ENDOMETRIOSIS AND LIVEJOURNAL: HOW WOMEN USE SOCIAL MEDIA FOR HEALTH COMMUNICATION

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Abstract

This thesis examined how women who have or are affected by endometriosis use the social blogging site LiveJournal as a means of communicating about the disorder, and what gratifications they received in the process. The philosophical framework for this study stemmed from Martin Buber’s (1923/1958) work on “dialogic ethics.” The theory that grounded this study is a version of Uses and Gratifications theory that has been expanded so that it is applicable to social media. The data was gathered as part of a content analysis study in which blog posts and their comments were collected, coded, and analyzed. The results show that women use LiveJournal to fulfill one or more of the following communication needs: cognitive, personal integrative, affective, and social integrative. The results additionally showed that depending on the blog post content and responses received, the gratifications found to occur were: acknowledgment, advice, information, empathy, well wishes, emotional support, validation, the benefit of a different perspective, catharsis, conversation, sympathy, and appreciation. These findings will serve to further communication studies in regards to social blogging, particularly health communication on social media platforms.
We the undersigned, certify that we read this thesis and approve it as adequate in scope and quality for the degree Master of Arts.

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Chapter 1 – Introduction

Importance of the Study

In recent years, online social media has greatly altered the way in which people communicate in general, and that is no different within the area of health communication. With modern technology making it easy and convenient to establish blogging communities and other places online for discussion about important issues, individuals have turned to social media as a forum for health communication. Today there are Twitter accounts, Facebook campaigns, and even a LiveJournal community all dedicated to providing information and assistance to women who have or are affected by endometriosis. While it is true that many of these social media accounts are run by medical professionals or endometriosis-focused organizations, others are run by everyday women.

In the area of online health communication, social media has had a great impact on the purpose and means through which such communication occurs; there have even been studies conducted to see how social media can be used to form a social support group for those suffering from specific chronic illnesses (Finlayson & Cho, 2011; Hwang, Ottenbacker, Lucke, Etchegaray, Graham, & Thomas, 2011; Nicholas, Picone, Vigneux, McCormick, Mantulak, McClure, & MacCulloch, 2009). However, no one has conducted a study of the content already present on an established communication forum. Additionally, there has been no research conducted specifically on how women with endometriosis use social media as a means of online health communication. It is important to understand how they are using it because endometriosis is a condition that is difficult to understand despite its prevalence—it is a gynecological disorder that is known to affect at least one in ten women. The condition is often very difficult to diagnose—it does not follow a fixed pattern of progression—and as a result it is entirely possible
that it is even more common than the medical community believes it to be (Ballweg, 1995; Shah, Moravek, Vahraitian, Dalton, & Lebovic, 2010).

Statement of the Problem

Since many professional health care providers are hesitant to give advice about endometriosis knowing that it varies greatly on a case-by-case basis, women who are affected by the disease are taking matters into their own hands and communicating about endometriosis among one another—often without professional health care providers. By examining the ways in which women use social media to communicate about endometriosis, a better understanding of both the health condition and the functions of health communication online can be achieved.

Definition of Terms Used

Key terms used in this study include health communication, endometriosis, social media, and social blogging. Below are brief definitions of each of the above terms.

Health Communication: A means of sharing, discussing, processing, and understanding health-related information with the goals of informing, aiding, and interacting with other individuals.

Endometriosis: A gynecological disorder that is believed to affect nearly one in ten women; the condition varies greatly from case to case in symptoms, severity, and progression.

Social Media: Provides a platform for users to create and share user-generated content and communicate about the content if they choose to do so.

Social Blogging: A subsection of social media that involves the process of creating and sharing blog posts online in a way that allows other individuals to communicate with the author or creator of the posts as well as other readers.
Organization of Remaining Chapters

This study is organized into five chapters, and the remaining chapters provide an in-depth analysis of how women who have or are affected by endometriosis are utilizing the LiveJournal community *Endometriosis*. Chapter two begins with an overview of the philosophical and theoretical frameworks—Martin Buber’s dialogic ethics and Uses and Gratifications theory—which form the basis that the study is built upon. The rest of the chapter is primarily comprised of a literature review that examines published articles and studies relating to the major components of the study: health communication, endometriosis, social media, and social blogging. Chapter three describes the methodology used to collect and analyze the data in this study. Chapter four presents the results of the study, explains the analysis of the data, and discusses the significance of the findings in relation to the existing literature. Chapter five explains the limitations of the study, suggests possible recommendations for further study, and summarizes the conclusions of the study.
Chapter 2 – Literature Review

The objective of this study is to determine how women who have or are affected by endometriosis use the social blogging website LiveJournal as a means of communicating about the health condition. This study is significant, as it will aim to fill a void within existing research by examining the role that a social blogging community has within the area of online health communication. The purpose of this chapter is to establish the foundation of the study, first by explaining the philosophical and theoretical frameworks that the study is built upon, and secondly by providing a description of findings from literature relevant to the topic of study. The philosophical and theoretical frameworks will provide an overview of Martin Buber’s philosophy of dialogic ethics and also the Uses and Gratifications theory, both of which provide the basis for the research questions of this study.

Philosophical and Ethical Assumptions

In social blogging, an individual creates a blog post and shares it with an audience, with the intention of beginning a discussion about the subject matter with readers—the members of the audience. This process is significant, because the resulting dialogue can be very different than a dialogue held face-to-face about the same subject. This method of online communication depends greatly on both the audience and the initial blogger’s willingness to be open and honest in their communication. Martin Buber, a Jewish philosopher and theologian, developed an ethical approach called dialogic ethics, which examines the relationships between individuals, particularly two relationships he called the I-It and I-Thou relationships (Buber, 1923/1958; Griffin, 2009).

An I-It relationship is a one-sided relationship in which there is little to no dialogue. In these relationships, there is often a lack of real depth in the communication, and whatever
communication occurs can be manipulative or even false in nature, to benefit one member of the relationship (Buber, 1923/1958; Griffin, 2009). In contrast, an I-Thou relationship is a two-sided relationship in which both participants strive to treat the other in the same manner that they wish to be treated. The communication in this type of relationship is a dialogue, with both individuals talking with one another to form an arena in which positive communication can occur (Buber, 1923/1958). To Buber, true dialogue is ethical communication because with dialogue, individuals are communicating with the sole objective of developing a mutual understanding of a subject and of one another as well (Buber, 1923/1958; Griffin, 2009).

Dialogic ethics considers how the relationship that forms through dialogue can reflect an individual’s desire to be an ethical communicator. Dialogue allows individuals to speak openly and honestly, while steering communication away from extreme perspectives and communication methods. Through self-disclosure in dialogue, people are able to form a relationship based on a mutual understanding of a situation, by staying true to one’s own self while remaining open to another person simultaneously (Buber, 1923/1958). So dialogue—and in turn dialogic ethics—represents the objective of health communication on social blogging websites. Individuals who are complete strangers come together on the social blogging sites in order to form relationships with other people with whom they can have conversations—dialogue—about the subjects that matter to them. Understanding more about how women use social blogging to communicate about their health will result in a better understanding of the ways ethical communication occurs within online social blogging communities.

**Theoretical Framework**

The objective of this study is to shed some light on how women who have or are affected by endometriosis use the social blogging site LiveJournal to communicate about the health
disorder by selecting and reading their blog posts. But simply viewing their posts will not
provide sufficient data on how these women are using the site to communicate—these posts need
to be analyzed and interpreted to determine the value and purpose of the posts. In this study, this
will be accomplished by applying the Uses and Gratifications theory to the text. The theory has
evolved greatly over the years to account for the changing landscape of communication. Since
the internet has greatly altered the ways in which people communicate with one another, it is
important to note the effects that the internet has had on the development of the theory.

**Uses and Gratifications Theory**

At its core, Uses and Gratifications theory seeks to explain the relationship that exists
around an individual’s needs, their behavior in engaging with media, and the gratifications or
outcomes that result (Katz, Blumler, & Gurevitch, 1973; Ruggiero, 2000). This theory assumes
that when media consumption is intentional, it is done with the goal of fulfilling an individual’s
need or needs; the outcome(s) of that media consumption for the individual in question may or
may not be anticipated but they are all a direct result of the media consumption. However, the
theory can prove difficult to understand and apply because some gratifications are not the same
from one situation or audience to the next. It is vital to consider the audience before conclusively
determining the uses and gratifications in any situation (Katz, Blumler, & Gurevitch, 1973).
Additionally, the theory can be a challenge simply because it has changed greatly over the years.
The landscape of communication is not the same today as it was when theorists began
formulating the theory; at that time, the theory was primarily concerned with explaining why
media consumers used the radio and early television media content (Ruggiero, 2000; Stafford,
Stafford, & Schkade, 2004). As a result, the theory is constantly evolving as new methods of
communication are developed and implemented.
Katz, Blumler, and Gurevitch (1973) found that as theorists worked to redefine Uses and Gratifications theory, they constantly struggled to define some needs or gratifications, but failed to conclusively determine the parameters of all of the variables because each theorist looked at the theory in a slightly different manner. Some theorists focused on the medium of the content, while others focused on the genre of the content itself. Others examined how the theory functioned on a personal level, while others chose to study the big picture of how it applied to society as a whole (Katz, Blumler, & Gurevitch, 1973). However, as the theory has continued to evolve, certain criteria have come to be considered the accepted needs of media users. Katz, Gurevitch, and Haas (1973) named five different needs that are still valid when applying them to internet media. They are: cognitive needs, affective needs, personal integrative needs, social integrative needs, and escapist needs (Cho, De Zúñiga, Rojas, & Shah 2003). Cognitive needs are concerned with acquiring knowledge and information, which is something that the internet has made increasingly convenient (Cho et al., 2003; Stafford et al., 2004). Affective needs are primarily about emotional experiences. Personal integrative needs are about confidence, self-esteem, and sense of self. Social integrative needs are about interacting with others, be it family, friends, or strangers. Escapist needs are aimed at finding a diversion or a means of eliminating stress or tension (Cho et al., 2003; Katz, Gurevitch, & Haas, 1973). However, as this study is only concerned with online health communication, only four of these needs appear to be relevant: cognitive, affective, personal integrative, and social integrative needs. Escapist needs are unlikely in health communication because individuals who turn to the internet for the purpose of health communication are doing so with a specific intent or goal in mind, and therefore health communication is not a type of diversion.
Unlike prior media formats like radio, television or film, internet usage is a very deliberate act—people typically go online for a specific reason or purpose. As Cho et al. (2003) explain, “Internet use is characterized by frequent choice and greater reflection on the value of what is encountered in relation to the gratification sought” (p. 49). However, what those gratifications are is a subject that scholars are still working to determine. The vastness of the internet means that it can easily fulfill a great number of needs in different situations, but because of that depth and breadth, determining the most probable gratifications can prove difficult (Cho et al., 2003). In fact, though one study may be able to determine the gratifications of the internet usage in that particular situation, it often cannot be applied to other situations (Cho et al., 2003; Ruggiero, 2000). Between the vastness of the internet, and differences among the audiences consuming online media, as well as other variables such as the web content itself, it is important to not adhere to broad generalizations about gratifications.

**Literature**

In order to gain a better understanding of the research topic—how women who have or are affected by endometriosis use the social blogging website LiveJournal as a means of communicating about the condition—it was necessary to look to already published research to determine what information already exists. Although there are numerous studies that examine the role of social media in the changing landscape of health communication, there have been no studies focused on women with endometriosis. So, as there are no existing research studies directly relating to the research topic as a whole, this literature review focuses individually on the components that make up the research question, namely health communication, endometriosis, online social media, and social blogging.
Additionally, while online social media deals solely with the mediums through which individuals communicate online, social blogging is quite different. Social blogging is the process of creating posts online in a manner that allows others to communicate with the author as well as other readers. Even though the focus of this study is a specific area of online social blogging, to understand its significance, it is essential to first gain a better understanding of the area of health communication.

Health Communication

Traditionally, individuals have received their health information from their own trusted medical professionals: specialists, general physicians, etc. (Smith, 2011). But in this modern age with the new means of communication that technology offers, that no longer remains the case. Instead, people are able to acquire health information from a variety of sources. There are the medical professionals seen on television talk shows or heard on the radio, there are websites to aid in self-diagnosis, and there are the always eager-to-help friends and family members willing to share their medical knowledge (Koch-Weser, Bradshaw, Gualtieri, & Gallagher, 2010; Macario, Ednacot, Ullberg, & Reichel, 2011; Smith, 2011). All of these methods represent different forms of health communication, and there are in fact countless other ways in which such communication occurs. The term is a broad one, and as a result there are varying definitions for health communication. From the perspective of medical professionals, health communication is about, “improving health outcomes by encouraging behavior modification and social change” (Schiavo, 2007, p. 7). However, for the purpose of this study health communication will be defined as a means of sharing, discussing, processing, and understanding health-related information with the goals of informing, engaging, assisting, and supporting other individuals (du Pré, 2010; Hanson, Thackeray, Barnes, Neiger, & McIntyre, 2008; Schiavo, 2007).
Health communication is a subject that is becoming increasingly important, as individuals are encouraged and have the ability to take on more responsibility for their health and wellness (Cline & Haynes, 2001; Macario et al., 2011; Smith, 2011). It is not only a very important area of study, but also an important part of day-to-day life and society in general. When understood and utilized properly, health communication can greatly impact a person’s life for the better by encouraging positive healthcare interactions, minimizing unhealthy misconceptions, saving both time and money, improving a person’s mental and emotional well-being, and also increasing a person’s ability to handle current and future health complications (du Pré, 2010). Successful health communication can also lead to more efficient medical practices which can in turn result in—among other things—faster or more accurate medical diagnoses (du Pré, 2010; Schiavo, 2007). However, as mentioned earlier, health communication is more than information shared between a patient and his or her physician; there is much more to be considered and examined in the area of health communication.

Today with over 50% of adults looking to sources beyond healthcare professionals for health information, it is important to look at what sorts of information are available, as well as how healthcare consumers utilize such information (Cline & Haynes, 2001; du Pré, 2010; Koch-Weser, et al., 2010; Macario, et al., 2011; Schiavo, 2007; Smith, 2011). Healthcare consumers receive so many messages regarding their health and well-being that it is imperative that they weigh each message carefully to determine its trustworthiness. With so much information available online or through other sources, it comes as no surprise that some of the health information present online is unverified, inaccurate, or just misinformation in general (Cline & Haynes, 2001; Macario et al., 2011; Smith, 2011). “The challenge for public health communicators is to overcome the traditional tendency to disseminate unidirectional messages
and, instead, empower health information consumers to assess the quality and veracity of information they derive from ever-compounding sources” (Macario et al., 2011, p. 146). In turn, healthcare consumers need to learn how to discern what is credible healthcare information when it comes from other sources.

Research suggests that healthcare consumers are not turning to alternative health information sources as a replacement for healthcare professionals, but rather they use them in addition to seeing medical professionals (Macario et al., 2011; Smith, 2011). In the event that an individual is unable to get an appointment with their physician, he or she may look to the internet for health information. Others use the internet as a second opinion of sorts, which can be a risky practice as a search for one particular symptom could easily turn up thousands of sites dealing with a number of different health conditions (Cline & Haynes, 2001; Macario et al., 2011; Smith, 2011). That is why it is important for healthcare professionals to be more aware of online interactive health communication.

They need to also learn how to advise their patients in order to ensure that healthcare consumers find trustworthy websites and sources when looking beyond their healthcare professionals for their health information (du Pré, 2010; Koch-Weser et al., 2010; Macario et al., 2011; Smith, 2011). That is not to say that there are no valuable sources to be found outside of one’s own physician—the internet actually does provide information that can be very beneficial to healthcare consumers (Cline & Haynes, 2001; du Pré, 2010; Macario et al., 2011; Rains & Keating, 2012; Smith, 2011). Many legitimate medical organizations and societies have websites where they provide medical information or advice to those who visit their sites. The information available online may simply be information that is not available from a medical professional, as the internet allows for interactivity with other individuals, faster distribution of new information,
widespread access, a combined knowledge base, and even the security of anonymity when it is preferred (Koch-Weser et al., 2010; Preece & Ghozati, 2001; Rains & Keating, 2012). However, this does not negate the potential risks available with seeking out information online, the literature does show that there is value to be found in health communication online. And in the case of the health condition endometriosis in particular, there is often valuable information to be found from someone outside the health care field—information that a medical professional may be unaware of, or even reluctant to share with a patient.

Endometriosis

As mentioned earlier, endometriosis—commonly referred to as endo for short—is a gynecological disease believed to affect close to one in ten women while they are in their reproductive years (Ballweg, 1995; Shah et al., 2010). The name itself describes the condition, as the term endometriosis is derived from endometrium which is, “the tissue that lines the inside of the uterus and builds up and sheds each month in the menstrual cycle” (Ballweg, 1995, p. 10). In endometriosis such tissue is found outside of the uterus, in other parts of the body. There the tissue develops into growths such as adhesions, lesions, nodules, tumors, etc. Depending on factors such as size, location, and proximity to other organs in the body, the growths can cause pain, infertility, and other health problems (Ballweg, 1995; Brosens & Benagiano, 2011; Mills & Vernon, 2002). Although most growths are located in the abdomen and other areas of the pelvic cavity—particularly the ovaries, fallopian tubes, and outer surface of the uterus—growths have also been discovered in other areas of a woman’s body including, but not limited to, the intestines, the bladder, vagina, thigh, arms, and lungs (Ballweg, 1995; Brosens & Benagiano, 2011; Mills & Vernon, 2002).
Though known cases of the disorder date back to at least 1920, there is still no known cause for endometriosis (Ballweg, 1995; Brosens & Benagiano, 2011; Mills & Vernon, 2002). As a result there are a number of theories that serve to explain why some cases likely exist; however, no theory has managed to provide an explanation that accounts for all cases of endometriosis (Ballweg, 1995). Instead, for all intents and purposes, women and medical professionals have to rely solely on a list of symptoms to determine whether an individual even has a problem such as endometriosis. Such symptoms can include worse or abnormal pain during a menstrual cycle, infertility, fatigue, lower back pain during periods, intestinal irregularities, and pain during sexual activity; however it is important to mention that some women never even experience any symptoms or pain despite having endometriosis (Ballweg, 1995).

Symptoms of endometriosis can present themselves as early as stage one, or as late as stage four, but those symptoms are frequently indicative of other health problems (such as cancer, polycystic ovarian syndrome, adenomyosis, etc.) and are therefore unreliable in regards to identifying the presence of endometriosis (Ballweg, 1995; Brosens & Benagiano, 2011). Additionally, the degree of pain that a person feels also has no bearing on the severity of their case of endometriosis; just as one person’s body differs from another, so too does the condition itself (Mills & Vernon, 2002). A woman can have stage one endometriosis and massive amounts of pain, while yet another may have stage four and no pain whatsoever (Ballweg, 1995). These inconsistencies with endometriosis are largely responsible for the length of time between the onset of the disease and an accurate diagnosis, which is typically between four and nine years (Shah et al., 2010). Ultimately a diagnostic surgery, such as a laparoscopy, is the best means of providing a conclusive diagnosis of endometriosis (Ballweg, 1995; Brosens & Benagiano, 2011; Mills & Vernon, 2002).
Just as there is no known cause of endometriosis, there is also no guaranteed cure for the disease either (Ballweg, 1995; Brosens & Benagiano, 2011). There are some treatments available to help women with their cases of endometriosis, such as birth control pills to limit the number of menstrual cycles or dietary and lifestyle changes, but ultimately these help women manage their endometriosis, not cure it (Ballweg, 1995; Mills & Vernon, 2002). For some women, endometriosis goes away on its own due to natural hormonal changes, like the ones that occur during pregnancy and menopause. Some women who have had hysterectomies have noted that their cases of endometriosis were gone afterwards, but others were not as fortunate. Additional treatments such as hormonal therapy injections have proven effective in eliminating endometriosis and curing infertility for many women, but again, this is not true for all women (Ballweg, 1995; Brosens & Benagiano, 2011; Mills & Vernon, 2002).

With so many cases differing in cause, nature, and resolution, it is no wonder that the complex condition is not commonly known despite its prevalence. In fact, a study conducted suggests that most individuals only become aware of the existence of endometriosis once they are affected by it (Shah et al., 2010). This typically occurs as a result of being diagnosed with endometriosis or by knowing someone else who has endometriosis (Ballweg, 1995; Mills & Vernon, 2002). However, it is important to note that with the increased usage of the internet, information about diseases like endometriosis is more readily available to all individuals with access to an internet-enabled device—instead of only those who are directly affected by the condition.

Social Media

The internet, or World Wide Web, has been around for decades now, but its purpose and development have greatly evolved over time, creating an internet that is very different today than
it was originally created to be. The current age of the internet is commonly called Web 2.0 to highlight the changes in how the internet is designed and used (Hanson et al., 2008; Kaplan & Haenlein, 2010). Web 2.0 does not refer to the actual structural changes of the World Wide Web; it instead emphasizes the prevalence of user generated content—media content of all forms which is created by anyone and made publicly available (Hanson et al., 2008; Kaplan & Haenlein, 2010). In turn, user generated content led to the development and popularity of social media websites. Social media takes the basic ideas behind Web 2.0, and moves them even further to allow not only the creation and sharing of user generated content, but provides a platform for users to communicate about the content (Hanson et al., 2008; Kaplan & Haenlein, 2010).

Social media sites—particularly social networking websites—like Facebook, Twitter, Tumblr, and also blogging communities such as LiveJournal and Dreamwidth, have changed the way in which individuals represent and express themselves online (Jiang, Bazarova, & Hancock, 2011; Kaplan & Haenlein, 2010). Before these websites existed, online profiles were more formal and reserved, but as the sites continue to grow in popularity, a growing trend of self-disclosure and openness has emerged (Hanson et al., 2008; Jiang et al., 2011; Kaplan & Haenlein, 2010; Palmieri, Prestano, Gandley, Overton, & Qin Zhang, 2012). Self-disclosure, or revealing personal information about one’s own self is a common practice on these websites where individuals are able to create their own accounts, generate their own content and share it freely. It is interpersonal and computer-mediated communication all at once, and because it is easily updated, the social connections generated in such communication can be quite strong depending on mutual openness (Jiang et al., 2011; Palmieri et al., 2012). Openness and self-disclosure often abound when in conjunction with anonymity, as a sense of distance and safety can grant individuals the peace of mind they need in order to speak their minds freely and reveal
personal information (Cline & Haynes, 2001; Hwang et al., 2011; Jiang et al., 2011; Kaplan & Haenlein, 2010; Koch-Weser et al., 2010). Though this is evident throughout virtually every online social media platform, self-disclosure is especially evident on social blogging websites.

Social blogging sites like LiveJournal, Dreamwidth, WordPress, and numerous others, allow individual users to generate blog posts and communicate with readers who leave comments or ask questions of the authors. But some sites are also social networking sites; on LiveJournal, it is also possible for individuals to follow other bloggers and join communities where others post about a certain topic, be it sports, politics, current events, pop culture, or even healthcare. LiveJournal, Inc. identifies their website as a, “community publishing platform, willfully blurring the lines between blogging and social networking” (LiveJournal, Inc., 2012). LiveJournal emphasizes and promotes creativity, diversity, community and self-expression, encouraging open discussion about topics amongst its users. Additionally, depending on the privacy settings for each particular community or personal journal, individuals who are not themselves members of LiveJournal may also be able to participate and interact with others online (LiveJournal, Inc., 2012). The social structure of LiveJournal lends itself well to both social blogging and social networking because it provides users with a virtual community where they are welcome to blog about whatever subject they choose and communicate with others who are interested in the same subject as well (du Pré, 2010; Hanson et al., 2008).

Social Blogging

One way in which self-disclosure has become more prominent online is through the increasing popularity of social blogging. Since this study is examining how women are using LiveJournal to communicate about endometriosis, this section on social blogging will only focus on studies about blogging related to health communication. Blogging allows individuals to
publicly or privately communicate, “their concerns, insights, and experiences living and coping with a health condition,” and interact with any followers or commenters on the blog (Rains & Keating, 2011, p. 512). A blog has an audience who can often provide direct feedback to the author in a manner much like face-to-face interpersonal communication provides. Health blogs in particular allow individuals to share personal thoughts or stories, while also acquiring a social support system of a sort (Hanson et al., 2008; Preece & Ghozati, 2001; Rains & Keating, 2011; Rains & Keating, 2012).

Social support is communication that increases perceptions of control regarding one’s life; though it has traditionally been found in face-to-face communication, social media has made online social support a very powerful and often valuable occurrence (Nicholas et al., 2009; Preece & Ghozati, 2001; Rains & Keating, 2011; White & Dorman, 2001). As social support can be such a beneficial aspect of health blogging, it makes sense that there are websites and online communities with the sole function of being a social support group for a particular purpose, such as weight-loss, or a particular health condition like chronic kidney disease or endometriosis.

A support group differs slightly from social support; social support is the benefit that an individual can receive from a support group, which is in turn a group that shares a common goal of providing education and information that helps people cope with their condition or place in life (du Pré, 2010; Finlayson & Cho, 2011; Nicholas et al., 2009; Pagano, Post, & Johnson, 2011). The online social support group can serve as a standalone support system, or it can be used in conjunction with other support systems in an individual’s life. “The expansion of one’s personal network may be particularly useful for individuals who are stigmatized by their health condition or those with restricted mobility” (Hwang et al., 2011, p. 199). For those who are unable to get the support that they need within their everyday lives, online health communication
provides them with the potential to receive that support, help, or understanding (Cline & Haynes, 2001; du Pré, 2010; Hwang et al., 2011; Nicholas et al., 2009; Rains & Keating, 2011). Health blogs are especially common for diseases or disorders that have fewer methods of treatment or are more difficult to understand (White & Dorman, 2001). In most cases, online communities are accessible twenty-four hours a day, which also increases the likelihood that individuals will be able to find the social support that they need at any given time (Preece & Ghozati, 2001; White & Dorman, 2001).

Online social support, as mentioned earlier, can be a great benefit to an individual as support promotes psychological well-being (du Pré, 2010; Rains & Keating, 2011). However, it is not the only purpose of health blogging; sharing experiences of dealing with or having an illness or traumatic health experience are actually the most common forms of health blogging (Rains & Keating, 2012). In such cases, health blogging can be informative for readers, while also providing a sense of catharsis to the individuals who are sharing their experiences. Even if they are not receiving social support, the process of health blogging can still provide the bloggers with emotional and mental well-being (Rains & Keating, 2012). For those suffering specifically from endometriosis, health blogging provides access to a potentially wider knowledge base—one that did not exist until social blogging came about. As there is still a relative lack of knowledge about endometriosis—stemming from the unknown nature of the condition, health blogging presents a solution of sorts to these individuals. Health blogging encourages information sharing amongst endometriosis sufferers, while simultaneously providing them with an avenue for social support.

**Summary of Literature**

Although health communication has existed as a field of study for many years now, the
field has evolved greatly, especially in recent years as internet usage has increased. There is now a great deal of health-related information available online—some from professional medical sources, others from patients’ first-hand experiences, and others still that are inaccurate and misleading. It is important to examine how this information is being used, as some individuals rely on it heavily—especially when it comes to health conditions like endometriosis.

Endometriosis, a gynecological disorder that affects close to one in ten women, is also a condition that varies greatly on a case-by-case basis. As a result, medical professionals are often reluctant to disclose a great deal of detailed information to women with the disease, preferring to instead use known generalizations about the condition to avoid giving information to a patient that does not pertain to her. The lack of information from their doctors has led women to turn to alternative information sources, particularly health-related websites and blogs online. Social blogging communities have created a forum for communication that combines health-related blogging and social networking. This allows individuals to share and receive information while also interacting with others who are interested in the same subject matter.

**Rationale**

The purpose of this study is to examine how women who have or are affected by endometriosis use the social blogging site LiveJournal as a means of communicating about the condition. Although there have been studies done that focus on how individuals use the internet to form virtual support groups, and other articles on how the role of health communication has evolved online, there are no studies examining how individuals use a social blogging community to communicate about a health issue. Endometriosis is a condition that varies so greatly from one individual to the next that studying the methods of information distribution can prove very valuable to the healthcare providers. Additionally, there are very few studies focusing on women
who have endometriosis in general, let alone how they communicate with one another. This study will aim to fill a void in the existing literature and bring awareness to an issue that could benefit many areas of both study and society.

By using Uses and Gratifications theory to examine actual blog posts from women who have or are affected by endometriosis, the posts can be sorted by determining what needs they fulfill. As mentioned earlier, the theory identifies four kinds of needs that posting online could be fulfilling for the bloggers: cognitive, affective, personal integrative, and social integrative needs. By identifying the needs being met, and examining the content of the posts and comments themselves, it will be possible to identify at least some of the resulting gratifications that the women experience. These results can then in turn contribute to further studies in the areas of health communication, social blogging, and uses and gratifications theory itself. At the start of this study, the initial research question was: How do women who have or are affected by endometriosis use the social blogging site LiveJournal as a means of communicating about the disorder? After reviewing literature relevant to the topic, that question still remains the core focus of this study as there is currently no existing research on that subject. However, an additional question has arisen: What are the gratifications that these women are receiving from communicating about endometriosis through LiveJournal?
Chapter 3 – Scope and Methodology

The Scope of the Study

This study is focused on how women who have or are affected by endometriosis use the social blogging site LiveJournal as a means of communicating with one another about the condition. Through the social blogging site, individuals are able to create blog posts expressing their communication needs in relation to endometriosis, i.e. emotional support, advice, searching for information, wanting to have a conversation, and so on. Although a search of the term “endometriosis” returns a multitude of results relating to endometriosis and other areas of women’s healthcare, many of the social blogging communities are no longer active—they only function as an archive now, as opposed to a forum for open communication. However, there is one community on LiveJournal that has remained a relatively active community for over eleven years—a community called Endometriosis.

On LiveJournal, the format for blogging is very simple—anyone can register for a LiveJournal account, and with that, they are free to blog on their own personal accounts whenever they choose to do so, and also control who has permission to view and comment on their posts. Additionally, having an account allows users to post in LiveJournal communities as well; the communities—unlike personal journals—allow multiple site users to post blog entries about a subject that is the community’s focus. The community can have public posts—which anyone can read—or “members only” posts. In this study, the LiveJournal community being studied is the Endometriosis community, a community that has grown over the past decade to become a prominent resource on LiveJournal for those affected by the condition.

The LiveJournal community Endometriosis lists over 900 members, with an additional 550+ registered LiveJournal users monitoring the community without joining it. However it is
not necessary to be a LiveJournal account holder to see some of the information posted to the community. Over eleven years of being an active, self-moderated community, there have been more than 5,000 posts made in the *Endometriosis* community. Many of these are members only posts, thus requiring both a LiveJournal account and also membership in the *Endometriosis* community, however when viewing the community as a non-LiveJournal member, there are still more than 400 posts that are easily accessible. Since there is so much data available in just this one community, the study is limited just to posts and comments made in the *Endometriosis* community.

**Methodology of the Study**

**Design and Procedures**

Content Analysis will be the methodology utilized to collect and examine the data for this study. Since the purpose of the study is to examine how women are using LiveJournal to communicate about endometriosis, it is logical to focus solely on posts made on the social blogging community *Endometriosis* to see how users are already using the community. A content analysis study is designed to take a close look at communication messages in a systematic manner, with the goal of determining something about the content of the messages, those who create the messages, and even the audience of the messages (Rubin, Rubin, Haridakis, & Piele, 2010). For the purpose of this study, the posts in the *Endometriosis* community have been sorted and analyzed by applying Uses and Gratifications theory. Since Uses and Gratifications theory focuses on the reasons why individuals consume certain kinds of media as well as what they receive from that media consumption, the theory formed the basis for the study. By examining the reasons that the women turned to LiveJournal to fulfill their communication needs, it was then possible to determine what gratifications they were receiving in the process.
The content analysis was conducted as follows. The blog posts were first sorted by their obvious purposes, which were also the communication needs being met by creating and sharing the blog posts. The women indicated their needs by using different phrases or by giving readers descriptions of their specific situations. For example, women who used phrases that suggested they were confused, uncertain, or in need of advice, were indicating that they had personal integrative needs that they were trying to meet. Overall, the communication needs being met were: searching for information (cognitive needs), looking for emotional support or sharing an experience (affective needs), asking for advice or help (personal integrative needs), and posting to generate a discussion—by asking a question, sharing a story, etc.—(social integrative needs).

After carefully reading through each post, focus moved on to the comments section of the posts where other women were able to respond to the bloggers.

It is in the comments that it could be determined whether or not the women succeeded in achieving their communication needs. By reading each comment, it was possible to infer what they were offering the women, be it emotional support, advice, validation, or simply well wishes. Those who were looking for information of some sort, achieved their cognitive needs when they got the answers to their questions or additional resources to check out. Though there were only four main kinds of communication needs being met, there were more gratifications that the women received, some of which were: empathy, sympathy, and acknowledgment.

**Sampling**

As there are posts in the LiveJournal community that are members only posts, it was necessary to select a purposive sample in a manner that would allow the study to be replicated by someone in the future, regardless of whether that individual is a LiveJournal account holder. Therefore, only posts that were made completely public were used for this study. Additionally,
since there were over four hundred public posts made since 2009, it was also necessary to choose a smaller, more manageable sample size for the study. Instead of analyzing all of the publicly viewable posts, this study will only cover posts made from September 2011 to October 2012, which is a little over fifty posts. By narrowing the sample to a year’s worth of posts, the data collected still includes a wide variety of posts which fall under the different needs highlighted by Uses and Gratifications theory.

**Ethical Considerations**

All of the posts were made publicly available on the LiveJournal community *Endometriosis*, so there was no need to receive permission from the bloggers or the commenters. Although it is possible to reach out to members of LiveJournal, for the purpose of this study, no attempt was made to contact, identify, or learn more about any of the individuals who posted publicly in the community in an effort to respect their privacy.

An additional point of consideration from an ethical standpoint is the fact that the researcher is a woman who has and is affected by the gynecological disorder endometriosis. As such, every effort has been made to ensure that the study was conducted in an objective manner. However, due to firsthand experience, it is possible that some needs and gratifications were identified because of prior knowledge.

**Validity & Reliability**

The data collected and analyzed via content analysis is valid because the data accurately represents the information that the study was designed to examine (Rubin et al., 2010). The blog posts are all by women who have or are affected by endometriosis, and they are all communicating about the condition in some manner. These posts have similarities that allow
them to be studied as a collective whole, while still being different, allowing for a greater range of data to be analyzed.

The reliability of the data is somewhat harder to determine, largely because the condition endometriosis varies so greatly on a case-by-case basis. Individuals posting in the *Endometriosis* community may each have very different experiences in coping with and managing the condition, and as such, if this study were replicated, it is possible that the findings may differ from the ones presented in this study. As any individual is free to post information online, it is not possible to verify the veracity of the bloggers’ claims and posts in general. Additionally, because the data is collected from public blog posts, all of the data are the result of each individual’s own perspectives on the matter, and also subject to their own recollections of their experiences.

To ensure that the data for this study is coded in a reliable manner, there will also be an additional coder analyzing and coding a portion of the data (Neuman, 2006). The additional coder was trained by the researcher to read and analyze the data in the same manner as the researcher. The second coder was instructed to first read the initial blog post. Then determine what reason(s) the individual had for posting. Those were the communication needs—the uses part of Uses & Gratifications theory. After identifying the needs, the coder was to read the comments, and then determine what the comments provided, the “gratifications” of the interaction. The coder was then instructed to look for any indications that signaled potential unforeseen gratifications. These were possibly unanticipated benefits for the original blogger, such as acknowledgment. Overall, the second coder examined seven of the blog posts, which accounted for close to 12.7% of the total data collected for this study.
Chapter 4 – The Study

Introduction

The study examined blog posts made in the LiveJournal community *Endometriosis* over a period of thirteen months, from September 2011 through October 2012. Although there were hundreds of posts made within that time frame, only those that were made public to all individuals—as opposed to just members of the community—were coded and analyzed. Through a method of structured content analysis, the study examined: 1) the communication needs expressed by women through their blog posts in the community, 2) the comments they received from other affected women, and 3) any comments they provided in response to those left by the other women. The content analysis was completed in November 2012. In this chapter, the process of coding and analyzing the LiveJournal blog posts is described, the results are presented, and the findings are discussed in regards to Uses and Gratifications theory, dialogic ethics, and related published studies.

Results of the Study

The purpose of this study was to examine how women who have or are affected by the gynecological disorder endometriosis use the social blogging site LiveJournal as a means of communicating about the condition. In order to determine this, a thorough analysis of the blog posts and any additional comments was conducted. As described in Chapter 3 of this study, the content analysis utilized Uses and Gratifications theory to determine both the communication needs expressed by the women in their posts, as well as the gratifications they received from the act of blogging and receiving comments.

As mentioned earlier, on LiveJournal anyone with an account is free to blog on his or her own personal account whenever they choose to do so, and they may also control who has
permission to view and comment on their posts. Having an account also allows users to post in LiveJournal communities as well. In this study, the LiveJournal community being studied is the Endometriosis community. In this community, there are both public and members only posts, so for the purpose of this study, only those that were made public even to non-LiveJournal users were analyzed.

For this study, all public posts—from the beginning of September 2011 through the end of October 2012—were read, coded, and analyzed. Within that time frame there were 55 public posts in total, which were written and posted by 22 distinct bloggers. As mentioned in the previous chapter, to ensure intercoder reliability an additional person coded a representative sample of the collected data. After comparing the primary researcher’s coded findings with those of the additional coder, the intercoder reliability was found to be 0.91667, or roughly 91.67%. The researcher and even the additional coder examined the blog posts carefully to determine what communication need(s) the women were expressing. Though each post only had one author, there was frequently more than one communication need expressed by the individual in that post. The following table, Table 1, shows how many times social bloggers expressed each communication need—cognitive, affective, personal integrative, and social integrative—in the Endometriosis blog posts examined in this study.

**Table 1: Communication Needs Expressed by Social Bloggers in Endometriosis**

<table>
<thead>
<tr>
<th>Communication Need Expressed</th>
<th>Number of Posts</th>
<th>Percentage of Data Sample</th>
</tr>
</thead>
<tbody>
<tr>
<td>Personal Integrative</td>
<td>33</td>
<td>60.00%</td>
</tr>
<tr>
<td>Cognitive</td>
<td>26</td>
<td>47.27%</td>
</tr>
<tr>
<td>Affective</td>
<td>22</td>
<td>40.00%</td>
</tr>
<tr>
<td>Social Integrative</td>
<td>22</td>
<td>40.00%</td>
</tr>
</tbody>
</table>
Table 1 displays how frequently each communication need was expressed within the initial blog posts. As the researcher initially hypothesized, for the women posting to the Endometriosis community, escapist need was not a communication need that was being expressed or fulfilled, presumably due to the fact that these women are deliberately taking action in pursuing health communication.

Personal integrative needs were the most frequent needs expressed, as the women posting asked for advice or help in 33 of the posts. Examples of the language used when expressing personal integrative needs included phrases like, “What should I do? Does anyone have any experience with…” (emkachan, 2011), or even, “I had a hard time getting a doctor who would actually listen to me until recently” (aliciamae09, 2012). In 26 of the posts, the bloggers expressed a cognitive need, a search for information of some sort, be it details about a medical procedure, a new medication on the market, or even how to cope with daily pain. For example, one LiveJournal user turned to the community to ask other readers, “I was just wondering if anyone here has taken or takes ginger to help relieve their endo pain” (disturbedme, 2011a).

Affective communication needs were expressed in 22 of the posts as the women shared stories about being unable to find adequate support systems at home, or shared their circumstances in an effort to find someone who understood their pain. An example of the language used to indicate an affective need is, “I’m kind of worried/anxious right now” (disturbedme, 2011b). In 22 of the posts, women tried to start a discussion about endometriosis with someone else, signaling the social integrative needs they were trying to fulfill. Another LiveJournal member, was one of those who used their blog posts to begin a discussion by asking, “I was wondering how everyone was diagnosed with Endo?” (endotrip, 2011). In each blog post,
the language used may have been different, but the bloggers were still expressing some combination of the same communication needs.

Following the identification of the communication needs expressed by the women, the comments left in response to the post were then coded and analyzed to determine what gratifications the original posters received. The gratifications included both explicitly stated and implied gratifications; as with the communication needs, there were frequently multiple gratifications stemming from each blog post and its ensuing comments. The following table, Table 2: Gratifications Received by Social Bloggers in *Endometriosis*, shows the gratifications received by the women posting in the *Endometriosis* community, as well as the frequency of their occurrences.
Table 2: Gratifications Received by Social Bloggers in *Endometriosis*

<table>
<thead>
<tr>
<th>Gratification Received</th>
<th>Number of Posts</th>
<th>Percentage of Data Sample</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acknowledgment</td>
<td>50</td>
<td>90.91%</td>
</tr>
<tr>
<td>Help or Advice</td>
<td>33</td>
<td>60.00%</td>
</tr>
<tr>
<td>Information</td>
<td>30</td>
<td>54.54%</td>
</tr>
<tr>
<td>Empathy</td>
<td>29</td>
<td>52.72%</td>
</tr>
<tr>
<td>Well Wishes</td>
<td>27</td>
<td>49.09%</td>
</tr>
<tr>
<td>Emotional Support</td>
<td>25</td>
<td>45.45%</td>
</tr>
<tr>
<td>Validation</td>
<td>20</td>
<td>36.36%</td>
</tr>
<tr>
<td>Different Perspective</td>
<td>13</td>
<td>23.64%</td>
</tr>
<tr>
<td>Catharsis</td>
<td>12</td>
<td>21.81%</td>
</tr>
<tr>
<td>Conversation or Dialogue</td>
<td>11</td>
<td>20.00%</td>
</tr>
<tr>
<td>Sympathy</td>
<td>9</td>
<td>16.36%</td>
</tr>
<tr>
<td>Appreciation</td>
<td>5</td>
<td>9.09%</td>
</tr>
</tbody>
</table>

Table 2 above, identifies each of the gratifications that were determined that the initial blogger received after all of the comments were taken into consideration. The gratifications that women blogging in the *Endometriosis* community received were: acknowledgment, help or advice, information, empathy, well wishes, emotional support, validation, the benefit of a different perspective, catharsis, conversation with another person, sympathy, and appreciation. Acknowledgment was the most prevalent gratification, and it was likely also one that never even occurred to the bloggers as it stemmed from simply receiving a comment from another person. Commenting on a blog post not only gives the author a specific message from the reader, but it also tells the author that their initial message has been heard or read by someone else.
Help, advice, and information were the next most common gratifications, generally due to the fact that they were direct responses to questions or needs explained in the blog posts. Advice and help was given to the bloggers in different ways depending on the situation described in the initial blog post. Examples of the language used in the comments of the blog posts are, “I would say start slow, but do start,” (finally10pm, 2011b) and also, “If you are finding the side effects (hot flashes, mood swings) that bothersome, you might want to talk to your doctor about that,” (my_redshoes, 2011). As for information, it was usually provided on an as needed or as requested basis—typically as a response to a question asked in the blog post the commenter was leaving a message on. One LiveJournal user said, “It’s possible for a cyst to disintegrate on its own,” in response to a question posed by another Endometriosis member (neonrose5, 2012).

Empathy, well wishes, and emotional support were gratifications commonly found in combination with one another as the respondents who had experienced similar situations as the bloggers shared their knowledge and experiences with them in a sign of solidarity and understanding. Even though they are found in conjunction with other gratifications, each of these serves a different purpose though. Well wishes are simple phrases or statements telling the bloggers that the commenter(s) hope things work out for them, hope they feel better, and generally wishing them the best. “I hope whatever they gives [sic] you gets you out of pain,” (avalokita, 2012).

Empathy, much like sympathy, involves the thoughts, feelings, and attitude of the commenter towards the social blogger. The two are not the same though, as sympathy is a person’s ability to recognize and acknowledge another person’s unhappiness or distress, whereas empathy is a person’s ability to recognize, acknowledge and identify with another person’s distress—often due to his or her similar experience or knowledge. In the comments in
Endometriosis, though sympathy was expressed, empathy was far more prevalent as many of the women shared their similar experiences and problems with the bloggers. Comments such as, “I can hear your fear and I have been there,” remind these women that they are not the only ones affected by this condition, and that there are others out there who understand the situation that they are experiencing (finally10pm, 2012a).

As mentioned earlier, many women received emotional support from the process of blogging in the Endometriosis community. As one member said in response to comments left on her post, “I find it comforting to talk to other sufferers, my family and friends are great, seriously great, but they still don’t truly know what I go through” (sarah_fbi, 2011). The community members are able to fulfill a void in this individual’s life and provide the emotional support that she craves. Often, along with the empathy and emotional support came validation—letting the blogger know that there was nothing wrong with how they felt or what they were experiencing. Comments such as, “You’re not alone. Everyone has hard times with their disease,” go a long way towards helping a person cope with this condition and the way that it impacts their life (somniumdraconae, 2012). This became even more evident when bloggers returned to the community to post as their health progressed or deteriorated, and they came to Endometriosis searching for emotional support.

Many of the women found that the different perspectives of the other women were invaluable and therefore a gratification. However, it is worth noting that this was a difficult gratification to determine when coding the data, because in order to determine whether or not the original poster benefitted from the different perspective of the commenter, a conversation or dialogue between the two needed to have occurred. In some instances, those conversations that took place within the comments of the blog post were also an additional gratification depending
on the effect that it had on the blogger. Interactions in which an individual expressed that they were happy to discuss endometriosis problems with another commenter were those posts that had having a conversation with another person as a gratification.

There was one gratification in particular that was more difficult to determine than the others, and that was catharsis. Though some women indicated that they were relieved to have somewhere to share their stories, others were not as clear in expressing their emotions over getting their story out there to those who would understand it. The final gratification that was found through coding the data was appreciation. Most of the time it was in response to someone sharing general information in their posts, such as information about developments in the medical field relating to endometriosis. A quick message thanking the author for sharing the information indicated appreciation for the informative post.

Discussion

The results show that the women who used the LiveJournal community *Endometriosis* as a means of communicating with other women who have or are affected by the condition, did so for a variety of reasons. Each woman had one or more communication needs that they were expressing to the other women. Some women wanted information, others advice, or even emotional support, while others still wanted to interact with others who understood the condition. All of these represent things that they were unable to get at home from family, friends, or even medical professionals. Even though their specific needs may have been different, each woman used the *Endometriosis* community to fulfill those needs in a space they perceived as safe and welcoming.

On its own that would be an interesting selection of data to examine closer, but when combined with the gratifications that these women are also receiving from their interactions
online, it becomes an important, interesting area of social blogging and health communication. The women turning to the *Endometriosis* community are receiving many benefits from the community and the other members who they are communicating with. From emotional support to validation, and sympathy to empathy, this community provides these women with a safe forum where they can share their stories and try to get some much needed help in order to cope with the realities of having a health condition that causes chronic, often debilitating pain.

As mentioned in Chapter 2, many people are turning to the internet for health communication purposes, especially with the goal of acquiring information about a particular health-related topic. The findings of this study corroborated that, as the most frequent gratifications—after acknowledgement—were information and help or advice. Like the existing literature examined in Chapter 2 suggested, the findings indicate that the majority of the bloggers are seeing healthcare professionals on a regular basis, which in turn suggests that they are using the community as a supplemental resource for information regarding endometriosis. By using the *Endometriosis* community to fulfill their cognitive communication needs, women who have or are affected by endometriosis are able to get help in finding the answers to their questions.

Although there can be a wide variety of answers in some cases, at the very least, individuals get a starting point from which they can continue their search for additional information. Despite the concerns that information online can be misleading or false, the data analysis showed that whenever inaccurate information was posted, other members questioned it, critiqued it, and worked to correct the misunderstanding (bluedragon776, 2012). The data suggests that *Endometriosis* members do not want false information getting out; they want the community to be a viable resource for women in need of help or advice, and so they worked to police the correct information in the comments of the misleading post.
This study shows that the community is invaluable to these women who have or are affected by endometriosis. Through health blogging, it is possible to have widespread information sharing amongst endometriosis sufferers, while simultaneously providing them with the means of fulfilling any other communication needs that they may have. Overall, *Endometriosis* can provide these individuals with archives of information that they can search, feedback and answers to their questions, stories from others who have been through or are experiencing situations that are similar to those of the individuals, and arguably most importantly, a source of emotional support. The members of *Endometriosis* provide emotional and social support to its fellow members because everyone there shares the common goal of helping one another find the information they need in order to have a better understanding of their health and experiences. Due to this common objective, the community functions as a somewhat informal support group dedicated to helping one another cope with endometriosis and the struggles stemming from the condition.

As LiveJournal is a social blogging site that promotes interaction and communication between its members, it comes to no surprise that self-disclosure is a large part of the communication taking place online. As mentioned previously in Chapter 2, self-disclosure is revealing personal information about one’s own self—something that is quite simple to do on LiveJournal and in the *Endometriosis* community. According to the coded data, the most frequently expressed communication need in the blog posts was personal integrative need—expressing a need for help or advice in relation to a personal experience or situation. It is likely that these women felt comfortable expressing their stories because they were among like-minded individuals, and were also protected by the anonymous nature of the internet. As the online format of LiveJournal allows its users to communicate across vast distances, the women in the
Endometriosis community, were able to speak their minds freely, and share deeply personal stories in an effort to benefit from the communication experience. Additionally, because of the degree of anonymity provided by LiveJournal, these interactions may have been even more open—featuring more self-disclosure—than the same interactions in a face-to-face context.

Women are using the community Endometriosis—that much is evident by looking at the community’s statistics alone. What this study highlights is the ways in which women who have or are affected by endometriosis are using this social blogging forum. Unlike other health studies that have been conducted, this study examined the content of an already established forum for women with endometriosis. In closely studying how these women post entries and benefit from using the social blogging site, a few things have become evident.

The community offers resources unavailable to many of these women in their day-to-day lives. It has been mentioned throughout this study, that endometriosis is a difficult health condition to diagnose despite the fact that almost one in ten women has the disease to a certain degree. Endometriosis may be a prevalent health condition, but it is not easy to find support groups in person. Without understanding friends and families, many of these women have no other choice but to look elsewhere for support. Some never manage to find a support system on their own, and as a result they are left to continue on with the inadequate resources they already possess. Endometriosis has the benefit of being an eleven year-old social blogging community with over a decade of posts by women who have or have been affected by endometriosis.

Fifty-five posts in a little over a year may not seem like a great deal of activity, but those posts examined in this study are only the public posts. There are just as many—if not more—posts made at the Endometriosis community that are only accessible by community members. If those journal entries were included, there would be well over one hundred posts within the same
time frame that this study covered. This is a valuable resource for women who have endometriosis, however, they are not the only ones who could benefit from examining the Endometriosis community further. Women’s healthcare providers, gynecologists, and other researchers may all benefit from gaining a better understanding of the community and its uses. For the most part, the women who use the Endometriosis community are not one-time users; they are members who return to the community whenever they need additional support, advice, or a virtual shoulder to lean on. By further studying this valuable resource, healthcare professionals could benefit from the wider collection of personal stories, descriptions of treatments, and the willingness to help others affected by this condition in general.
Chapter 5 – Summaries and Conclusions

Limitations of the Study

Though the research study conducted did present an accurate representation of how women who have or are affected by endometriosis are utilizing the social blogging site LiveJournal to communicate about the condition, the study did still have a few limitations worth noting. First and foremost, although there is more than a decade’s worth of data present in the archives of the Endometriosis community, this study only examined public posts made during a little over one year of that time frame. This means that there is a great deal of available, additional data that can also be coded and analyzed in the same manner as the data collected for this study.

An additional limitation of this study was that the focus was solely on the Endometriosis community. When conducting a search on LiveJournal, there are numerous other communities that turn up as having at least some mention of endometriosis. They are not all active communities—some exist solely as archives—and others are dedicated to broader subjects such as general women’s health issues. That is why the Endometriosis community was selected as the focus—it deals solely with endometriosis, and is still a very active community. However, focusing on just the one community meant that there is potentially a large amount of additional information present on LiveJournal that can also be analyzed.

Along those same lines, focusing solely on a LiveJournal community meant that all other social networking websites and blogging platforms were ignored over the course of this study. Twitter, Tumblr, Facebook, and other blog sites all yield a significant number of search results when searching for the term “endometriosis” on the websites. Even though there was a large amount of publicly available data present in the Endometriosis community on LiveJournal,
examining data from these other sites is still valuable, as it is possible that they represent a
different area of health communication and social blogging and may provide valuable insights.

Finally, the last limitation of the study stemmed from the method of data analysis used to
examine the data. The researcher analyzed the data only by conducting a content analysis. While
this did provide a great deal of insight into the ways in which women who have endometriosis
use the LiveJournal community to talk about the condition, and the data coding also determined a
number of gratifications that stemmed from the social blogging process, it is still possible that
there were gratifications that the research did not perceive. Conducting interviews or surveys
with the women who posted those blog posts may potentially reveal additional gratifications that
were missed by the coders of this study.

**Recommendations for Further Study**

Though this study focused solely on how women who have endometriosis utilize the
*Endometriosis* community on LiveJournal, it has wider implications for areas of further study.
This study showed that there is value in examining both how individuals use social blogging to
fulfill their communication needs and what gratifications they receive from the process of social
blogging. Social blogging can be more than just sharing details about the mundane aspects of
life—something that is commonly expected on the social micro-blogging platform Twitter—it
can be focused on raising awareness of a serious issue, uniting like-minded individuals, or just
providing a safe space for bloggers to express themselves.

Health blogging in particular is an area that is deserving of further study, as it is an area
of health communication that is becoming increasingly popular and convenient with the
emergence of modern technologies. Healthcare providers and those concerned with the evolution
of health communication are largely neglecting online health communication at present, even
though it is no longer a new medium of communication. This study focused on the Endometriosis community, which has proven itself to be a valuable resource for those who utilize it. However this is not the only area for health communication about endometriosis, and endometriosis sufferers are not the only individuals turning to the internet for additional information, assistance, or emotional support. Gaining a better understanding of online health communication will benefit the field of health communication, healthcare providers, and healthcare consumers. It is also worth noting that though there is no mainstream magazine or print journalism covering endometriosis-related health communication, it may be an avenue worth examining in future research endeavors.

**Conclusions**

The purpose of this study was to examine how women who have or are affected by the gynecological disorder endometriosis use the social blogging site LiveJournal as a means of communicating about the condition. The results of the study produced two important findings in particular. The first finding is that the women who post blog entries in the Endometriosis community do so in an effort to fulfill one or more communication needs. These needs are cognitive, personal integrative, affective, and social integrative needs. Each need represents a communication need that is unfulfilled in the individual’s life prior to posting in the community. The second finding is that in posting in Endometriosis and interacting with others who comment on the blog post the women benefited by both fulfilling their communication needs and receiving gratifications depending on their situation, initial blog post, and responses received. The gratifications that women blogging in the Endometriosis community received were a combination of: acknowledgment, help or advice, information, empathy, well wishes, emotional
support, validation, the benefit of a different perspective, catharsis, conversation with another person, sympathy, and appreciation.

Even though the communication process that occurs in the *Endometriosis* community is a simple one, the variety of gratifications is all due to the interaction between the different individuals. Martin Buber’s ethical approach of dialogic ethics places great value on the relationship that forms through dialogue. From Buber’s perspective, dialogue allows individuals to speak openly and honestly, and can develop a mutual understanding of a situation through self-disclosure (Buber, 1923/1958). In the LiveJournal community, the women shared their stories, experiences, and thoughts with one another openly, out of a desire to get help and form a connection with other people who understood the realities of living with endometriosis. Therefore, dialogic ethics represents a core ideal of health communication on social blogging websites. Complete strangers come together on sites like LiveJournal to form connections with people who also want to be open and speak about a shared interest or topic. It is that willingness to converse with one another that allows for so many gratifications to develop, and for the women who blog in *Endometriosis* to benefit from the experience.

Uses and Gratifications theory was developed on the basic premise that when people deliberately consume media, they do it to fulfill some sort of need or needs. The actual outcomes of that media consumption may or may not be anticipated, but they all stem from the media consumption. In this study, women posted in the LiveJournal community, received and read comments left by other members, and sometimes interacted with those members. In doing so, they received a number of different gratifications. Some were straightforward—information or advice in response to a question, empathy from an audience who understands, etc. The gratifications cannot always be predetermined, but as the data was analyzed, it became evident
that the communication process was not just a simple exchange of information. There was more value behind those interactions, and the resulting greater meaning translated into the variety of gratifications that the women received.

Endometriosis is a condition without a cure; for many of these bloggers, it is a condition they have been coping with for years. It is a condition that they do not fully understand, a condition they cannot predict, and a condition that they cannot handle on their own. The Endometriosis community provides these women with a wide base of firsthand knowledge, an archive of past blogs, and empathetic ears. The study showed that there is value to be found in examining how these women use social blogging to communicate about endometriosis, and it highlighted the benefits that they received from social blogging. The study can contribute to different fields of study, and can help guide future research towards further examining online health communication, and the benefits of social blogging.
References


http://digilib.unsri.ac.id/downla04.pdf


Appendix A

Mentor Agreement

You have been asked to serve as a Mentor for Beena Gohil, who is completing the requirements for her Master’s Degree in Communication and Leadership Studies. As a mentor you are asked to share ideas with this student and read the next to final draft of her thesis. You are not expected to directly supervise this student’s work but rather meet with her as a “young colleague.” If you are willing to serve as a Mentor for her, please sign this agreement.

I am willing to serve as a Mentor for Beena Gohil as she completes her thesis. I realize I do not need to supervise her work in any direct fashion and will only serve as a more experienced colleague with a younger colleague. I will provide help in the way of suggestions, ideas and resources and am willing to review drafts of her written work. I also agree to read the next to last draft of the student’s thesis and will sign my name on the title page of her final draft. My signature on the thesis only indicates that I have read it and is no indication of the quality of the work. I will not be asked to assign a grade or make any evaluative comments to the course convener.

Signature ____Dr. Crandall (electronic)__________________________

Title _______ Asst. Professor __________________________

Email and telephone number ____x6491___________________________

Date ____9/10/12________________________