USES AND GRATIFICATIONS OF AMPUTEES' ONLINE SOCIAL NETWORKS

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The Supervisory Committee certifies that this ***disquisition*** complies with North Dakota State University's regulations and meets the accepted standards for the degree of

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ABSTRACT

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The following thesis examined amputee support groups on Facebook. Having an amputation can be a life-changing experience, and social support may be necessary to understand one's amputation. Hundreds of amputee groups exist on Facebook, and many of them foster active online communities. This study sought to accomplish two goals: describe how amputees use these groups, and uncover the predictors that lead to engagement in socially supportive behaviors, particularly providing informational support and emotional support. While not all groups are active, this study found that amputees do connect with others through Facebook, sometimes quite frequently. Posting on group walls significantly predicted use of informational support behaviors, and age, overall health condition, and posting on group walls significantly predicted use of emotional support behaviors.

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Dr. Helgeland, thank you for mentoring me and believing in me these past years. I never would have imagined where I would be at today when I first took your New Testament class seven years ago. You have profoundly changed my life, and I will do my best to continue the good work you began in me.

~Dennis Owen Frohlich

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1. INTRODUCTION

Limb loss presents a unique health situation for amputees. Amputation is often the result of disease. The majority of amputations, 82%, are dysvascular-related (problems associated with blood vessels), often caused by diabetes (National Limb Loss Information Center, 2008a). Other amputations are caused by trauma (such as a car accident), cancer, or congenital abnormalities. Approximately 1.7 million amputees currently live in the U.S., or roughly 1 in 180 people (NLLIC, 2008a). Just as online support groups exist for other medical conditions, numerous support networks provide a forum for amputees to meet others like them (National Limb Loss Information Center, 2009).

Online support groups increasingly play a major role in the treatment and management of health conditions and diseases. Horrigan and Rainie (2006) found that 49% of Internet users have helped another person with a major illness or medical condition, and that 26% of these users said the Internet played a crucial or important role in making decisions about their health. The report also found that 19% of Internet users have dealt with a major illness or medical condition themselves, and that 28% of these users said the Internet played a crucial or important role in managing the illness.

Past research has looked at how certain populations use the Internet to find social support (Beaudoin & Tao, 2007; Bunde, Suls, Martin, & Barnett, 2006; Josefsson, 2005; Mo & Coulson, 2008; Peterson, 2009). Research into online support groups includes support groups for disabled persons (Braithwaite, Waldron, & Finn, 1999), HIV/AIDS patients (Reeves, 2000), irritable bowel syndrome patients (Coulson, 2005), people with food allergies (Coulson & Knibb, 2007), infertile men (Malik & Coulson, 2008), and complex regional pain syndrome patients (Rodham, McCabe, & Blake, 2009). People in

these populations may have difficulty attending a physical support group, or their illness or condition might be too embarrassing to talk about interpersonally with others. This study extended online support group research to a population with unique health concerns, and expanded on previous research by looking at which variables best predict the frequency of social support behaviors.

Research Focus: Amputees and the Need for Social Support

Amputees deal with many challenges beyond the cause of limb loss. Challenges include post-surgery complications, changes in routine, prosthetic fitting, physical therapy to understand how to use a prosthesis, and emotional needs (Rossbach, 2008). Amputees also deal directly with changes to their identity. Braidotti (2006) argued that technology "de-stabilizes" the very notion of "the human" (p. 197), and that is especially true of amputees who wear prosthetics. Prosthetics help amputees maintain independence, and advances are continually being made in high-tech prosthetic technology (Broadwater, 2010; Dao, 2010; Mraz, 2010). But amputees who wear prosthetic limbs are constantly reminded that their biological bodies are incomplete, especially if the prosthetics do not even approximate real limbs, such as colored hooks for children with missing hands (Hilhorst, 2004). Prosthetics do serve a practical function, but at what expense? Amputees have to deal with body image issues, and possible social stigma of living with an amputation.

Amputees may need support from other amputees to fully accept their limb loss, and to learn how to engage with their prosthetic. Being told how to live with limb loss by a surgeon who has not had an amputation may not be sufficient in helping amputees cope with their situation. Vanderford, Jenks, and Sharf (1997) suggested that instead of looking at patients as mere receivers of health messages, either from their provider or from health

campaigns, patients should be seen as "active interpreters, managers, and creators of the meaning of their health and illness" (p. 14). As creators of meaning, patients are central and their health experiences matter. Vanderford et al. (1997) argued that patient identity is crucial to understanding illness, but that individuals cannot be "reduced to being merely a patient" (p. 15).

Online communities serve several functions. Patients bring together their collective knowledge of medical information and share their personal experiences with others (Josefsson, 2005). Finfgeld-Connett (2005) suggested that online social support is an interpersonal process involving the exchange of information. Additionally, family and friends make up the majority of peoples' social support networks, not health care professionals. Beaudoin and Tao (2007) developed a model of online social support to explain the benefits patients receive from such groups. The researchers found that online support is characterized by asynchronous communication, which leads to social interaction and then social support from others. These may lead to positive health outcomes in terms of coping with depression and stress. Synchronous online communication, operationalized as instant messaging and chat rooms, was not a significant predictor of social interaction, and reasons for this are unclear. While the evidence for positive outcomes from support groups is numerous (Bennett et al., 2001; Cohen & Wills, 1985; Hale, Hannum, & Espelage, 2005; Lee, Arozullah, Cho, Crittenden, & Vicencio, 2009), very little research has looked at the factors that influence how people engage in socially supportive behaviors.

Rationale for Study

Many studies on online social support are descriptive accounts of the types of support messages found on message boards and forums. Studies have not thoroughly

examined, however, what variables predict how often people use various online social support. This study expands on previous research by examining what factors predict online social support activities in amputee groups. Understanding the predictors of online social support behaviors is of great importance to both the communication and medical disciplines. For communicators, this research goes beyond describing how groups are used to explaining some of the use. Health practitioners benefit by understanding how people with a health condition create spaces to meet and support each other.

Definitions

Before proceeding, some terms commonly used in this thesis will be defined. These concepts will also be explained in more detail Chapters 2 and 3.

Emotional support is defined as empathizing with another who is going through a similar life situation. It includes both giving emotional support to another and receiving emotional support.

Facebook groups in this paper refer to Facebook groups and Facebook fan pages collectively. Facebook makes a technical distinction between these terms, as will be elaborated upon in Chapter III, but because users can engage in almost all the same activities under both classifications, the two terms will be referred to collectively.

Informational support is defined as giving and receiving medical information.

Network support is defined as establishing support networks between people in similar health situations. Network support refers to the connections made between people, not the content of the interactions through those connections.

Online social networks refer to formal websites that make establishing and maintaining relationships with others easier. The online social network examined in this thesis is Facebook.

Online support groups refer to formal or informal groups of people created around a medical condition. Online support groups can be formed on independent websites, or through online social networks, such as Facebook.

Social support is an umbrella term for the various ways people with a medical condition can support one another and receive support from one another. Under the term "social support" exist more specific types of support, such as informational, emotional, and network support.

Wall posting is an online activity unique to Facebook. Facebook groups have a common message board, known as the wall, where people can leave messages, post links, and upload photos and videos. Other people can then respond to these postings. Public communication visible to most people is primarily achieved by posting on walls.

Summary

This thesis examines amputees and their uses of online support groups on Facebook. In Chapter 2, primary uses of online support groups are identified and serve as the foundation for the research study. Chapter 3 details the survey methodology used to administer online surveys to amputees recruited from Facebook groups. Chapter 4 reports the results of this survey, and Chapter 5 concludes with a discussion of the results and final thoughts on the thesis, including limitations and future research direction.

2. LITERATURE REVIEW

To understand how amputees are using online support groups, relevant literature on face-to-face social support and online social support will be examined. Specific types of social support likely to be used online—informational support, emotional support, and network support—will also be conceptualized and explained.

Online Social Support

Being supported socially is vitally important for people with medical issues, particularly life-altering health conditions. The literature about online support groups is extensive and suggests that patients receive many benefits from online support groups. A national survey of seniors' perceptions of social support in general, without reference to online social support, found that:

> More than 7 million older persons, or 17% of this population, were dissatisfied with the extent of emotional support available to them. More than 2 million older persons (5%) reported not having any source of emotional support, with the majority of older persons (more than 26.5 million, or 59.6%) receiving their emotional support from family members only. (White, Philogene, Fine, & Sinha, 2009, p. 1874)

Saito, Sagawa, and Kanagawa (2005) found that receiving social support from a neighbor, particularly emotional and instrumental (or tangible) support, predicted improved health status for older adults living in Japan, particularly single women. In a study of a general national sample of Swedes, Östberg and Lennartsson (2007) found that discussing personal problems is not the greatest type of social support, but rather having the ability to borrow money and have company nearby. The Internet, though, cannot keep patients

company by putting them in physical proximity with others, and it is unlikely that Internet use facilitates greater borrowing of money and other financial resources for individuals of lower socioeconomic classes.

Most social support research, then, has focused on the types of social support patients can provide to one another in a mediated context. In a content analysis of messages posted to an online HIV/AIDS community, Mo and Coulson (2008) found that the most frequent types of social support messages posted were: informational support (44.5%), emotional support (35.2%), and esteem support (12.4%). While the frequencies between types of social support change from study to study and online community to online community, these frequencies are similar to those found by other researchers. In a study of an online support group for hysterectomy patients, Bunde, Suls, Martin, and Barnett (2006) found that 61% of messages contained informational support and 31% contained emotional support. Civan and Pratt (2007) also found that informational and emotional support messages were predominant in a study of breast cancer communities.

A third type of social support found online is network support, or the measure of the size and quality of one's social network. While online network support messages inviting people into a group appeared infrequently in online HIV/AIDS support group (6.9% of messages; Mo & Coulson, 2008), network support, sometimes identified as "belonging", is associated with better health and health perceptions (Hale, Hannum, & Espelage, 2005). Segrin and Passalacqua (2010) argued that the quality of social connections is more important than quantity, at least when associated with decreasing loneliness in people. Research on the relational uses of online social networks has focused primarily on

MySpace and Facebook, the two largest social networking sites. Research finds that maintaining relationships is the primary purpose of online social networks.

Raacke and Bonds-Raacke (2008) found that the vast majority of MySpace and Facebook users use these networks to keep in touch with old friends (96%), or keep in touch with current friends (91%). Not only do users maintain friendships, but many also use social networking for dating purposes, and to connect with new friends (Bonds-Raacke & Raacke, 2010). Sheldon's (2008) survey of students' use of Facebook found that females use Facebook for maintaining relationships more than males, and females also use Facebook to pass time and for entertainment. Males and younger respondents use Facebook more to meet new people or to develop a new relationship. Research into uses of Facebook groups, sub-networks within the larger social network, found the same general uses: socializing, entertainment, and information seeking (Park, Kee, & Valenzuela, 2009). Urista, Dong, and Day (2009) found that social networking is used for efficient and convenient communication, to become more popular, and to formulate new relationships. However, users do make a distinction between online and face-to-face friends.

Online social support happens in three stages, according to a model developed by Tichon and Shapiro (2003). First, individuals self-disclose information about themselves and the illness or condition to elicit social support from others. Second, other individuals self-disclose to provide social support. Finally, two or more individuals in a reciprocal social relationship self-disclose to each other, continuing the social support.

Research on why people join online support groups is limited, but provides an essential background for this study. In studying why people seek health information through new media sources over traditional sources of health information, Rains (2007)

found that distrust in traditional sources of health information is correlated with increased web use. Distrust of health care providers and entertainment-oriented media lead people to using the Internet first, even over other traditional sources of information, such as magazines. Wright (2002) examined motives for using online support groups and found, not surprisingly, that convenience is the most important motive for using online support groups. This could be because a patient does not have a physical support group to attend close by, or attending a support group is made difficult because of scheduling or other obligations. Online support groups are available any time of the day or night, giving patients a safe place to go at any time. Wright (2002) also found that patients use online support groups on a daily basis either to pass time or to fulfill interpersonal needs by communicating with other patients.

Effects of Social Support

There is mounting evidence that social support can lead to positive health outcomes. Before widespread use of the Internet, Cohen and Wills (1985) suggested that research provided ample evidence that socially supportive communication can lead to positive health outcomes, such as increased self-esteem and quicker healing. Bennett et al. (2001) found that higher "social support scores . . . were associated with emotional quality of life" (p. 679). Strine, Chapman, Balluz, and Mokdad (2008) suggested that inadequate social and emotional support is correlated with a lower health-related quality of life and negative health outcomes. Changing social networks from one that supports drinking to one that supports sobriety was associated with more healthy drinking behaviors (Litt, Kadden, Kabela-Cormier, & Petry, 2009). Hale, Hannum, and Espelage (2005) found that belonging to a group and having strong connections with a group predicted better health perceptions

for women and fewer physical symptoms for men. The researchers did not find evidence that self-disclosure, social intimacy, or tangible support directly predicted any health outcomes. However, Hale et al.'s (2005) population was a general population of college students who exhibited few physical symptoms of illness.

In a two-year longitudinal study of amputees following lower limb amputations, Williams et al. (2004) studied social integration, one aspect of social support, defined as "the extent to which an individual participates in a broad range of social relationships" (p. 863). Williams et al. (2004) found that most amputees reported moderate to very high levels of perceived face-to-face social support, and that social integration remained relatively high and stable during the study period. Widowed and divorced amputees were, however, more likely to report lower scores of face-to-face social support than others in the study. Lee, Arozullah, Cho, Crittenden, and Vicencio (2009) studied whether interaction of health literacy and social support affects health status. The researchers found that for older adults with high health literacy, social support had a more positive association with physical health. The implication is that individuals who already have strong social networks and are health literate receive more health benefits through social support than individuals who do not have as strong of networks.

While some researchers found positive health outcomes from social support, such as Westaway, Seager, Rheeder, and Van Zyl's (2005) study of patients with diabetes mellitus, other researchers, such as Eysenbach, Powell, Englesakis, Rizo, and Stern (2004), argued that the evidence for health effects of online support group is inconclusive. Complicating the study of online support groups is that not all online support groups function the same way, and not every group is set up similarly. For instance, it might make

a big difference in the effectiveness of online support groups if the group has open borders, allowing anybody to join, post, and view comments, or if the group has closed borders, such as a support group for men with HIV that only allows people to post positive comments, not negative or whiny comments (Peterson, 2009). Most research connecting social support to health outcomes looks at face-to-face social support, so more work is needed to uncover the health benefits of online social support.

Research Goals

Past research about online support groups has sufficiently described the type of social support messages found in these groups, and has sought to link activity in support groups to health outcomes (Hale, Hannum, & Espelage, 2005). The present study was different from previous studies of online support groups in several ways, and expanded upon previous research. First, the online support groups previously studied were often independent message boards or websites. This study looked at amputee support groups on Facebook, a platform used for a multitude of activities. Second, previous research identifies types of social support messages likely to be transmitted through online forums, but has not examined the variables that best predict use of online social support.

Facebook may be a newer platform for online support groups, but it is not necessarily the best platform. A support group that functions through a message board platform, for instance, can be very user-friendly. Forums or threads can be created for specific topics of interest. Users can often create their own profiles and interact with other members privately. And contact information for various websites and patient experts can be listed on easy-to-use pages. These same functions exist in Facebook support groups, but they are not as user-friendly or multifaceted as other support groups. Group leaders also

have limited control over the design of their support group's page. Group members, though, may find other ways of contacting each other outside of Facebook's public channels for communication. Examining support group interaction solely within the confines of Facebook support groups, then, tells only part of the picture of how these support groups are used. To see if group members are contacting each other in different channels after first connecting through Facebook, the following research questions were proposed:

RQ1a: How often do amputees interact with others using various channels on Facebook?

RQ1b: How often do amputees interact with others using channels of communication outside of Facebook, such as private email, phone, and in-person meetings?

To understand what variables best predict socially supportive behaviors, the following research questions were proposed:

RQ2a: Controlling for age, sex and race, do amputees' physical health and psychological adjustment predict the frequency of sending and receiving informational and emotional support messages via Facebook?

RQ2b: Controlling for the previous variables, do amputees' level of perceived face-to-face social support predict the frequency of sending and receiving informational and emotional support messages via Facebook?

RQ2c: Controlling for all previous variables, does engagement in different Facebook activities predict the frequency of sending and receiving informational and emotional support messages via Facebook?

As previously detailed, researchers have connected social support to positive health outcomes, particularly social or emotional adjustment (Bennett et al., 2001; Cohen & Wills, 1985; Hale, Hannum, & Espelage, 2005; Williams et al., 2004). RQ2a sought to understand if an amputee's physical or psychological health predicted social support. Do healthier people engage in these activities more frequently, or do less healthy people have higher needs for social support? RQ2b sought to understand if perceived levels of face-to-face social support predicted use of online social support. Finally, using the data from RQ1, RQ2c sought to understand if frequency of different communication behaviors predicted use of online social support.

Summary

In this review of literature we have discussed the constructs of social support most relevant to online support groups. The next chapter will discuss the methodology used to answer the research questions. The sampling frame and participants will be defined, and the recruitment strategy is detailed. The specific measures used to answer the research questions will be explained extensively.

3. METHODOLOGY

To understand how amputees are using online support groups, a survey methodology was employed. This best answered the research questions because it solicited responses from a large group of people, giving the results some generalizability. The target population—amputees who use online support groups—was very specific and posed some challenges to recruitment. In this chapter, we'll examine the sampling procedures used to find respondents. Next the participant group will be defined, and the recruitment strategy will be explained. The measures that best answer the research questions will be explained, along with the survey procedure. Finally, the data analysis plan will be detailed.

Sampling

The sample was defined as amputees who use social networking sites, rather than online support groups that are closed to outsiders, such as private forums for amputees, for several reasons. First, social networks are an emerging space for support and have not been examined as often as more traditional online support groups. Second, social network support groups are easier to access, both from a research perspective, and from the perspective of an amputee seeking to connect with other amputees. Social networks provide a user-friendly platform for meeting with other amputees, and one of the goals of this study is to uncover how amputees use these support groups.

While there are many different social networking sites online, particularly social networks for health issues, not all of them have large amputee communities. Health networks such as Wellsphere, PatientsLikeMe, and Spark People all have strong patient communities, but nothing specifically devoted to amputees. At least two amputee social networks exist, Amputee Empowerment Partners (AEP) and Less Than Four, but these

networks are smaller in size (between 1,500-2,200 members each), and appear to be communities relatively closed to outsiders. In light of the difficulties of recruiting from a variety of social networks, the sample for this study is defined as amputees who are involved in at least one Facebook group specifically devoted to amputees.

At the time of this writing, there are over 500 million Facebook users, and Facebook users interact with roughly 900 million objects, which include pages, groups, events and community pages (Facebook, 2010). A quick search of *amputees, prosthetics,* and *limb loss* yields thousands of results. Group size varies from 5 or less (perhaps failed groups that never got support from those who started them) to groups numbering 2,000 or more. Facebook features an ample amount of social support groups to study.

Amputee groups exist primarily in two forms: Facebook "groups" and Facebook "pages." Originally Facebook intended a distinction between groups and pages (Pineda, 2010). Pages are intended for public figures, businesses, and organizations, and are automatically visible to everybody on the Internet by default. Facebook groups are meant for regular users who happen to have common interests. Membership in Facebook groups can be more strictly managed. However, in actual use, Facebook amputee groups can be official organizations of people, and likewise Facebook amputee pages can be more informal in nature and not officially tied to a legitimate public figure, business, or organization. For the purposes of this study, the word "group" will be used to refer to both Facebook groups and pages. The use of this word is intended to focus more on the group of people, not the technical definition of how that group came to exist on Facebook. In reality, members of an amputee groups and pages have very similar media experiences. In both

spaces, users can perform the exact same activities, such as write on walls; comment on other users' posts; post pictures, videos, and links; and start discussion threads.

Most of the amputee groups on Facebook were eligible for study, with some exceptions. Groups that are very small in number (less than 30 individuals) were not included in the study because larger groups tended to have more active members (as evidenced by the frequently of posts on the groups' walls and discussion boards). Additionally, groups that were created in a country that does not speak English were not included because of the language barrier between the researcher and the participants. English-speaking groups can still have members who are from non-English speaking countries, and those members were free to participate.

Finally, closed groups were not examined. Closed groups are those that require an acceptance by the group to join. These groups were not included for three reasons. First, they were generally smaller groups, such as a local chapter of a face-to-face support group. Second, trying to make comparisons between usage of closed groups and open groups would have been difficult given that the number of amputees involved in closed groups seems significantly less than amputees involved in open groups. Third, searching for amputee groups will only yield publically visible closed groups. Users can create, however, closed groups that are not publically visible in searches ("secret" groups). These groups are impossible to find, thus sampling amputees from closed groups would never provide a complete picture on how closed group usage differs from open group usage.

Participants

The target population was amputees who had joined at least one Facebook group or page devoted to amputee issues and concerns. Participants were allowed to define

"amputee" themselves. Participants could be of any demographic characteristic, but needed to be over 18 years of age. Amputee groups are not necessarily composed entirely of amputees. Some groups advertise that amputees and amputee supporters are welcome. An amputee supporter could be somebody who knows an amputee, is related or married to an amputee, or otherwise has an interest in amputees. While these people have a valuable opinion and may provide social support to other amputees, they were not included in the target population as the research goals are focused on how amputees use online groups.

Users can also be people who are about to become amputees and turn to these groups to get an idea of how to cope with their amputation. While this sub-group has a meaningful perspective, it is too specific to make meaningful comparisons with the general amputee population. Additionally, not every person can anticipate becoming an amputee, such as soldiers who are injured in combat or people involved in motor vehicle accidents.

Total, 98 people took the survey. Not all responses were usable: 18 responses were eliminated as the participants said they were involved in zero amputee groups on Facebook, and thus not part of the target population. Additionally, three responses were removed for other reasons: one participant said she was 15 years old, and two said they were not amputees but family members of amputees. This left 77 useable responses.

The demographics of the respondents are as follows: 29 female and 25 males (23 did not respond). The average age was 44.22 (SD = 10.92, $Range$ = 18-69). The majority, 90.7%, indicated they were white/Caucasian (49 responses) and 5 were of another race (23 did not respond). The average amount of time since the amputation was 9.38 years (SD = 9.31, $Range$ = 1-44). Figure 1 indicates the cause of the amputation. Some of the causes in the *Other* category included: allergic reaction to heparin, birth defect, dehydration, fibula

hemimelia, infection, meningitis, meningococcemia, negligence, neuropathy, sepsis, and
spina bifida.
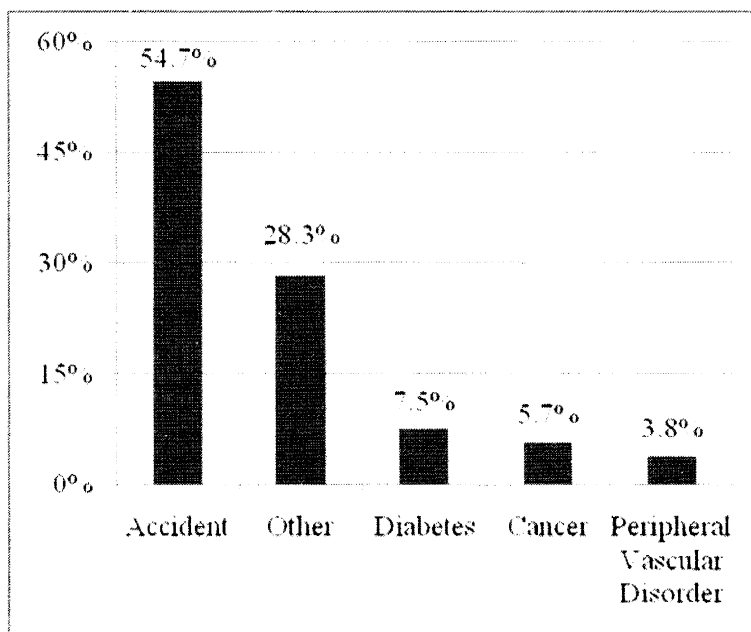
Figure 1. Causes of amputations ($N = 53$)

General questions were also asked of participants' connection to other amputees.
Participants were involved with an average of 3.63 groups on Facebook ($SD = 6.05$, *Range*
$= 1$-43), and spent an average of 33.46 minutes a week on these groups ($SD = 53.61$, *Range*
$= 0$-180). Participants were also asked how many online support groups they were involved
with outside of Facebook: average involvement was 5.39 groups ($SD = 24.82$, *Range* $= 0$-
193). However, this number is misleading as two participants reported very high numbers
of involvement outside of Facebook: 100 and 193 online groups. Removing these outliers,
participants were involved with an average of 1.52 online amputee groups ($SD = 2.15$,
Range $= 0$-12). Participants were also asked how many amputees they knew face-to-face:
participants knew on average 67 amputees ($SD = 256$, *Range* $= 0$-2,000). This number
again is misleading as five participants reported very high numbers of face-to-face

connections: 200 (twice), 300, 1,000 and 2,000. With these outliers removed, participants

knew an average of 19 amputees (*SD* = 26, *Range* = 0-100).

Recruitment

Recruitment of amputees who use Facebook groups proved the most difficult phase

of the project. Recruitment lasted approximately six weeks. No list of amputee Facebook

users' emails and contact information is available, so group members must be recruited by

alternative methods. Simply going to online amputee groups and posting a link to the

survey without prior contact with the group was not likely to be productive. In a study of

World of Warcraft videogame users, Williams and Xiong (2008) found that gamers

considered the researchers spammers, a particularly foul categorization, for posting

recruitment letters frequently on message boards. Instead, multiple methods of recruitment

were employed to capture as large of a sample as possible (Steward, 2003). Researchers

have used Facebook for research in a variety of ways: from actively recruiting research

participants to monitoring public profiles and groups without the participants' notice to

creating fake profiles to gauge participants' perceptions of other Facebook users

(Rosenbloom, 2007). For this study, it was best to be upfront about the research goals.

Sample recruitment emails and Facebook messages are included in Appendix A.

First, creators of Facebook groups and pages were contacted to gain permission to

post survey links and to recruit members from the groups. Permission was asked to post

survey links on group walls or discussion boards, or to have the group creator send the

survey link to group members through the "Message all Members" function, which can

only be done by the group creator and can only be done in Facebook groups, not Facebook

pages. The survey invitations were as short as possible, without being blunt or demanding,

so that group members would be more likely to read the invitation in its entirety (Dillman, Smyth, & Christian, 2009). The primary goal of the survey invitation was to get the group members to click on the link: once taken to the survey, group members were presented with a more fully developed invitation and explanation of the survey.

One potential problem in recruiting amputees was being viewed as an outsider. The survey asked amputees about their personal lives, their amputation, and their use of Facebook amputee groups—all private to semi-public information. As somebody who is not an amputee, it seems on the surface as if I had nothing in common with my target population. However, I appealed to the group members as somebody who is related in another way. Two years ago I had my entire colon and rectum removed after suffering with ulcerative colitis for a year. This surgery radically altered my life, and changed the way I live. While I cannot empathize with losing a limb, I can empathize about losing a body part. Additionally, since that surgery I have created a website and Facebook group for other people who have been diagnosed with inflammatory bowel disease and who have had surgery themselves. In my contact with the amputee community I emphasized my own involvement with online groups for people who have undergone personal changes, and how I wanted to learn more about the particulars of other similar, but distinct, online groups.

I searched for groups and pages using the search terms: *amputee, amputees, prosthetics,* and *limb loss.* Because it is impossible to rank search results in Facebook by group size, I examined every result and identified groups that were active and had more than 30 members. I contacted 87 groups through Facebook messages. Total membership in these groups was 23,100 ($M = 265$, $SD = 393$, *Range* = 18-2,104). It is impossible to account for people who are involved with multiple groups, and impossible to account for

how many of those members were amputees over the age of 18. Quality amputee Facebook pages were not as numerous, so I contacted 9 pages with total "Likes" (similar to membership) of 4,161 (M = 462, SD = 290, *Range* = 128-915). I received 35 responses from group leaders, most indicating that it was okay to post a link on the group's wall. Many also expressed that they would send the link through Facebook message to the group members. A reminder was sent to group leaders after 2 weeks if they were unresponsive to the first message. Most ignored the second message.

After the exhaustive contact of Facebook group members, participants who had taken the survey and completed it was exceedingly low. A second method of recruitment was attempted: contacting face-to-face amputee support groups to see if any of their members were involved with Facebook amputee groups. The Amputee Coalition of America has extensive contact information for support groups published online and publically visible (ACA, 2011). Face-to-face support groups exist in most states, and most provided email contact information. The groups with public email addresses listed were contacted and sent a recruitment letter similar to the letter sent to Facebook group leaders. The email specified that people were eligible to take the survey if they were involved in at least one Facebook amputee group. A total of 144 groups were contacted, and a reminder email was sent a week later. A total of 41 people responded. Most indicated that they had taken the survey themselves and would let group members know about the survey, either through email and/or at the next face-to-face group meeting. It is unknown how many amputees were reached through this method of recruitment, or the average group size.

A third method of recruitment was snowball sampling. Van Hoye and Lievens (2007) found that snowball sampling was one effective means of recruitment for Internet

research. At the end of the survey, participants were asked to recommend the survey to other amputees. Many of the group leaders also expressed that they knew amputees who were not involved directly in either their face-to-face group or Facebook group, but they had their email address and would send the link on to them. It is unknown how many people received such emails.

A final method of recruitment was the creation of a Facebook page specifically for the survey. Researchers have created Facebook groups in the past, such as one group created by a United Kingdom researcher, as explained in the group's description, entitled "Are you an amputee or do you know anyone who is an amputee?" When a Facebook user searches for something on Facebook, search results that show up first are ones with the keywords directly in the group or page title. So somebody searching "amputee" or "amputees" would be more likely to come across a group titled "Survey for Amputees" than a title that does not contain the word amputee. A page was created for the survey, but was ineffective as a recruitment tool: only one person "liked" the page in its two months of existence. The page was deleted at the end of the recruitment period.

Other recruitment methods were considered but never implemented. For instance, amputees could be recruited through Facebook advertisements, which can be an effective means of recruitment (Bhaskaran, 2010), though the cost of such ads is a major limitation of this approach. Considering the poor response to Facebook recruiting thus far, spending money on ads for the likelihood of another low response rate seemed inefficient. A second method is getting recruitment help through the Amputee Coalition of America, a national non-profit group representing amputees. An application for research recruitment is required: the cost is $100 and the turnaround time to hear a decision is 15 days. If

approved, the ACA posts a recruitment letter on their website and provides some discounts for advertising in their magazine *inMotion.* Again, this recruitment method would likely attract a few additional participants but the benefits were not likely to outweigh the costs.

Measures

The survey featured multiple measures to answer the research questions. Some of these measures were designed by others and adapted for this survey, whereas others were created based on previous research. The measures used are listed below, along with an explanation of the research questions they answer. The complete survey protocol can be found in Appendix B.

Interactions between amputees. First the survey asked amputees about their use of Facebook groups. Bunde, Suls, Martin, and Barnett (2006) suggested that researchers ask participants about how often they use support websites, what other sites they use, how often they post, and other descriptive characteristics to get a sense of how people use medical community sites. Sample questions included: "How many amputee support groups are you involved with on Facebook?" and "In an average week, how many minutes do you spend on amputee support groups on Facebook?"

Participants were asked to describe their friendships in the Facebook groups as well. Previous research has confirmed that people frequently use social networking sites to maintain relationships and start new relationships (Bonds-Raacke & Raacke, 2010; Park, Kee, & Valenzuela, 2009; Raacke & Bonds-Raacke, 2008; Sheldon, 2008; Urista, Dong, & Day, 2009). Participants identified how many amputees they have connected with through Facebook, and how often they interact with them through email, phone, and in-person

meetings. This first section answers research question 1, and some of the data was used for research question 2c.

Informational and emotional support scales. Participants were asked about the types of informational and emotional support messages they send and receive through Facebook groups. Previous studies found that these types of messages appear most often in online support groups (Bunde, Suls, Martin, & Barnett, 2006; Civan & Pratt, 2007; Mo & Coulson, 2008). Questions reflected the types of support messages likely to be transmitted online based on previous research and pre-examination of posts on amputee support group walls (Braithwaite, Waldron, & Finn, 1999). Participants rated the frequency of sending and receiving these messages on a 6-point scale ranging from "Never" to "Daily."

Eight questions measured informational support: 4 for sending messages and 4 corresponding responses for receiving messages. An example of sending an informational message is: "Share news stories relevant to amputees" and an example of the corresponding response question is: "Read news stories relevant to amputees." Twelve questions measured emotional support: 6 for sending messages and 6 corresponding responses for receiving messages. An example of sending an emotional message is: "Give encouragement to somebody" and an example of the corresponding response question is: "Receive encouragement from somebody." The informational and emotional support scales both had high reliability, Cronbach's alphas being .90 and .96 respectively.

Finally, participants were given the chance to respond to the open-ended question: "Do you have any other interactions with amputees through Facebook that are not mentioned here? Please detail the type of interaction and the frequency of the interaction." This question ensured that all types of social support messages used in these groups were

represented, though comparisons between responses in this section cannot be made statistically.

Trinity Amputation and Prosthesis Experience Scales (TAPES). To measure health conditions a portion of the TAPES was used (Gallagher & MacLachlan, 2000; Gallagher & MacLachlan, 2004). The subscales measure psychosocial adjustment, activity restriction, and satisfaction. The scale was recently revised after undergoing classical test theory analysis and Rasch analysis to simplify and improve the scale (Gallgher, Frachignoni, Giordano, & MacLachlan, 2010). Although the scales were developed for lower limb amputees, a scoring guide exists to adjust the scale to people with upper limb amputations (Gallagher, Desmond, & MacLachlan, 2007).

The TAPES contains four subsections, though only the first section was used. The first section is related to psychosocial health, something that is easy to measure given our survey design. While the previous research reviewed showed that support groups can induce physical health outcomes, confirming participants' physical health outcomes with an Internet survey is more challenging. Although a participant may receive physical benefits from being in an online support group, such as learning how to use a prosthesis, physical health conditions are not as likely as mental health conditions to be changed simply by being involved in an online support group.

The psychosocial adjustment scale is divided into three subsections: general adjustment, social adjustment, and adjustment to limitation. Participants rate their experiences on a 4-point scale ranging from "Strongly Disagree" to "Strongly Agee." An example of a general adjustment question is: "I have adjusted to having an artificial limb." An example of a social adjustment question is: "I don't care if somebody looks at my

artificial limb." An example of an adjustment to limitation question is: "Having an artificial limb makes me more dependent on others than I would like to be." The reliabilities for the subscales were high: Cronbach's alpha for general adjustment was .89, social adjustment was .80, and adjustment to limitation was .83.

Two questions were also included asking about the participant's general health: "In general, would you say your health is—" and "In general, would you say your physical capabilities are—" which were rated on a 5-point scale ranging from "Very Poor" to "Very Good." These questions measured the amputees' physical health, whereas the psychological scales measured the amputees' mental health.

Multidimensional Scale of Perceived Social Support (MSPSS). The second model of predictors tested measures of face-to-face social support. The MSPSS was developed to measure levels of perceived social support in a person's life (Zimet, Dahlem, Zimet, & Farley, 1988). The 12-item scale is divided into three factor groups: social support from families, social support from friends, and social support from a significant other. A sample family question is: "I can talk about my problems with my family." A sample friends question is: "My friends really try to help me." A sample significant other question is: "I have a special person who is a real source of comfort to me."

Participants rated their experiences on a 7-point scale from "Very strongly disagree" to "Very strong agree." The scale has been found to be psychometrically sound across multiple populations, and has demonstrated internal reliability, factorial validity, and subscale validity (Başol, 2008; Cecil, Stanley, Carrion, & Swann, 1995; Dahlem, Zimet, & Walker, 1991; Duru, 2007; Kazarian & McCabe, 1991; Stanley, Beck, & Zebb, 1998; Zimet, Powell, Farley, Werkman, & Berkoff, 1990).

The MSPSS is short and the questions are understandable, making the scale easy to administer. Unwin and Clarke (2009) used the MSPSS as part of their study of positive adjustment to lower limb amputation, and found that the scale is useful for measuring the subjective outcomes of amputation. The original scale did not make a distinction between social support received face-to-face and social support received through electronic communication, such as cell phones, email, and chat rooms. Certainly a person can receive much support from their family, for instance, through these new communication technologies so the following directions were created to preface the measure:

"We are interested in how you feel about the following statements. Read each statement carefully. Indicate how you feel about each statement. For each statement, think of people outside of your online support groups. These should be people you have a face-to-face relationship with."

The three subscales all had high reliability: the Cronbach's alpha for family support was .94, friend support was .92, and significant other support was .94.

Demographic data. Questions were kept to a minimum to ensure compliancy in answering all the questions. Basic demographic data gathered was age, sex, and race or ethnicity. Data about the participant's amputation was useful simply to identify that the participant was indeed an amputee. Participants were asked the year they had their amputation, and were given a chance to report the cause of the amputation. The cause question was taken from the TAPES, which featured the most likely causes of amputations—peripheral vascular disorder (obstruction of arteries that causes a lack of blood supply to extremities), diabetes, cancer, and accident. An "other" category with text box was also included in case the participant's cause was not listed.

Survey Design

The survey was created using Survey Monkey, an online tool that had enough sophistication to design a survey that met my needs and answered my questions. The survey link was distributed in a variety of ways (through Facebook messages, wall posts, and email). The first page of the survey was a combination recruitment letter and informed consent. The page started with a brief recruitment and explanation of the survey. I explained who I was and why I was interested in this research. I also referenced the support group that I run on Facebook as a way of building trust with the audience. This recruitment was necessary, as posting a link on a Facebook wall, for instance, leaves very little room to fully explain the nature of the survey.

Following the recruitment section was the informed consent featuring all of the elements asked for by NDSU's institutional review board. At the end contact information was included for Dr. Nan Yu, IRB, and me. By clicking "Next" participants gave their consent and were allowed to take the survey. The survey should have taken approximately 15 minutes to complete. At the end of the survey participants were thanked for their time and asked to forward the survey to other amputees they knew.

Data Analysis Strategies

RQ1 was answered with descriptive data about how amputees use Facebook groups and what sorts of connections they have made with other amputees through these groups. To answer this question, simple frequencies such as mean and standard deviation were used. RQ2 was answered by conducting linear regressions. Each part of the research question builds off the last by adding more possible predictors. Linear analyses were conducted for use of both informational support and emotional support.

Summary

Amputees who use Facebook support groups are a very specific population, so great care was taken in the sampling and recruitment procedures. This project needed to balance several things, such as designing a survey that sufficiently answered the research questions and hypothesis while at the same time being easy to understand and complete. This population proved much harder to reach than initially planned, but the data gathered from the survey is valuable for the research areas of health communication and new media. In the next chapter I will report the survey results according to each research question and hypothesis.

4. RESULTS

After the surveys were administered, the data was cleaned and analyzed using SPSS statistical software. In this chapter each research question will be answered with appropriate statistical tests. The preliminary meaning of the results, particularly the regression analyses, will be explained as well.

RQ1a sought descriptive data on how amputees use Facebook and its various channels for communication. Respondents were asked how often they participate in various Facebook activities: posting on walls, posting on discussion boards, and uploading pictures or videos. The results show that support group use in these activities is relatively minimal. Amputees post an average of 1.17 wall posts per week (SD = 1.72, $Range$ = 0-10), an average of .81 discussion board posts per week (SD = 1.56, $Range$ = 0-10), and an average of .49 pictures or videos per week (SD = 1.41, $Range$ = 0-10). Amputees did report, however, that they had connected with a large number of amputees through Facebook: respondents connected with an average of 21.21 amputees through Facebook (SD = 45.11, $Range$ = 0-300).

RQ1b asked how often they connect with amputees through communication channels outside of Facebook: private email, phone, and in-person meetings. This provides a sense of how support groups are used beyond the publicly visible channels on Facebook. Figure 2 below summarizes how often amputees use these three communication channels. Amputees contact each other most often through email: 68% of amputees email each other at least once a month. This is considerably higher than the amount of amputees who call each other at least once a month (28%) or see each other in person at least once a month (25%). Many amputees, 18.3%, email each other at least once a week. Few people contact

each other more than once a week through email (8%), phone (0%), or in person (1.3%).

Through responses to a qualitative question, some amputees also identified other modes of

communication: blog posts, chat rooms, Facebook chat, instant messaging, listservs, online

dating, snail mail, text messaging, and Twitter.
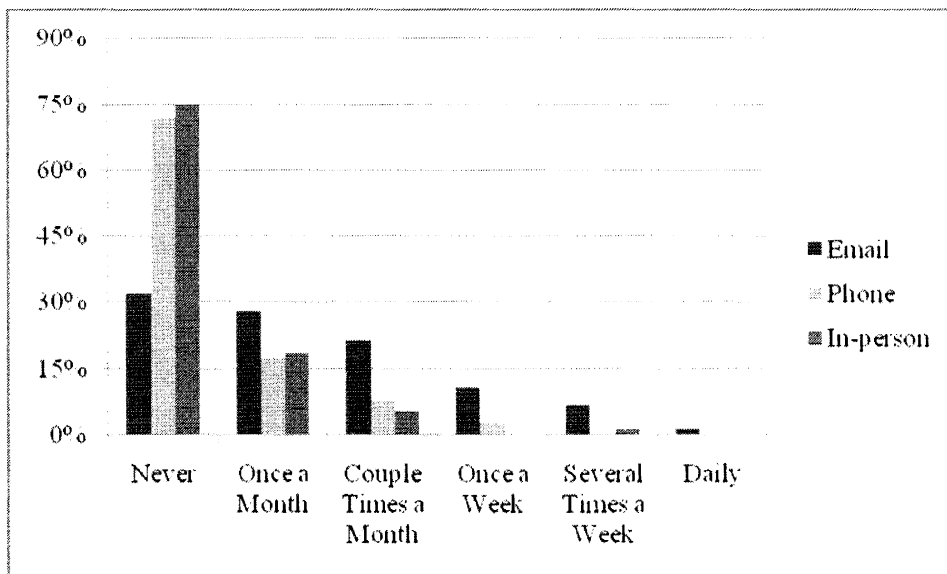
Figure 2. Percentage use of communication activities outside of Facebook between amputees who met on Facebook

RQ2 sought to understand which variables best predicted use of informational and

emotional social support in Facebook amputee groups. Several models were tested with

more variables added each time. Participants reported having informational support

interactions an average of once a month ($M = 2.12$, $SD = 1.02$), and emotional support

interactions an average of once to a couple times a month ($M = 2.61$, $SD = 1.28$).

For RQ2a, age, sex, race and physical and psychological health were the

independent variables used to predict frequency of using informational and emotional

support. For race, white/Caucasian was coded as 1 ($N = 49$, 90.7%), whereas every other

race was coded as 0 ($N = 5$, 9.3%). Participants rated their overall health as good ($M = $

4.15, SD = .73) and their physical capabilities as good (M = 4.04, SD = .79). Participants

overall agreed with the general adjustment measures (M = 3.49, SD = .68) and social

adjustment measures (M = 3.65, SD = .49), showing positive adjustment, but disagreed

with the adjustment to limitation measures (M = 2.64, SD = .80).

The results of the linear regression models are presented in Table 1. For

informational support, the overall model was not significant, $F(5, 39)$ = .58, R^2 = .01, p =

n.s. For emotional support, age was a significant predictor (β = -.38, t = -2.32, p < .05), but

the overall model was not significant, $F(5, 39)$ = 1.02, R^2 = .04, p = n.s.

Table 1. Linear regression assessing predictors of frequency of use of informational and emotional support in Facebook amputee groups. (RQ2a)

Independent Variables	Informational Support			Emotional Support		
	Standardized beta	t value	p value	Standardized beta	t value	p value
Age	-.11	-.64	n.s.	**-.38**	-2.32	**.03**
Sex	.17	1.04	n.s.	-.02	-.11	n.s.
Race	-.18	-1.15	n.s.	.08	.50	n.s.
Overall health	-.02	-.11	n.s.	**-.35**	-1.90	**.05**
Physical capabilities	.23	1.17	n.s.	.29	1.54	n.s.
General adjustment	.01	.03	n.s.	-.08	-.39	n.s.
Social adjustment	.15	.68	n.s.	.18	.85	n.s.
Adjustment to limitation	.00	.00	n.s.	.06	.34	n.s.
	R^2 = .01			R^2 = .04		

For RQ2b, perceived levels of family, friends, and significant other social support

variables were added to the model. Participants mildly to strongly agreed that they had

family support (M = 5.25, SD = 1.55), friends support (M = 5.64, SD = 1.33), and

significant other support (M = 5.70, SD = 1.57).

The results of the two linear regressions are presented in Table 2. For information

support, the overall model was not significant, $F(3, 36)$ = .12, R^2 = -.06, p = n.s. For

emotional support, age was still a significant predictor (β = -.38, t = -2.31, p < .05), and

overall health was a significant predictor (β = -.41, t = -2.12, p < .05), but the overall model

was not significant, $F(3, 36)$ = .99, R^2 = .04, p = n.s.

Table 2. Linear regression assessing predictors of frequency of use of informational and emotional support in Facebook amputee groups. (RQ2b)

Independent Variables	Informational Support			Emotional Support		
	Standardized beta	t value	p value	Standardized beta	t value	p value
Age	-.10	-.59	n.s.	**-.38**	-2.31	**.03**
Sex	.18	1.01	n.s.	.08	.45	n.s.
Race	-.17	-1.04	n.s.	.10	.61	n.s.
Overall health	-.01	-.05	n.s.	**-.41**	-2.12	**.04**
Physical capabilities	.22	1.07	n.s.	.27	1.43	n.s.
General adjustment	-.02	-.07	n.s.	-.17	-.78	n.s.
Social adjustment	.17	.77	n.s.	.18	.85	n.s.
Adjustment to limitation	-.01	-.04	n.s.	.05	.27	n.s.
Family support	-.07	-.30	n.s.	.10	.45	n.s.
Friend support	.12	.58	n.s.	.18	.93	n.s.
Significant other support	-.02	-.11	n.s.	.03	.17	n.s.
	R^2 = -.06			R^2 = .04		

Finally, RQ2c added the three Facebook communication activities—posting on

group walls, posting on discussion pages, and uploading pictures or videos—to the model.

The results of the two linear regressions are presented in Table 3. For informational

support, wall posting was a significant predictor (β = .77, t = 3.87, p < .01), and the overall

model was significant, $F(3, 33)$ = 8.75, R^2 = .36, p < .001. Emotional support had three

predictors in the final model: age (β = -.53, t = -3.76, p < .01), overall health (β = -.35, t = -

2.16, p < .05), and wall posting (β = .82, t = 4.18, p < .01). The overall emotional support

model was significant, $F(3, 33)$ = 7.59, R^2 = .38, p < .001.

Summary

From the survey, much important information as gathered about how amputees use

support groups on Facebook. This data provided an understand of how these groups are

used, which was useful in its own right, but was also useful in determining with variables

best predicted engagement in socially supportive activities. While very few of the variables

predict social support behaviors, significance was achieved with a few factors. Age was a

negative predictor of emotional support, meaning the younger people were, the more they

engaged in emotional support. Likewise, overall health was a negative predictor: the less

healthy participants were overall, the more they engaged in emotional support. Posting on

walls had a strong positive relationship for both informational and emotional support,

meaning the more people post on Facebook walls, the more likely they engage in

informational and emotional support. The next chapter concludes the thesis by discussing

what these findings mean and how future research can build on the findings.

Table 3. Linear regression assessing predictors of frequency of use of informational and emotional support in Facebook amputee groups. (RQ2c)

Independent Variables	Informational Support			Emotional Support		
	Standardized beta	*t* value	*p* value	Standardized beta	*t* value	*p* value
Age	-.28	-1.91	n.s.	**-.53**	-3.76	**.00**
Sex	.05	.34	n.s.	-.05	-.37	n.s.
Race	-.13	-1.00	n.s.	.14	1.10	n.s.
Overall health	.07	.44	n.s.	**-.35**	-2.16	**.04**
Physical capabilities	.07	.40	n.s.	.15	.90	n.s.
General adjustment	-.09	-.48	n.s.	-.22	-1.17	n.s.
Social adjustment	.32	1.76	n.s.	.30	1.72	n.s.
Adjustment to limitation	.22	1.40	n.s.	.23	1.52	n.s.
Family support	.11	.57	n.s.	.25	1.27	n.s.
Friend support	.11	.68	n.s.	.18	1.11	n.s.
Significant other support	-.08	-.47	n.s.	.00	-.02	n.s.
Wall posts	**.92**	4.61	**.00**	**.82**	4.18	**.00**
Discussion boards	-.14	-.62	n.s.	-.04	-.19	n.s.
Pictures/video	-.28	-1.18	n.s.	-.29	-1.27	n.s.
	$R^2 = .36$			$R^2 = .38$		

5. DISCUSSION

This study has some interesting findings and is a good step in social support research in online communities. In this chapter, I will discuss how the results can be interpreted. As this is preliminary research, I will end by discussing the limitations and future direction of this project.

Description of Amputee Groups

One goal of this study was to understand how these amputee groups work and how people use them. Sampling and recruiting alone showed that amputee groups on Facebook, while prevalent, are not always the most active. Well over a thousand groups and pages exist for amputees, but many have extremely low membership. By examining public walls and discussion pages, it is clear that many of these groups are used very infrequently. Some of the data from the survey backs up this observation: participants post on average once a week on group walls, and less than once a week on group discussion pages. For a small group of relatively anonymous people, posting this infrequently probably is not enough to create a solid supportive environment. Some amputee groups, however, are very large, with hundreds to thousands of members. With these groups, even a fraction of the members posting once a week might be enough to foster a supportive environment.

While every amputee group might not function as a support group, it is clear that many amputees do connect with others through these Facebook groups. Amputees connected with an average of 21 other amputees through Facebook, which seems high. This supports other research that social networking is used by most people for relationship maintenance (Raacke & Bonds-Raacke, 2008) and for meeting new people (Urista, Dong, & Day, 2009). More importantly, many of these amputees connect with each other through

channels outside of Facebook. Almost 50% of amputees report contacting another Facebook amputee through email once or twice a month. Surprisingly, 28% of amputees call another Facebook amputee at least once a month or more frequently, and 25% report meeting another Facebook amputee in person at least once a month. This study did not measure the content of these communications, but chances are these communications are at least somewhat supportive if they happen this frequently.

Future research may want to look at the amount of online contact a person with a medical condition needs with somebody else online with the same condition to be supported. Having a few strong relationships with other amputees may be just as good or better than being connected with an online support group that exposes one to hundreds of low-quality, mostly anonymous relationships. This sample also reported high levels of perceived family, friends, and significant other social support. While these sources of social support did not significantly influence the regression models, they may explain how amputees use social networks. Researchers like to articulate simple relationships between concepts. While it might be preferable to explain, for example, that the more face-to-face social support people have, the less they will use support groups, the data do not point to a clear relationship between face-to-face support and use of online support groups. What the data show is that some people do connect with other amputees through Facebook groups, and that this connection leads to myriad communications outside of Facebook. Other people do not connect with any amputees through Facebook and do not even engage in Facebook communication, like posting on group walls.

Predicting Social Support Behaviors

The most significant findings from this study come from identifying the variables that predict social support behaviors: providing and receiving informational and emotional support messages through Facebook. Not surprisingly, amputees engage in these behaviors just like people engage in these social support behaviors in other online situations (Bunde, Suls, Martin, & Barnett, 2006; Civan & Pratt, 2007; Mo & Coulson, 2008). For informational support, the only significant predictor was posting on group walls. Facebook walls are designed to share little bits of information, and to link to other websites that give information. An amputee can very easily share information about new research, news stories, or prosthetics through this function. This predictor had a very strong correlation: the more people post on walls, the more likely they are to engage in informational supportive behaviors.

Even more significant, emotional support has three predictors: age, overall health, and posting on walls. The posting on walls behavior also has a positive correlation: the more people post on group walls, the more likely they are to engage in emotionally supportive behaviors. The age and overall health predictors, however, show a negative relationship. The younger a person is, the more likely they are to engage in emotionally supportive behaviors. Perhaps young adults do not have as extensive support networks as older adults do, or perhaps they do not have the life experiences needed to properly process a significant life-changing event like having an amputation. Because of their inexperience, they may engage in more emotionally supportive behaviors than older adults.

The relationship of overall health to emotional support also makes sense: the less healthy somebody is, the more they engage in emotionally supportive behaviors. 20% of

participants rated their overall health as "fair," which was the lowest category that had a response. Perhaps these people, because they have more health concerns, engage in emotionally supportive behaviors to cope with their health situation. 34.5% of people reported having "very good" overall health, so the data shows these people are less likely to engage in emotionally supportive behaviors. If their health is already very good, they might not need as much emotional support from other amputees, particularly if they already have strong face-to-face support networks.

Additional utility in the regression models also comes from explaining what were not significant predictors. Race and sex have no influence on socially supportive behaviors, though it needs to be noted that the majority of the sample was white, so race was not adequately represented. Sheldon (2008) found that the sexes do use Facebook differently: females are more likely to use Facebook for maintaining relationships, whereas males are more likely to use Facebook to meet new people. These differences were not apparent in this study.

Also of interest was the lack of predictive power in the psychological health measures. The three psychological health subscales have been rigorously tested and used in multiple amputee studies in the past, so the fault is not with the instrument design. The data from this study showed that one's level of psychological adjustment to an amputation had no effect on how often people engage in socially supportive behaviors online. We cannot say with any certainty that amputees who have not adjusted to their amputation use amputee groups any differently than amputees who have adjusted positively to their amputation.

The face-to-face sources of social support also did not predict support group use, which is a little unfortunate that there is not a clearer link between the online world and the offline world. It is not surprising, though, that other Facebook activities—posting on discussion boards and uploading pictures or videos—did not predict use of social support, as these two activities amputees engage in less than once a week on average.

The informational support model explains .36 of the variance, and the emotional support model explains .38 of the variance. Accounting for this much variance alone is an important first step in understanding why people use online support groups the way they do. Future research, then, will want to look at other variables that predict social support behaviors better than these models do.

Limitations and Future Direction

The most obvious limitation of this study is the small sample size. A lot of work went into the survey recruitment, but this population proved particularly challenging to reach. At this present time, the survey is still public, and I occasionally receive contact from an amputee group leader telling me that s/he will pass the survey link to group members. The hope is that more people will take the survey in the weeks ahead. With more respondents, the tests will be stronger as will the results.

The sample size is a limitation for three reasons. First, because of the small size, it is harder to generalize the results. The people who took the survey might be qualitatively different from the people who did not take the survey, so the results only reflect the attitudes of amputees who took the survey, not all the amputees on Facebook. This leads to the second limitation: the people who took the survey may very well be support group leaders, not the rank and file support group members. Recruitment emails were sent to

support group leaders, who were gatekeepers for access to the rest of the group members. When recruitment emails were sent out, people would respond right away, suggesting that the people who took the survey were the leaders who received the emails. Most leaders offered some support to contacting their group members, or offered to send the survey onto amputees they knew, but very few people took the survey after the group leaders offered their support. Support leaders, who try to maintain a vibrant online group, are probably more active online than group members, so this possibility needs to be considered when interpreting the results. Finally, a small sample size limited the statistical power of the tests. Had there been more respondents, we may have seen more predictors of online social support behaviors. The fact that the tests did reveal significant predictors, however, shows that the sample size was not so low that these tests could not be conducted.

Reasons for low response rate. It is well-known that Internet research can have low response rates depending on how the survey is designed (Kaplowitz, Hadlock, & Levine, 2004; Porter & Whitcomb, 2003). In this study, the problem was not with people failing to finish the survey due to poor survey design; the problem was getting people to click on the survey link in the first place. Several possibilities exist for why recruitment was so difficult with this study.

Average age of amputees is higher than the average age of Facebook users. Many face-to-face group leaders expressed that they were interested in the survey, but felt that the majority of their members did not use Facebook or even computers. Some expressed that Facebook is more of a toy or game used by kids and is not a serious space for social support. It is possible that, of the members in Facebook groups, many are older adults who are not using Facebook in the same way younger adults do. Some statistics back up this

anecdotal explanation. Smith (2009) estimated that 70% of Facebook users were between the ages 13-34; only 5% were listed in the 55-65 demographic, the highest age group in the study. The average participant age in this study was 44.22 (SD = 10.92, Min = 18, Max = 69). While an overall statistic of the average age of amputees could not be obtained, the average age of lower-extremity amputations is 66 years for diabetes-related amputations and 71 years for non-diabetes-related amputations (NLLIC, 2008b). There is a strong likelihood that there is an age difference between amputees who use Facebook actively and those who do not, accounting for the low response rate.

Facebook groups are not as active as they initially seemed. At the outset of this study, it appeared that many Facebook groups are active spaces for social support. But looking at the frequency and timelines of wall posts and discussion posts may have skewed this perception. A few frequent posters on Facebook groups can give the impression that the group is very active. Data from the survey, which will be reported in chapter 3, confirms that amputees do not frequently use the public communication channels on Facebook. Many amputees may have gotten the survey invitation, but chose to ignore it based on their lack of active participation in amputee Facebook groups.

Amputees seem to be frequent research targets. Other anecdotal evidence indicates that perhaps amputees are targeted too frequently in research and have research fatigue. It was not uncommon to see recruitment letters from other researchers posted on Facebook walls. Some group leaders expressed to me that they have participated in research before and that group members may not respond to another survey request. Since beginning my study, I have been aware of at least two other research recruitments happening in amputee groups on Facebook, so the competition for participants is intense.

Survey links may have been misinterpreted as spam. Between the time when this study was first conceived and recruitment started, amputee Facebook groups were hit with much spam. I saw the same posts on dozens of group walls. Some of the posts were for amputee products or services, and some were for medical products in general, such as acai berry nutrition products. Many of these spam posts were all in a row and group members had not posted since getting hit with the spam or group leaders did not delete the spam posts. As such, my survey link listed in close proximity to these links may have discredited my survey.

The amputee community, particularly online, has some distrust of outsiders. There will always be some distrust of outsiders in medical communities, but I tried to limit this distrust as much as possible by explaining my medical situation and getting permission from group leaders before conducting recruitment. Some distrust was still likely present. Some group leaders warned me that amputees distrust outsiders due to bad past experiences with amputee "devotees." This is a term in the amputee community to describe people, particularly men, who have sexual fetishes for amputees. Many groups on Facebook are specifically anti-devotee, or do not understand where this attraction comes from. In some cases, I saw the same men post messages across dozens of groups looking to make contact with amputees, especially women. While nobody accused me of harboring such attractions, it is unfortunate that the devotee subculture exists and has turned so many amputees off to outsiders looking to make contact with their community.

One strategy that I think will be more fruitful is conducting the survey again but with a different medical community. I have lots of connections within the online inflammatory bowel disease and ostomy communities, and I would like the conduct the

study again with this population. Because of my connections with the community, I think it will be easier to access groups as I am already an insider. This will hopefully lead to a higher response rate, and a comparative study between the amputee group results and the IBD group results could be conducted. In general the IBD online community seems more active, so different variables might influence how often they engage in social support behaviors.

Conducting the study with the online IBD/ostomy community will necessitate changing the survey in some ways. In particular, the psychological measures will need to be removed, as they were specifically designed for amputees. The psychological variables were not significant predictors of social support usage, so one option is to leave them out of the IBD/ostomy survey. Or, a measure of psychological health and adjustment specific to inflammatory bowel disease patients, such as a Inflammatory Bowel Disease Questionnaire or related measure, could be used, which has been validated in many studies (Halder et al., 2004; Pallis, Mouzas, & Vlachonikolis, 2004; Oliveira et al., 2007; Smith, Watson, & Palmer, 2002). Additionally, the wording of the social support measures will need to be changed to reflect types of informational support likely to be changed in the IBD/ostomy community, though these adjustments will be small.

Conducting the study in a new population does bring up other concerns. My presence in the IBD/ostomy community is primarily through a series of education websites about how to live with IBD and ostomies. I have been active in this community for more than two years, and have built up a substantial list of contacts. My presence in the community, though, might bias the survey results. Because I have helped other people deal with IBD, they might feel obligated or compelled to take my survey, and furthermore might

respond in a way that they think I want them to respond. Additionally, if people are bothered by surveys, my relationship in this community might be tainted if people feel I am using my presence to benefit myself. This community, though, does not seem to be researched as much as amputees are, from my personal observations, so hopefully people would not be too bothered by a survey. Even though my relationships in this community might bias survey results, the risk is worth it as this population may prove just as hard to reach as the online amputee community.

Conclusion

This thesis examined amputee support groups on Facebook, how they function, and what variables best predict socially supportive behavior. As Facebook groups created for medical conditions become more prevalent and active, it will be important for researchers to examine how people are using these groups, and to examine if these groups are meeting patients' needs. This study had significant findings, both in describing how these groups work, how amputees connect with other amputees through the groups, and in uncovering the factors that lead to informational support and emotional support.

This investigation, though, is only preliminary. I will continue to study amputee groups on Facebook, hopefully generating a higher response rate to the survey. Additionally, comparing amputees groups to another medical community's groups, such as the inflammatory bowel disease/ostomy community, will shed light on how groups are used differently, and if different factors predict how a people use one group compared to another.

REFERENCES

Amputee Coalition of America. (2011). Support group listings. Retrieved from the
    Amputee Coalition of America website: http://www.amputee-
    coalition.org/support_groups/npn_group_list.asp

Başol, G. (2008). Validity and reliability of the multidimensional scale of perceived social
    support-revised, with a Turkish sample. *Social Behavior and Personality, 36*(10),
    1303-1314.

Beaudoin, C. E., & Tao, C. (2007). Benefiting from social capital in online support groups:
    An empirical study of cancer patients. *CyberPsychology & Behavior, 10*(4), 587-
    590. doi: 10.1089/cpb.2007.9986

Bennett, S. J., Perkins, S. M., Lane, K. A., Deer, M., Brater, D. C., & Murray, M. D.
    (2001). Social support and health-related quality of life in chronic heart failure
    patients. *Quality of Life Research, 10,* 671-682.

Bhaskaran, V. (2010, July 23). Social media research: Using Facebook for survey
    invitations and market research. Retrieved from the Research Access website:
    http://researchaccess.com/2010/06/social-media-research-using-facebook-for-
    survey-invitations-and-market-research/

Bonds-Raacke, J., & Raacke, J. (2010). MySpace and Facebook: Identifying dimensions of
    uses and gratifications for friend networking sites. *Individual Differences Research,
    8*(1), 27-33.

Braidotti, R. (2006). Posthuman, all too human: Towards a new process ontology. *Theory,
    Culture & Society, 23*(7-8), 197-208.

Braithwaite, D. O., Waldron, V. R., & Finn, J. (1999). Communication of social support in

computer-mediated groups for people with disabilities. *Health Communication,*

11(2), 123-151.

Broadwater, L. (2010, August 30). APL works on prosthetic arm controlled by user's

thoughts. *The Sun (Baltimore),* A3.

Bunde, M., Suls, J., Martin, R., & Barnett, K. (2006). Hystersisters online: Social support

and social comparison among hysterectomy patients on the Internet. *Annals of*

Behavioral Medicine, 31(3), 271-278.

Cecil, H., Stanley, M. A., Carrion, P. G., & Swann, A. (1995). Psychometric Properties of

the MSPSS and NOS in psychiatric outpatients. *Journal of Clinical Psychology,*

51(5), 593-602.

Civan, A., & Pratt, W. (2007). Threading together patient expertise. *AMIA Annual*

Symposium Proceedings, 140–144.

Cohen, S. & Wills, T. A. (1985). Stress, social support, and the buffering hypothesis.

Psychological Bulletin, 98(2), 310-357.

Coulson, N. S. (2005). Receiving social support online: An analysis of a computer-

mediated support group for individuals living with irritable bowel syndrome.

CyberPsychology & Behavior, 8(6), 580-584.

Coulson, N. S., & Knibb, R. C. (2007). Coping with food allergy: Exploring the role of the

online support group. *CyberPsychology & Behavior, 10*(1), 145-148. doi:

10.1089/cpb.2006.9978

Dahlem, N. W., Zimet, G. D., & Walker, R. R. (1991). The multidimensional scale of

    perceived social support: A confirmation study. *Journal of Clinical Psychology,*

    47(6), 756-761.

Dao, J. (2010, August 19). High-tech knee holds promise of improving the lives of veterans

    young and old. *The New York Times,* A18.

Dillman, D. A., Smyth, J. D., & Christian, L. M. (2009). *Internet, mail, and mixed-mode*

    surveys: The tailored design method. Hoboken, New Jersey: John Wiley & Sons,

    Inc.

Duru, E. (2007). Re-examination of the psychometric characteristics of the

    multidimensional scale of perceived social support among Turkish university

    students. *Social Behavior and Personality, 35*(4), 443-452.

Eysenbach, G., Powell, J., Englesakis, M., Rizo, C., & Stern, A. (2004). Health related

    virtual communities and electronic support groups: Systematic review of the effects

    of online peer to peer interactions. *BMJ, 328*(1166). doi:

    10.1136/bmj.328.7449.1166

Facebook. (2010). Press room: Statistics. Retrieved from the Facebook website:

    http://www.facebook.com/press/info.php?statistics

Finfgeld-Connett, D. (2005). Clarification of social support. *Journal of Nursing*

    Scholarship, 37(1), 4-9.

Gallagher, P., & MacLachlan, M. (2000). Development and psychometric evaluation of the

    Trinity Amputation and Prosthesis Experience Scales (TAPES). *Rehabilitation*

    Psychology, 45(2), 130-154.

Gallagher, P., & MacLachlan, M. (2004). The trinity amputation and prosthesis experience scales and quality of life in people with lower-limb amputation. *Archives of Physical Medicine, 85*(5), 730-736.

Gallagher, P., Desmond, D., & MacLachlan, M. (2007). A guide to the Trinity Amputation and Prosthesis Experience Scales (TAPES). Retrieved from the Dublin Psychoprosthetics Group website: http://www.tcd.ie/Psychoprosthetics/A%20guide%20to%20TAPES%20with%20reported%20usage_2007.pdf

Gallagher, P., Frachignoni, F., Giordano, A., MacLachlan, M. (2010). Trinity amputation and prosthesis experience scales: A psychometric assessment using classical test theory and Rasch analysis. *American Journal of Physical Medicine & Rehabilitation, 89*(6), 487-496. doi: 10.1097/PHM.0b013e3181dd8cf1

Halder, S. L. S., Locke, G. R., Talley, N. J., Fett, S. L., Zinsmeister, A. R., & Melton, L. J. (2004). Impact of functional gastrointestinal disorders on health-related quality of life: A population-based case-control study. *Alimentary Pharmacology & Therapeutics, 19*, 233-242. doi: 10.1111/j.0269-2813.2004.01807.x

Hale, C. J., Hannum, J. W., & Espelage, D. L. (2005). Social support and physical health: The importance of belonging. *Journal of American College Health, 53*(6), 276-284.

Hilhorst, M. (2004). "Prosthetic fit": On personal identity and the value of bodily difference. *Medicine, Health Care and Philosophy, 7*, 303-310.

Horrigan, J., & Rainie, L. (2006). The Internet's growing role in life's major moments. Retrieved from the Pew Research Center's Internet and American Life Project

website: http://www.pewInternet.org/Reports/2006/The-Internets-Growing-Role-in-Lifes-Major-Moments.aspx

Josefsson, U. (2005). Coping with illness online: The case of patients' online communities. *The Information Society, 21,* 143-153. doi: 10.1080/01972240590925357

Kaplowitz, M. D., Hadlock, T. D., & Levine, R. (2004). A comparison of web and mail survey response rates. *Public Opinion Quarterly, 68*(1), 94-101.

Kazarian, S. S., & McCabe, S. B. (1991). Dimensions of social support in the MSPSS: Factorial structure, reliability, and theoretical implications. *Journal of Community Psychology, 19*(2), 150-160.

Lee, S. D., Arozullah, A. M., Cho, Y. I., Crittenden, K., & Vicencio, D. (2009). Health literacy, social support, and health status among older adults. *Educational Gerontology, 35*(3), 191-201.

Litt, M. D., Kadden, R. M., Kabela-Cormier, E., & Petry, N. M. (2009). Changing network support for drinking: Network Support Project 2-year follow-up. *Journal of Consulting & Clinical Psychology, 77*(2), 229-242. doi: 10.1037/a0015252

Malik, S. H., & Coulson, N. (2008). The male experience of infertility: A thematic analysis of an online infertility support group bulletin board. *Journal of Reproductive and Infant Psychology, 26*(1), 18-30. doi: 10.1080/02646830701759777

Mo, P. K. H., & Coulson, N. S. (2008). Exploring the communication of social support within virtual communities: A content analysis of messages posted to an online HIV/AIDS support group. *CyberPsychology & Behavior, 11*(3), 2008. doi: 10.1089/cpb.2007.0118

Mraz, S. J. (2010, September 9). Engineering a sense of touch. *Machine Design, 82*(15), 50-53.

National Limb Loss Information Center. (2008a). Amputation statistics by cause: Limb loss in the United States. Retrieved from the Amputee Coalition of America website: http://www.amputee-coalition.org/fact_sheets/amp_stats_cause.pdf

National Limb Loss Information Center. (2008b). Diabetes and lower extremity amputations. Retrieved from the Amputee Coalition of America website: http://www.amputee-coalition.org/fact_sheets/diabetes_leamp.pdf

National Limb Loss Information Center. (2009). Online communication resources for those with limb loss. Retrieved from the Amputee Coalition of America website: http://www.amputee-coalition.org/fact_sheets/amp_stats_cause.pdf

Oliveira, S., Zaltman, C., Elia, C., Vargens, R., Leal, A., Barros, R., Fogaca, H. (2007). Quality-of-life measurement in patients with inflammatory bowel disease receiving social support. *Inflammatory Bowel Disease, 13*(4), 470-474.

Östberg, V., & Lennartsson, C. (2007). Getting by with a little help: The importance of various types of social support for health problems. *Scandinavian Journal of Public Health, 35,* 197-204. doi: 10.1080/14034940600813032

Pallis, A. G., Mouzas, I. A., Vlachonikolis, I. G. (2004). The inflammatory bowel disease questionnaire: A review of its national validation studies. *Inflammatory Bowel Disease, 10*(3), 261-269.

Park, N., Kee, K. F., & Valenzuela, S. (2009). Being immersed in social networking environment: Facebook groups, uses and gratifications, and social outcomes. *CyberPsychology & Behavior, 12*(6), 729-733. doi: 10.1089/cpb.2009.0003

Peterson, J. L. (2009). "You have to be positive." Social support processes of an online

    support group for men living with HIV. *Communication Studies, 60*(5), 526-541.

Pineda, N. (2010, February 24). Facebook tips: What's the difference between a Facebook

    page and group? Retrieved from the Facebook website:

    http://blog.facebook.com/blog.php?post=324706977130

Porter, S. R., & Whitcomb, M. E. (2003). The impact of contact type on web survey

    response rates. *Public Opinion Quarterly, 67*(4), 579-588.

Raacke, J., & Bonds-Raacke, J. (2008). MySpace and Facebook: Applying the uses and

    gratifications theory to exploring friend-networking sites. *CyberPsychology &*

    Behavior, 11(2), 169-174. doi: 10.1089/cpb.2007.0056

Rains, S. A. (2007). Perceptions of traditional information sources and use of the world

    wide web to seek health information: Findings from the Health Information

    National Trends Survey. *Journal of Health Communication, 12*(7), 667-680.

Reeves, P. M. (2000). Coping in cyberspace: The impact of Internet use on the ability of

    HIV-positive individuals to deal with their illness. *Journal of Health*

    Communication, 5, 47-59.

Rodham, K., McCabe, C., & Blake, D. (2009). Seeking support: An interpretive

    phenomenological analysis of an Internet message board for people with complex

    regional pain syndrome. *Psychology and Health, 24*(6), 619-634. doi:

    10.1080/08870440802563245

Rosenbloom, S. (2007, December 17). On Facebook, scholars link up with data. Retrieved

    from the New York Times website:

    http://www.nytimes.com/2007/12/17/style/17facebook.html

Rossbach, P. (2008). Points to know and consider when preparing for and undergoing an amputation. Retrieved from the Amputee Coalition of America website: http://www.amputee-coalition.org/fact_sheets/undergoingamp.html

Saito, E., Sagawa, Y., & Kanagawa, K. (2005). Social support as a predictor of health status among older adults living alone in Japan. *Nursing and Health, 7*, 29-36.

Segrin, C., & Passalacqua, S. A. (2010). Functions of loneliness, social support, health behaviors, and stress in association with poor health. *Health Communication, 25*(4), 312-322. doi: 10.1080/10410231003773334

Sheldon, P. (2008). Student favorite: Facebook and motives for its use. *Southwestern Mass Communication Journal, 23*(2), 39-53.

Smith, G. D., Watson, R., & Palmer, K. R. (2002). Inflammatory bowel disease: Developing a short disease specific scale to measure health related quality of life. *International Journal of Nursing Studies, 39*, 583-590.

Smith, J. (2009). Number of US Facebook users over 35 nearly doubles in last 60 days. Retrieved from the Inside Facebook website: http://www.insidefacebook.com/2009/03/25/number-of-us-facebook-users-over-35-nearly-doubles-in-last-60-days/

Stanley, M. A., Beck, J. G., & Zebb, B. J. (1998). Psychometric properties of the MSPSS in older adults. *Aging & Mental Health, 2*(3), 186-193.

Strine, T. W., Chapman, D. P., Balluz, L., & Mokdad, A. H. (2008). Health-related quality of life and health behaviors by social and emotional support: Their relevance to psychiatry and medicine. *Social Psychiatry & Psychiatric Epidemiology, 43*, 151-159. doi: 10.1007/s00127-007-0277-x

Tichon, J. G., & Shapiro, M. (2003). The process of sharing social support in cyberspace. *CyberPsychology & Behavior, 6*(2), 161-170.

Unwin, J., & Clarke, C. (2009). A prospective study of positive adjustment to lower limb amputation. *Clinical Rehabilitation, 23*(11), 1044-1050.

Urista, M. A., Dong, Q., & Day, K. D. (2009). Explaining why young adults use MySpace and Facebook through uses and gratifications theory. *Human Communication, 12*(2), 215-229.

Van Hoye, G., & Lievens, F. (2007). Investigating web-based recruitment sources: Employee testimonials vs. word-of-mouse. *International Journal of Selection & Assessment, 15*(4), 372-382.

Vanderford, M. L., Jenks, E. B., & Sharf, B. F. (1997). Exploring patients' experiences as a primary source of meaning. *Health Communication, 9*(1), 13-26.

Westaway, M. S., Seager, J. R., Rheeder, P., & Van Zyl, D. G. (2005). The effects of social support on health, well-being and management of diabetes mellitus: A black South African perspective. *Ethnicity and Health, 10*(1), 73-89.

White, A. M., Philogene, S., Fine, L., & Sinha, S. (2009). Social support and self-reported health status of older adults in the United States. *American Journal of Public Health, 99*(10), 1872-1878.

Williams, D., & Xiong, L. (2010). Herding cats online: Real studies of virtual communities. In E. Hargittai (Ed.), *Research confidential: Solutions to problems most social scientists pretend they never have* (pp. 122-140). Ann Arbor, Michigan: University of Michigan Press.

Williams, R. M., Ehde, D. M., Smith, D. G., Czerniecki, J. M., Hoffman, A. J., & Robinson, L. R. (2004). A two-year longitudinal study of social support following amputation. *Disability and Rehabilitation, 26*(14/15), 862-874. doi: 10.1080/09638280410001708878

Wright, K. (2002). Motives for communication within on-line support groups and antecedents for interpersonal use. *Communication Research Reports, 19*(1), 89-98.

Zimet, G. D., Dahlem, N. W., Zimet, S. G., & Farley, G. K. (1988). The multidimensional scale of perceived social support. *Journal of Personality Assessment, 52*(1), 30-41.

Zimet, G. D., Powell, S. S., Farley, G. K., Werkman, S., & Berkoff, K. A. (1990). Psychometric characteristics of the multidimensional scale of perceived social support. *Journal of Personality Assessment, 55*(3&4), 610-617.

APPENDIX A

Recruitment Email

(Sent to owners/operators of amputee Facebook groups)

Dear _____

My name is Dennis Frohlich, and I am a master's student in communication at North Dakota State University. For my thesis I am studying amputee support groups on Facebook. I am interested in the amputees who use these groups and what they get out of being in these groups.

I found your group while searching for amputees on Facebook, and I was wondering if you could help me with my project? I am conducting an online survey of amputees, and need help finding other amputees. If I could post a link to my survey on your group's wall I would appreciate it. Additionally, if you could message the members of your group asking them to take the survey I would be very grateful.

The survey will take approximately 15 minutes to complete and is voluntary; you may withdraw your consent at any time, for any reason. Your identity will be protected; no report or publication will contain any information that will be traced back to you.

To give you some background on myself, I also operate a support group on Facebook, "The United Colon Vlog." This group is for people with colon diseases, particularly people who've had their colon removed. I can empathize with missing a part of your body as I am missing my colon, though our experiences are different. This project will help me understand how other online communities based on a health condition operate.

Thank you and I look forward to hearing from you soon.

Sincerely,

Dennis Owen Frohlich
North Dakota State University
701.541.3608
Dennis.O.Frohlich@ndsu.edu

(Message posted on Facebook walls of groups)

Hello! I am a master's student at North Dakota State University researching amputee groups on Facebook. I am trying to understand this community and need your help. Please take 15 minutes to complete an online survey. Thank you.

Recruitment Email

(Sent to leaders of face-to-face amputee support groups)

Dear GROUP,

My name is Dennis Frohlich, and I am a master's student in communication at North Dakota State University. For my thesis I am studying amputee support groups on Facebook. I am interested in the amputees who use these groups and what they get out of being in these groups.

I found your support group while searching the Amputee Coalition's website. I was wondering if you could help me with my project. I am conducting an online survey, and need help finding other amputees. If you have emails of your group members, could you send a link to my survey to them? This survey is ONLY for amputees who are involved with at least one amputee group on Facebook. You DON'T need to provide me with anybody's contact information.

The survey will take approximately 10-15 minutes to complete and is voluntary; people may withdraw their consent at any time, for any reason. Their identities will be protected; no report or publication will contain any information that will be traced back to them.

Here is the link to the survey if you want to preview it first:
https://www.surveymonkey.com/s/amputeesurvey

To give you some personal background, I operate a support group on Facebook, "The United Colon Vlog." This group is for people with colon diseases, particularly people who've had their colon removed. I can empathize with missing a part of your body as I am missing my colon, though our experiences are different. This project will help me understand how other online communities based on a health condition operate.

Thank you and I look forward to hearing from you soon. I appreciate any help you can provide. If you have any technical questions feel free to contact my adviser Dr. Nan Yu at Nan.Yu@ndsu.edu

Sincerely,

Dennis Owen Frohlich
North Dakota State University
701.541.3608
Dennis.O.Frohlich@ndsu.edu

APPENDIX B

Informed Consent and Survey

Welcome!

We are asking you to participate in a research study that examines the use of amputee groups on Facebook. By participating in this study you will be providing a great service to our research by helping us understanding the role Facebook groups play in understanding one's amputation. Findings from this study will be prepared by May 2011 and a copy of this report will be available upon request.

To give you some background on myself, I also operate a support group on Facebook, "The United Colon Vlog." This group is for people with colon diseases, particularly people who have had their colon removed. While I can't fully understand what it's like being an amputee, as I am not one myself, I can empathize with missing a part of your body. This project will help me understand how other online communities based on a health condition operate.

If you agree to participate in this study, you will be asked to complete an online questionnaire that will take approximately 15 minutes to complete. Participation is not compensated. The information you provide will remain confidential and only the research team will have access to your answers.

Your participation is completely voluntary, and you must be 18 years of age to participate. You can refrain from answering any questions that you find objectionable, and you may withdraw from the study at any time without penalty. There are no apparent risks associated with your participation in this study.

You should feel free to ask questions at any time. If you have questions about this study, you can contact Dennis Frohlich, Department of Communication at 701-541-3608 or Dennis.O.Frohlich@ndsu.edu . If you have any questions about rights of human research participants, or wish to report a research-related problem, please contact Dr. Nan Yu at nan.yu@ndsu.edu, or the NDSU IRB office at 701-231-8908 or ndsu.irb@ndsu.edu .

Thank you very much for helping with this important study. It is only with the generous help of people such as yourself that our research will be successful.

By clicking the "Next" button, you are giving your consent to participate in this study.

With Fullest Regards,

Dennis Owen Frohlich
Dr. Nan Yu
North Dakota State University

Section 1

For the following questions, please provide your best estimates. Please enter numerical answers (e.g., 1, 2, 3).

1. How many amputee support groups are you involved with on Facebook?

2. In an average week, how many minutes do you spend on amputee support groups on Facebook?

3. In an average week, how many times do you post on amputee support groups' walls?

4. In an average week, how many times do you post on amputee support groups' discussion pages?

5. In an average week, how many times do you upload photos or videos to amputee support groups?

6. How many amputees have you connected with personally through Facebook?

7. Thinking about the amputees you've connected with personally through Facebook, how often do you interact with them through private email?

- Never
- Once a Month
- Couple Times a Month
- Once a Week
- Several Times a Week
- Daily

8. Thinking about the amputees you've connected with personally through Facebook, how often do you call them on the phone?

- Never
- Once a Month
- Couple Times a Month
- Once a Week
- Several Times a Week
- Daily

9. Thinking about the amputees you've connected with personally through Facebook, how often do you meet them in person?

- Never
- Once a Month

- Couple Times a Month
- Once a Week
- Several Times a Week
- Daily

10. Do you communicate with amputees from Facebook through any other method? Please detail the other forms of communication you've used.

11. How many online amputee support groups are you involved with outside of Facebook?

12. How many amputees do you know in real life?

Section 2

1. How often do you have the following interactions with other amputees through support groups on Facebook?

(Questions are answered on a Likert-type scale, with answer choices, "Never, Once a Month, Couple Times a Month, Once a Week, Several Times a Week, Daily").

- Provide information about policies or insurance
- Receive information about policies or insurance
- Provide sympathy to somebody
- Provide comfort to somebody
- Receive sympathy from somebody
- Receive thanks from somebody
- Provide information about prostheses
- Receive comfort from somebody
- Share my amputation story
- Receive a compliment
- Read news stories relevant to amputees
- Compliment somebody
- Give thanks to somebody
- Give encouragement to somebody
- Provide medical information
- Read another person's amputation story
- Receive medical information
- Receive information about prostheses
- Receive encouragement from somebody
- Share news stories relevant to amputees

2. Do you have any other interactions with amputees through Facebook that are not mentioned here? Please detail the type of interaction and the frequency of the interaction.

Section 3

1. Below are a series of statements concerning the wearing of an artificial limb. Please read through each statement carefully. Click the appropriate button to show how strongly you agree or disagree with each statement.

(Questions are answered on a Likert-type scale, with answer choices, "Strongly Disagree, Disagree, Agree, Strongly Agree, Not Applicable").

- Having an artificial limb limits the kind of work that I can do.
- As time goes by, I accept my artificial limb more.
- An artificial limb interferes with the ability to do my work.
- I feel that I have dealt successfully with this trauma in my life.
- I don't care if somebody looks at my artificial limb.
- I find it easy to talk about my limb loss in conversion.
- I find it easy to talk about my artificial limb.
- Although I have an artificial limb, my life is full.
- Being an amputee means that I can't do what I want to do.
- I don't mind people asking about my artificial limb.
- Having an artificial limb limits the amount of work that I can do.
- I have gotten used to wearing an artificial limb.
- I have adjusted to having an artificial limb.
- Having an artificial limb makes me more dependent on others than I would like to be.
- I don't care if somebody notices that I am limping.

2. In general, would you say your health is:

- Very Poor
- Poor
- Fair
- Good
- Very Good

3. In general, would you say your physical capabilities are:

- Very Poor
- Poor
- Fair
- Good
- Very Good

Section 4

We are interested in how you feel about the following statements. Read each statement carefully. Indicate how you feel about each statement.

1. For each statement, think of people outside of your online support groups. These should be people you have a face-to-face relationship with.

(Questions are answered on a Likert-type scale, with answer choices, "Very Strongly Disagree, Strongly Disagree, Mildly Disagree, Neutral, Mildly Agree, Strongly Agree, Very Strongly Agree").

- I can talk about my problems with my friends.
- I have friends with whom I can share my joys and sorrows.
- My family really tries to help me.
- I can talk about my problems with my family.
- There is a special person in my life who cares about my feelings.
- My friends really try to help me.
- I can count on my friends when things go wrong.
- There is a special person with whom I can share my joys and sorrows.
- There is a special person who is around when I am in need.
- My family is willing to help me make decisions.
- I get the emotional help and support I need from my family.
- I have a special person who is a real source of comfort to me.

Section 5

1. Age

2. Sex

- Female
- Male

3. What is your race or ethnicity?

- African or Africa-American/Black - not Hispanic
- American Indian or Alaskan Native
- Asian or Pacific Islander
- Hispanic or Latino
- White/Caucasian - not Hispanic
- Other (please specify)

4. When did you have your amputation?

5. What was your amputation a result of?

- Peripheral Vascular Disorder
- Diabetes
- Cancer
- Accident
- Other (please specify)

Survey Completed!

Thank you so much for taking the time to fill out this survey. If you know of anybody else who would like to take this survey, please send them a link.