their own experiences. The sharing of personal experiences not only provided members with salient information, but also helped to reinforce the credibility of the community.

Rather than being a series of dyadic dialogs between the author and each individual respondent, the replies within the discussion forum often elicited or provided clarification to earlier replies in the same discussion thread or provided a navigational aid to other relevant discussion threads in the forum. The conversation within a thread often evolved from answering the question posed by the original author to an interactive discussion between various members of the community. The result formed a "community knowledge base" representing the information and varied perspectives of the community in response to that question. Since the entire discussion thread was archived with its complete text, the cumulative responses to the discussion threads were available for members to review or discover when members searched for information within the site. I coined the combined knowledge contained within the discussion threads as “group guidance.”

While other studies have found similar empathic responses in discussion forums about other topics [88, 109], one of the unique findings of this study was the type of information support provided in the personal blog feature of the individual member profiles. One of the differences between Web 1.0 and Web 2.0 virtual communities is the ability for its members to create a personal profile (a member-centric webpage) with the personal information they want to share with the other members of the community. Members of Site 2 often used their one of these features, a personal blog, to describe their current state of affairs. Members using the feature created a multifaceted journal entry that reflected the many issues they faced in their daily activities. Concerns about work, family, health and vacations were some of the frequent topics of entries in their personal blogs. Similar to the discussion forums, these posts often elicited a response from other members of the community. The difference, however, was that respondents tended to be, or act like, what Granovetter would consider to be a strong tie in the individual’s social network [99]. Unlike the discussion forums, the information provided by the author was rarely about diabetes and tended to be more about the quality of their life in general. The advice given by respondents to the blog went beyond that described in the discussion forums to include more biblical references about how to live life. Personal experience with the topic, when it was shared, was enhanced by the respondent’s personal experience with the member, not just the topic. Frequent interactions between members seemed to create a strong bond between them, and were referenced by the respondent to attest to the positive personal attributes of the individual writing the personal blog entry. The combination of the discussion forums and the responses to the personal blogs provided the members the benefits of both weak ties for answering questions about their diabetes, and strong ties for addressing major or minor life events that were present on the member's mind.

### 8.2.3 Emotional Support Online

Emotional support was very common in both the online discussion forums and the features on the member profile. The experienced empathy and feedback provided in the discussion forums reinforced to the members that they were not alone in struggling to manage their diabetes. However, the emotional support from the discussion groups paled in comparison to the support provided by online friends and respondents to the personal journals (blogs) on Site 2. Responses to these entries were much more likely to include positive social interactions that included expressions of love for each other. As mentioned above, the relationships that formed between friends in the online social networks often demonstrated strong social ties.

In addition to the discussion forums and personal journals on Site 2, I observed a modernized version of the emotional lexicon (emoticon) used in earlier versions of electronic communication. Since written text lacks the nonverbal cues we rely on to convey the meaning of the words we use, chat rooms and bulletin board users quickly developed text-based cues to reveal the hidden meaning. Symbols such as ;) or :) or :o are fairly well established markers for winks, smiles and surprise in the online setting. Site 2 however created small graphic icons, often based on the familiar yellow smiley face, to convey virtual social interactions such as hugs, pats on the back, and giving flowers. As one of the most frequently used features in this study, exchanging these forms of emotional support was often used in a near-synchronous communication style that conveyed a deep sense of the *social presence* [66]. By using these icons the sender would indicate that she was thinking of the receiver rather than just communicating the literal meaning of the icon.

## 8.3 SOCIAL COGNITIVE THEORY ONLINE

One of the most commonly accepted theories in public health regarding behavior change is the social cognitive theory (SCT) promulgated by Bandura [56]. As described by Glanz, et al, [79] the five important constructs of SCT to modify behavior are: 1) providing knowledge and risks of behaviors; 2) increasing self-efficacy; 3) setting realistic expectations; 4) goal setting and planning, and; 5) increasing knowledge of barriers and facilitators. The section below will discuss how various features of Web 2.0 sites could facilitate health behavior change through the SCT perspective, as witnessed in our observation of the behavior of members in discussion forums and through their online profile pages.

### 8.3.1 Knowledge and risks of behaviors

According to Bandura, “knowledge of health risk creates the precondition for change.” [56] When a member posts a question to the online discussion forum pertaining to their diabetes management, respondents usually provided advice, their personal experience, and feedback regarding the requestor’s current behavior or some combination thereof. Discussions of inadequately controlled blood glucose levels tended to elicit explanations of the risk of leaving the levels uncontrolled in terms of the death of their pancreas or the amount of insulin and medications that would be required to keep the levels under control. Responses not only came from those who were concerned, but from those who had actually suffered consequences as a result of their poorly managed disease. As mentioned above, the combined set of responses often created a knowledge base for the community and future members to use to learn more about that particular aspect of diabetes. Discussion forums in particular seemed to focus on behaviors related to diabetes management more than the online blogs or other features on the members' profiles. The large number of unique individuals responding to questions in the discussion forum also reinforced the concept of the strength of weak ties as argued by Granovetter [99].

### 8.3.2 Self-efficacy

Given the correlation between self-efficacy and successful health behavior change [110], online activities that promote greater self-efficacy could have a dramatic impact on the health of community members. One way to increase self-efficacy is to provide members the vicarious success of salient role models for the change [111], such as other members of the community. The personal experiences shared in the discussion forums of the communities I observed provided the triumphs and tribulations of others and could help to instill confidence in the members' ability to modify their behavior. Not only will members learn from the experiences of others, but they can receive feedback on their own performance from an empathic community that truly understands the concerns of the individual soliciting the advice.

In addition to the experience and feedback from the weakly-tied members in the discussion forum, members also may receive positive reinforcement and stronger, more frequent and more intimate feedback about their behaviors through the features on their profile page. Members in the online network of friends on Site 2 received more positive social interactions including expressions of love and support through their online journal entries than did members in either of the discussion forums. The opportunity to provide both weakly tied and strongly tied social support may have a tremendous affect on the self-efficacy of members, particularly with those who lack similar ties in their physical social networks.

### 8.3.3 Realistic expectations

Regardless of whether health information is obtained through online sources, or through traditional media channels such as television or print media, the potential exists for people to hear stories of miraculous cures, herbal supplements that obviate the need for medicines or other dramatic claims. In the study of our two communities, one member related a claim about the benefits of eating only natural foods and engaging in two hours of exercise a day to control his blood sugar levels. Others inquired about the potential benefits of cinnamon capsules in controlling blood sugar. In almost every case where more extreme perspectives were presented in the community, others would reply that they too had tried similar behaviors or supplements in the past, without success. In reply to the therapeutic benefits of natural eating and significant exercise, many members of the community responded that they did not think that they personally could adhere to such dramatic lifestyle changes and cautioned members to continue their medications despite the concerns expressed in the post. The replies and counter replies helped to define what the community considered to be normative experiences related to that claim. Those who refuted the claims usually did not directly confront the members making the bold assertions, but rather would state simply that different people had different experiences and that “your mileage may vary,” which was a popular refrain among the members of Site 1.

In addition to countering the more extreme advice from the community members, the discussion forums also seemed to establish realistic expectations regarding care from medical professionals as well. If the discussion thread revealed what the community considered to be inadequate or inappropriate advice from the medical community, they were quick to advise the author to seek additional information from the existing healthcare provider, or to seek out a new provider. Endocrinologists and certified diabetes educators were frequently mentioned as useful consultants in diabetes management. As discussed in Chapter 4, the community also seemed to define a realistic role for itself in helping the member. Discussions about medications were frequently tempered with the observation that the community was not a replacement for medical care, and that discussions regarding medication use were best left to the member and her physician to make jointly.

### 8.3.4 Goal setting and planning

Site 2 had a feature on the profile page used by approximately half of the members in our sample that allowed them to explicitly define a goal for themselves and a timeline in which to complete that goal. The member appeared to enter the goal in the field as free text. Once defined, others in the community could provide encouragement and feedback to the member as they made progress towards their goal. Those who completed the goal received a small graphic of a trophy next to the goal to indicate their success. Interestingly, the most frequent goal listed by the members described their desire to find a new friend or partner through the site.

What appeared to be lacking from the feature however was a planning tool to assist the member in achieving her goal. Prompting the member to consider how to effectively implement the goal may be more likely to produce subsequent behavior change than just listing the goal itself [112]. Including a change plan worksheet could encourage the member to identify the implementation process of the goal, select those in the community who could help them achieve their goal and to identify and avoid triggers that might make them susceptible to relapse. Those and other prompts based on health behavior change theories will likely help make these features more effective aids at successfully adopting the new behavior.

### 8.3.5 Knowledge of barriers and facilitators

Members of the Web 2.0 communities I reviewed could increase their knowledge of potential barriers or facilitators of health behavior change through the discussion forums and the features of their personal profile page. As was previously discussed, however, the type of knowledge conveyed varied significantly between the two sites. Discussion threads in the type 2 diabetes forum tended to be related very specifically to issues pertaining to the members' unique questions about diabetes, whereas the personal blogs of the members tended to deal with other social, economic and environmental issues affecting them more holistically as a person. The discussion forum allowed members to solicit a broad range of experiences regarding diabetes management issues from those who often shared their personal experiences. Members shared their experiences on a wide variety of topics, from diet and exercise changes that they struggled with to managing the side effects of some of the diabetes medications. The result was usually a broad sample of behaviors that allowed the member to determine whether their experience was a normal one compared to the rest of the experienced group. The group also described the difficulties they encountered or provided tips on the behaviors they believe were critical to their successful behavior change.

The personal blogs and other near-synchronous communication tools allowed members to also receive positive social support and feedback on their management of problems that were occurring in other aspects of their lives. These more intimate forms of communications were indicative of strong social ties being developed between the member and their social network on the site. What these forms of communication highlight, and help address, are the multifaceted issues people with diabetes face while attempting to successfully manage their disease in the context of broader life issues. Rather than addressing barriers and facilitators of diabetes management independently, members of properly designed Web 2.0 sites may benefit from a more holistic perspective of the barriers and facilitators involved in diabetes care.

## 8.4 SOCIAL ECOLOGY

Chapter 2 explored the potential differences between social ecological determinants of health in the physical world, and those predicted in a virtual one. In the following section I will revisit the factors to determine whether the empirical findings support the earlier premises.

### 8.4.1 Intrapersonal Factors

As described earlier, members of both virtual communities in the study had to "write themselves into being [80]." However, unlike the behavior I predicted in Chapter 2, I found that age was not uniformly disclosed between the two sites. None of the female members and only two of the male participants disclosed their age to the community (out of ten members in each sample). Likewise on Site 1, those who chose to conceal their gender also concealed their age from the community. The disclosure on Site 1 varied significantly from that observed on Site 2, in that all members who disclosed their gender on Site 2 chose to reveal their age as well. Similar to those in the cohort who withheld their identity on Site 1, those in the same cohort in Site 2 also withheld their age. The differences between the two sites are believed to be the result of different cues available to the members during the registration process. Next to the field requesting the age of the member on Site 1 was a large button asking if the member wanted to keep that information private from the rest of the community.

In addition to the differences in revealing age, the profiles of each community differed in the information conveyed about the individual member. Site 1 member pages relayed information from a structured questionnaire that the participants completed during registration pertaining mostly to their experience with diabetes. Site 2 members were more likely to discuss themselves in relationship to all of their ailments, work or other non-healthcare related descriptions in response to the open-ended question they were asked during the registration process. The effect on the social interactions or other online behaviors of these different presentations is unclear, although members of the Site 1 community tended to make references to the diabetes information revealed on the profile page when responding to questions posed in the online forum. Members seemed to occasionally go to the profile page of the progenitor of the discussion thread to obtain information from the profile that may have been an important, but missing, piece of background from the discussion thread itself.

The online behavior of those withholding their gender information also appeared to be very different than those identifying with a gender. Despite the conceptual ability to ask questions free from traditional social stereotypes, members who did not reveal their gender seemed to interact on the site much less often than those who did. We cannot determine from the methodology used in this study whether they were more likely to “lurk” on the site as described on Chapter 2, or whether they simply did not use the site as often as the gender-identified cohorts.

One of the premises explored earlier relating to the construction of identity was the effect of anonymity on social interactions and whether any evidence would emerge of the hyperpersonal behaviors described by Walther [70].  While there was evidence of socially sensitive topics being discussed in the discussion forums (e.g. a post discussing the potential effects of type 2 diabetes on female libidos and another regarding the gastrointestinal side effects of diabetes medications), it was not clear that the conversation was facilitated in that setting by the relative anonymity of the discussants in the thread. The methodology employed by this study did not record the social links (if any) between the participants in the discussion thread, so a claim of complete anonymity cannot be made for certain among the respondents as described below. However, it is plausible that these discussions were at least partially facilitated by the fact that the participants would likely not recognize each other should they happen meet in the physical world.

The discussions occurring in the online journals of the members of Site 2 included intimate details of their lives more frequently than the discussion forums did. Members openly discussed frustrations pertaining to their family and friends in the physical world with their network of friends in the virtual community. This raises the question as to whether the participants could still be considered “anonymous” in the virtual setting, even if their online identity could not be linked to their physical one. Many members appeared to interact with their network frequently through one of the many communication channels available online. Can individuals who talk frequently, send hugs (albeit virtual hugs) regularly and provide emotional support during major life events still be considered anonymous even if they have never met in person? If members have shared identity cues such as photographs of their family, their pets, their favorite vacation spots or even themselves or if they have revealed their real name to their online friends, do they maintain the protection afforded by their anonymity in the physical world? Based on the intimate details and reciprocal disclosures on the journals, I would argue that Web 2.0 environments such as the online support groups I studied can produce strong-ties between the participants that can elicit the hyperpersonal discussions described by Walther [70], but without the precondition of anonymity. Instead it appears that a strong social presence [66] is sufficient to produce the types of intimate interactions Walther described. Social presence appeared to be enhanced by adding the additional identity cues through the use of features such as photo sharing and creating a network of friends within the community. Those who withheld their gender and age cues and who demonstrated low utilization of the other profile features appeared to have less social presence than those in the cohorts that revealed that information. Despite greater anonymity from the others on the site, the gender undisclosed cohort appeared less likely to engage in hyperpersonal behaviors online. This hypothesis should be explored further to determine whether the observed behaviors accurately reflect the online experiences of the undisclosed gender cohort using a more representative sample than was used for this exploratory study.

### 8.4.2 Interpersonal Factors

As mentioned in Chapter 2, our network of friends and family in the real world can have a significant effect on our health behaviors. As predicted, there was little evidence that the members interacted in both the physical and computer-mediated modalities. Physical world friends and family members did not appear to be active on the site, even when the member appeared to have joined because of the care-giving role they played for a loved one. Community members often encouraged caregivers to have their loved one join the site, but there was no evidence that this occurred during the study period.

In addition to the discussion blogs, the personal journals on Site 2 and the ability to provide and receive virtual social interactions (VSIs) appeared to play a significant role in the interpersonal communications on the site. As mentioned previously, the discussion forums focus on diabetes provided the benefits of a weakly tied social network, and the personal journals on Site 2 seemed to foster strong social ties. While there was evidence that the online network of friends was dynamic from week to week, it was also clear that certain online friendships had grown to be quite deep. In the most extreme case, one member had an online friend become the godmother to her daughter. That particular dyad also displayed one of the few face-to-face interactions, though verbal communications also occurred over the phone with a few of the other members and their online friends.

### 8.4.3 Institutional and Community Level Factors

Both of the sites I observed allowed the members to create subgroups within the community to focus on topics of interest to several of the members. On Site 1, the groups that the sample members belonged to tended to be focused on medically-related issues or on geographic proximity. On Site 2 the discussion forums in which the sample members participated tended to be more focused on a larger variety of special interests that may or may not have been health related. Although the activity of these small groups was beyond the scope of this study, the ability for members to create groups that represent a shared interest raises interesting potential for addressing health related behaviors.

The groups that were initiated by members appeared to play an important role for the members and the community. The groups provided members a place to interact on a specific topic of interest without relying on the dyadic ties represented in the network of friends, and without losing the topic in the myriad issues being addressed in the discussion forums. Providing members the opportunity to play a leadership role in the groups also encourages that member to become even more active on the site in order to develop and monitor the activities on the group's website. Member’s that created and added content to these smaller groups would help build the value of the entire website by its content and interactivity, essentially providing the site administrators a free and dedicated workforce that made the site more attractive to newcomers. Not unlike increasing the market value of all the houses in a neighborhood by having a few active and attractive locations nearby, providing a place for members to go “off-topic” while remaining on the site likely provides a needed respite from those who need a break for their disease-focused identities for awhile.

In addition to the member-initiated groups, Site 2 also offered several hundred administratively-created groups around various disease and health related behaviors. By allowing members to join as many groups as they like, the administrators created a multi-dimensional community that allowed members to interact with those who shared experiences on many health and disease related issues. This multifaceted type of support would be impossible to reproduce in a physical setting because of the logistics involved in having a sufficient number of members interacting simultaneously in several different forums. The asynchronous nature of the communications and the larger geographic reach of the Internet make these issues relatively uncomplicated endeavors online.

### 8.4.4 Public Policy

According to Kim, members need a clear sense of the purpose of the community before they will be willing to join [97]. Potential members and “lurkers” will likely observe the behaviors of the others in the community before registering to join [85]. Maintaining an empathic and pro-social environment will likely have a significant effect on the number of people willing to join the site. Knowing that the ability to provide new information to members will be dependant, in part, on the size of the community, the question becomes how administrators can reinforce the positive behavior and reduce or eliminate anti-social behaviors from their site. Both sites I observed used a couple of cues to help inform and remind members of the desired behaviors while on the site. The first, although likely not read thoroughly by the majority of the members, is the “end user agreement” that most websites require you acknowledge reading and obeying as part of the registration process. Here the sites explained what the site was for, and what limitations were in place regarding the use of the features and the content on the site.

A more visible reminder of the rules on Site 2 was displayed whenever a member sought to interact with another member. The reminder included a brief statement reiterating the purpose of the site in providing help and support to other members of the community. This “point of interaction” reminder may have helped maintain the pro-social interactions observed on the site. Assessing the content of the text to determine whether it complied with the policy did not appear to lie solely with site administrators however. Both sites had a feature that allowed the members to “report abuse” if a reply or interaction was outside of the acceptable boundaries of behaviors on the site. During the study period an obvious spam message was the only observation of a misuse of the community observed. Member report of the abuse was not clear, however, by the next day the discussion thread was closed to further comments. Since the discussion threads with the most recent activity were keep near the top of the lists of discussions, this had the effect of pushing the discussion forum off of the visible page fairly quickly, essentially burying it from view from other members by placing it in the archives of discussions. A more draconian measure, although not observed during the study period, is the ability for the site administrators to delete the offending discussion thread altogether. By eliminating or closing threads that don’t comply with the standards established by the administrators, new members are rarely, if ever exposed to discussions that don't comply with the desired behaviors. The technical ability to control such discussions has a significant impact on the culture of the site, and provides support for our hypothesis that technical and cultural determinants of health are unique to the online world.

### 8.4.5 Technical Determinants of Health

In the discussion of online social ecology in Chapter 2, I hypothesized that technology would mediate every interaction on the site, from the formation of the digital identity to the social interactions between the members. Our empirical evidence strongly supports the need to highlight the technical determinants of health in the online ecological model.

As discussed in the previous chapter, the formation of the online profiles differed significantly between the two sites in the sample. The difference in the registration process highlighted different facets of the identity of the members that, in turn, likely influenced the interactions between the members and discussions in the type 2 diabetes forums. Information about the individual's management of diabetes, including date of diagnosis, current medications and latest HbA1c levels were solicited from the members while registering for Site 1. As a result, replies in the discussion forums often included evidence that a respondent would go to the member's profile to obtain additional information they thought was pertinent to the discussion, without soliciting that information from the member through the thread. Such behavior was not possible and subsequently not observed on Site 2. Despite the fact that the features on the profile pages were very similar (e.g. photo sharing, personal blogs and friend networks were present on both), the information conveyed from the profile pages was very different.

Another example of technical determinism is the difference in utilization of a feature depending on how that feature is labeled on the site. The higher utilization of the “online journal” feature on Site 2 compared to the “personal blog” on Site 1 likely demonstrates the affect of labels on utilization, since both features appeared similar otherwise. Careful consideration should be given to the desired use of the features on the site when planning how to present the feature to the members. Consider that this feature also enabled the formation of strong social ties on Site 2, which did not appear on Site 1, despite the technical similarities between the two sites.

A final interesting example of technical determinants in the online world was the ability for the technology to provide a form of support for the member independent of the member’s interaction with others members on the site. Site 2 surveyed the words in the replies on the discussion threads to determine whether any matched the list of potential treatments in its databases. If a match existed, the technology automatically added a hyperlink to the word in the discussion thread ostensibly to make it convenient for a reader to learn more about the treatment by simply clicking on the word. While the technology lacked the ability to determine the meaning of the word in the context it was used, it nonetheless represents an entirely new opportunity for public health interventions. The support provided by the site was a simple hyperlink to additional text based information. That hyperlink could lead members to a site that uses more robust multimedia presentations. The link could have also triggered an intervention from other members, as was observed when members of Site 2 listed their emotional state as “horrible”. That event automatically listed their profile on the “members in need” webpage, and could have sent an email to friends in their online social network soliciting some type of virtual social interaction. In fact, technology existed in earlier iterations of gaming sites wherein the system could interact with a human, mimicking a social exchange. Rather than relying on the empathy of its human members, the technology could automatically generate an appropriate response from a virtual member offering its support for the member in need.

As public health interventions turn to the Internet to expand the breadth and depth of support available to individuals, the designers of those programs need to consider the social implications of the technical decisions they make about the site. In that regard, the software engineers building sites with Web 2.0 technologies are now also social engineers, both of which are new roles for public health practitioners.

### 8.4.6 Cultural Determinants of Health

As social engineers building online social support groups will not only involve choosing what technologies to include on the sites, but also taking an active role in establishing the culture of the site. In many physical world public health interventions, planning for the intervention to be “culturally sensitive” could have a significant impact on the adoption and effectiveness of the program. While care must be given to not exclude individuals with various cultural backgrounds from public health 2.0 sites, much more attention needs to be given on designing a new culture guiding interactions and utilization on the site. Although both sites in this study addressed type 2 diabetes, the cultures observed on the two sites in this study were different. The age of the members and gender proportions differed between the two, although further studies would be needed to determine what aspects of the sites made them more attractive than other sites to their members. Site 1 was much more focused on diabetes, including sharing information about new research or significant media events pertaining to diabetes. Site 2 tended to provide more food related discussions and was more likely to reflect strong social ties between the members. As mentioned above, these cultural differences are largely due to the technical differences between the sites, and reinforced with the technology available to ensure members adhered to the policies and preferred practices of the site. Planning and regulating not only policies, but the desired culture of the site reiterates the need for public health practitioners to work closely with those implementing the technical components of the intervention, rather than just turning over the development and maintenance of the site to an uninvolved technical support company. As public health programs and social networks expand, there will likely be a greater demand for technologists who understand the social and public health implications of various feature and design choices to actively assist those designing online public health interventions. I designed the following theory of online social support to be a starting point for building public health 2.0 interventions.

## 8.5 ONLINE SOCIAL SUPPORT MODEL

Public health practitioners who plan to use the new interactive features of the Internet will benefit from giving serious consideration to the following constructs to predict which outcomes can be influenced based on the features of the site.

### 8.5.1 Constructs

1. Use of technologies that enhance social presence within the community, such as custom profiles, photo sharing, friend networks and personal blogs would be expected to be positively correlated to perceptions of social support, and negatively correlated with perceptions of social isolation and depression.

    a. One would expect there to be a dose-responses relationship between those outcomes and the frequency and length of participation on the site.
    b. These technologies would likely also be positively correlated with the strength of the social ties that develop on the site, which could help members cope with negative life events.
2. Technologies that enable interactions between weakly tied members of the community in a disease-focused forum (such as discussion forums and smaller groups) are likely to increase their knowledge of that disease, enhance their self-efficacy in managing the disease, and enable them to establish more realistic outcomes for their disease than they would have compared to a historical control.
    a. These correlations would also likely exhibit a dose-response relationship based on the frequency and length of interaction with the technology.
    b. The size of the weakly tied network would also be correlated to the perceived social support. The site would have to be large enough for members to interact with salient others, but not so large that members feel unable to be heard in the discussions.
3. Both constructs will be positively affected by the amount of perceived empathy, the number of pro-social exchanges and the perceived optimism of the members on the site, and negatively affected by the physiological and psychological burden of the disease being discussed.
    a. Availability of technologies that allow members to help regulate anti-social behavior and that prompt compliance with the supportive culture of the site will be correlated to the perceptions of empathy, pro-social exchanges and optimism.

b. The availability of those technologies would also be positively correlated to perceptions of trust and credibility between the member and other participants on the site, and between the members and the community itself.
c. The availability of adequate and salient social support in the individual's physical support network or through other online sources of support will likely moderate the effects of the online community being studied.

Additional research will be necessary to determine whether the constructs proposed above hold true with samples that are more representative of the community and using various experimental designs. Based on our initial results however, the empirical evidence seems to support the idea that online social support communities can provide an effective complement to traditional medically-oriented care and to physical support networks.

## 8.6 CONCLUSIONS

The widespread growth and adoption of interactive, Web 2.0 technologies represent an unprecedented ability for public health practitioners to provide greater depth and breadth for health-related social support. Members of these support communities receive instrumental, informational and emotional support in ways that may not be possible in the physical world. In designing new web-based interventions that rely on these social technologies, public health practitioners would be well-advised to consider the differences between social ecological determinants in the physical world and those observed in virtual communities. The role of health advocates designing the sites may evolve more appropriately into both a technical and social engineer, given the dependence on the technologies necessary to create the community and the social impact of those choices.

# 9.0 SUMMARY DISCUSSION AND CONCLUSIONS

## 9.1 SUMMARY OF RESULTS

The first specific aim for this qualitative research was to determine how individuals with type 2 diabetes were using existing online social support groups with Web 2.0 features. By studying the discussion forums and individual member profiles we learned that the discussion forums were mostly used for members to ask questions about their diabetes medications, their blood glucose levels and food. In response to the questions the community shared their personal experiences and advice in a style I described as “experienced empathy.” Since the replies to the initials posts frequently addressed other replies to the post, the cumulative responses generated a community knowledge base that was not only helpful for the original author of the discussion thread but for other members of the community as well. Members clarified earlier replies and provided normative parameters around the recommendations based on their personal experience. I labeled the interactions between the replies and the resulting knowledge base on that particular subject as “group guidance.” The discussion forums also emerged as large network of weakly tied individuals that exemplified Granovetter’s “strength of weak ties” hypothesis [99]. A significant difference however was the discussion forums were often much larger and provided more salient experiences than would be expected in weakly-tied, physical social networks.

In addition to the larger body of knowledge of diabetes management available through the discussion forum, the features of the individual member's profile page induced more intimate and stronger social ties. On one of the two sites I reviewed members used a blogging feature labeled as an "online journal" where members reflected on their current triumphs and tribulations in life and rarely discussed their diabetes. The conversations that emerged from their network of friends provided frequent positive social interactions and feedback that was significantly different from the responses in the discussion forum. Responses to the journal were more likely to include expressions of love and to relate personal experiences in terms of the historical interactions between the respondent and the member writing the journal entry. These frequent and more intimate communications provided evidence that strong ties can emerge on websites using Web 2.0 features and seem to challenge Walther's previous finding that anonymity may be a precondition for hyperpersonal behavior [70]. Based on these findings, such behavior is possible when strong ties develop through social technologies. These technologies may provide complementary social support networks for individuals who are socially or geographically isolated.

The second specific aim of the study was to describe how the social ecology of virtual communities differed from physical communities. As predicted, components of every determinant of health differed in the online community compared to what one would expect in the physical world. We learned that technology mediates every determinant of health in the online community, from the registration process on the site that defined the online profile of the members to the presence or absence of features that had a direct affect on the range of social interactions that could occur. The social and software engineering roles played by the administrator of online communities provides the unique ability to enforce the desired culture of the site rather than simply reacting to the culture already established in a physical community.

The combined results of the discussion threads and profile features guided the development of the Theory of Online Social Support. By focusing on the social roles that could be regulated by the features of the website, theories from public health and computer-mediated communications were combined to help predict the affect that different social technologies would have on the perception of social support experienced by the members.

## 9.2 IMPLICATIONS FOR FUTURE RESEARCH

The research opportunities that still lie ahead of us are vast, considering the relatively nascent stage of Web 2.0 technologies being used for public health initiatives. To begin, further qualitative studies, including interviews and focus-group studies are necessary to determine how existing members of online support communities perceive the support they receive on the site. While this study was useful in codifying the interactions in our observational role, validating the findings with the members will help determine whether our assumptions about the nature of the interactions are correct. Future quantitative studies are necessary to determine whether our findings are generalizable to other web sites and health conditions, albeit with the caveat that one would expect some variance in the topics discussed and type of support provided based on the different technologies on the sites under review. We would also expect some variance based on the physical and emotional burden of the disease. Social network and other systems-oriented research could help measure and predict how social networks form online and whether certain features of the network could be leveraged to facilitate the widespread adoption of healthy behaviors. Future research should also focus on developing valid and reliable tools that measure social support, intimacy and other variables as they are perceived in the online setting compared to the physical settings for which many tools have already been developed.

Once the psychosocial assessment tools are developed and tested, a logical next step in a research agenda based on this work would be to conduct a pre and post test analysis of the changes in the perception of social support, prevalence of depression, measures of self-efficacy and the acquisition of new knowledge of the disease(s) of interest in users of an online social support group. By evaluating these measures one could determine whether the constructs of the Theory of Online Social Support are an accurate guide for developing online support groups. By monitoring the changes in those measures over a period of time we could also determine whether a dose-response relationship exists based on the frequency of the utilization of the site as predicted by the theory.

In addition to qualitative and quantitative studies, controlled experiments will help determine whether Web 2.0 features designed around traditional behavioral change models, social cognitive theory and other scientifically based health behavior interventions influence the perceived social support of the members and ultimately whether the interventions or utilization of these sites are linked to other health outcomes such as quality of life measures and healthcare utilization. Given the ability for members to participate in multiple groups simultaneously, researchers should also explore the application of online support groups which seem particularly well, if not uniquely, suited to develop intervention strategies for addressing the burden of syndemics [113]. Finally, given the importance of the technology that provides the infrastructure for online support groups, a new area of intervention design studies need to be considered that monitor the impact of the presentation of the various social technologies within the user interface of the site. The hypothesis that utilization of the personal blogging feature was influenced by its label as an “online journal” is just one of many examples of the potential impact of design choices on other online behaviors that could affect health status.

## 9.3 LIMITATIONS OF STUDY

Employing extant text analysis as the primary methodology was intentionally done to capture the genuine communications occurring between the participants without risking the research process influence on the social interactions occurring on the sites. Unfortunately the inability to communicate directly with those using the site also prevented the ability to determine whether our results accurately reflected the perspective of the community members. The lack of constituent authenticity was a known drawback during the study design but ultimately was felt to be less important than maintaining the authentic communications and avoiding the risk of undermining the trust of the community by introducing a potentially unwelcome review of their online behaviors.

Another weakness of the study was the lack of a multi-investigator coding process to ensure that data were being accurately and consistently coded according to the accepted coding schema. The limited resources available for the study dictated the single-coder approach to the data. To counter the lack of coding assistance, the investigator met with committee members on a frequent and regular basis during the coding process to discuss and resolve any potential coding concerns.

Finally, the results of this study were not designed to be generalized to activity in other websites or with other diseases. The purposive sampling technique I used for the online profiles was designed to explore the use of the Web 2.0 features on the sampled members profile pages and not designed to be representative of the utilization of those features for the entire population of the community members. Given the qualitative methodology used during the site, readers should be cautioned against using the results of the profile analysis to predict behaviors in other online settings.

## 9.4 ETHICAL CONSIDERATIONS

Social ties are often held together by the credibility and trust established between the participants [78]. Future researchers should avoid developing online social support communities for experimental conditions that they have little intention of maintaining after the research is complete. Based on the evidence of strong social ties I observed in one of the communities, discontinuing the online community without providing an alternative place to maintain those relationships after the study concludes could have a serious affect on the social support of the members in the short term and would likely increase their distrust of other similar communities in the future. The desire to sustain effective community-based research projects is certainly nothing new to public health research. However, the consequences of developing unsustainable initiatives are significantly magnified in online communities where the size of the community and the geographic scope of the intervention can be orders of magnitude larger than traditional, geographic community-based interventions. Rather than jeopardizing a few dozen people by shuttering effective interventions in physical community, unsustainable online support communities could negatively affect thousands of people throughout the world.

Similar to other accounts, the members' expectation of maintaining privacy in the online communities I studied was not clear [90]. While members could, and often did, mark their journal entries as private, the ones reviewed in this analysis consisted only of those that were publicly available. I chose to conceal the pseudonyms used and keep the sites anonymous in this report to add additional protection for the privacy of the members; even though there was no strong evidence that they expected their publicly available conversations to be private.

## 9.5 SIGNIFICANCE OF RESULTS

Three hundred million people have created an online identity on Facebook in what is likely still just the beginning phases of a broader cultural shift to participation in socially-immersive, computer-mediated communities. Today, "microblogging" features that apply members to briefly describe their current thoughts and mobile platforms through which individuals can access the Internet have made online social presence a nearly ubiquitous state 98]. Current and future generations will likely see the adoption of even more technologies that allow individuals to maintain and control their weak and strong social ties throughout their entire lifespan. They will also find it convenient to create new social networks that fulfill a particular informational or social support need. Public health advocates will have to expand their traditional distribution models to effectively use these new social networks and virtual communities as settings for public health interventions.

To reach these new communities, public health practitioners will need to rely on technologists that understand how to create and sustain virtual communities and how to best address the health determinants of the online social ecology model. Rather than adapting public health programs to an existing physical venue with various cultural considerations, future interventions will have to build the online venue and decide how best to enforce the culture expectations and how to regulate the social interactions without alienating the members of the community. In addition to relying on evidence-based interventions, public health programs designed for adoption in Web 2.0 enabled communities will need to rely on tested design and community management principles from other science domains to ensure that the interventions don't fail as a result of poorly constructed communities.

## 9.6 RECOMMENDATIONS

Providing social support online has been witnessed since Rheingold first coined the term virtual community in describing the interactions on a bulletin board system known as "The Well" [3]. Given that virtual communities and social networks have evolved from a hobby among a few computer buffs to a consistent presence for 300 million people, leveraging Web 2.0 technologies and social networking capabilities will be instrumental in the evolution of public health interventions. As such, public health practitioners need to partner with other computer science experts such as those familiar with computer-mediated communications and human computer interface theories. By collaborating with these technologists and others, more effective interventions can be developed that fulfill the need for the next evolutionary stage of public health.

# APPENDIX: FINAL CODING DEFINITIONS OF SOCIAL SUPPORT EXCHANGES

| **Type of support** | **Definition** |
|---|---|
| Personal Experience | Relates information pertaining to their own experience with the topic |
| Guidance | offering advice, information, or instruction other than that obtained through personal experience |
| Navigational Aid | Providing a hyperlink to a potentially useful or relevant website |
| Personal Assistance | Offering to collaborate or communicate individually with another individual |
| Positive Regard | Expressions of esteem, caring, understanding, empathy and empathic concern |
| Feedback | Feedback that includes appraisal of the individual or their actions. Could include positive or negative appraisal. |
| Supportive Statement | Well wishes, good luck, inclusion in prayers or other pro-social statements designed to encourage or show support for another |
| **Clarifications** | |
| Clarifying Question | A question designed to elicit more detailed information an author of an earlier reply or the author of the original quote. |
| Clarifying Statement | A reply that provides additional information not previously supplied. |

**Note:**

**Guidance** as used in the coding of the journals did not reflect the same type of information presented in the discussion threads. Guidance here was mainly to normalize whatever behaviors and feelings that the member was experiencing and to convey “Common sense” advice versus more specialized medical treatment information. It also includes more biblical references and mentions of God’s plan than in the forums.

**Pro-social Statements** included many more expressions of love than in the discussion threads.

**Personal Experience** sometimes includes the shared experiences of those writing the journal and those responding to it.

**Feedback-** I’m sorry, that’s great, and etc. have been added to the definitions based on the journal entries. These forms of feedback come much more frequently than on the discussion forums.

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*Identities for Site 1 and Site 2 removed to maintain the anonymity of the communities.