

**Types of Support Offered by Online Message Boards for People  
Diagnosed with Genital Herpes**

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Sincerely,

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## **Abstract**

Genital herpes is one of the most common sexually transmitted diseases, with approximately forty-five million Americans infected with this virus. After being diagnosed with genital herpes, the physical and psychological implications of such a disease can be difficult to manage. This affliction is also associated with a stigma that makes it difficult for those with genital herpes to overcome. Because of the private nature of the Internet, many people seek this medium for herpes related information. Many may also turn to Internet message boards for information, connecting with others who are in the same situations as well as seeking forms of support.

Understanding why those diagnosed with genital herpes turn to Internet message boards can be helpful to health care providers in educating and counseling such patients. The following study was completed focusing on why individuals seek out support from Internet message boards, the types of support these online message boards offer, and the advantages and disadvantages of the Internet compared to other means of health care information. For the sample used in this study, the Internet was found to be a safe place where participants can go to for different types of support and information, as well as developing relationships.

## I. Introduction

For all sexually active individuals, genital herpes is a risk, and the numbers of those infected is rapidly growing. In the United States, genital herpes affects about forty-five million adults with about half a million infections each year (Marr, 1998, p. 201). According to studies conducted between the late 1970s to the 1990s, genital herpes infections have increased by 30 percent. At least 45 million people ages 12 and older have had a genital herpes infection in their lifetime, and about 70 percent of primary infections of genital herpes are caused by HSV-2, which is one of the two strains of the herpes virus (Marr, 1998). Because of the social stigma usually associated with genital herpes, managing this disease can be difficult, both on a physical and emotional level.

Those diagnosed with this virus seek out different outlets of acquiring information and support. Of these sources, the Internet has proven to be a popular outlet for those with genital herpes. Many sites offer professional or peer-to-peer support relating to symptoms, suggestions on how to discuss herpes with a new sexual partner, information on diseases and conditions, wellness centers, videos, online journals, as well as message boards and chat rooms. According to past research, Internet message boards have shown to be a primarily positive influence on individuals as a means of social support (Kalichman et al., 2003; Preece, 2000; Maloney-Krichmar & Preece, 2000; Suzuki & Calzo, 2004; Reeves, 2001; Horrigan et al., 2001).

Social networking sites and message boards have proved to be beneficial in emotional relief and social connections for those coping with illnesses or conditions

(Reeves, 2001). The message boards offer peer-to-peer support, which allows others with the same or similar conditions to discuss their problems. There is also a strong connection between the people replying in the forums. It is unlikely these people know each other outside of cyberspace and for this reason, there may be a greater level of comfort between members.

This study investigated “herpes related” message boards found on health support websites. This exploratory study was designed to begin to understand a specific community on the message boards that has not been studied. The main objectives of this study are to better understand the motivations of individuals who seek out support from Internet message boards for genital herpes, to study the types of support these online message boards offer, and to identify the advantages and disadvantages of the Internet compared to other means of health care information. The purpose of this study is to examine why people use Internet message boards for genital herpes information, thus helping to determine the best forms of education and counseling. This will assist health care providers in understanding these types of support online message boards offer that may not be found in the physical world. For the purpose of this study, “health care provider” refers to anyone who delivers health care to an individual, concerning physical and emotional needs. This may include physicians, nurses, and physician assistants, as well as social workers and therapists, etc.

The two main methods used in this study, non-participant observation and qualitative email surveys, were employed to investigate how people use Internet message boards for genital herpes information and support. A qualitative design is important to this study because it allows for understanding of peoples’ experiences

from their own perspectives. By using this approach, this ensures a holistic picture of the group being researched. Since a system's properties cannot be completely understood separate from one another, it is important to look at all aspects of the group as a whole.

Observations were made from three websites: webmd.com, healthboards.com, and a third independently run website which will remain anonymous for confidentiality issues. These websites were geared solely toward "herpes" related questions and concerns. Non-participant observation was conducted on the three message boards, and participation was not limited for the observations of the postings. All posts were considered regardless of topic, gender, or usernames. Since it was strictly observation without participation, the relationship between researcher and participant was as objective as possible.

Data collection consisted of 20 in-depth qualitative email surveys (see Appendix C for questions). In these surveys, topics included the motivations and benefits, sources of information, types of support (informational, emotional, direct support, etc.), and advantages and disadvantages of using these boards. The interviews were returned to the researcher by email.

While the physical implications of acquiring genital herpes may remain until a cure is found, there are ways to educate and counsel those living with genital herpes to deal more effectively with the psychological issues of this disease. There are benefits to understanding the types of support, motivations, and hardships that these individuals face to better manage their care. The following chapters will explain how this study sought to investigate these types of supports and motivations, as well as themes that were found. Chapter 2 focuses on previous literature in the field of social

networking sites, including the types of emotional supports and general treatment for genital herpes. Chapter 3 explains the methods utilized in this study, with a description of the results of those findings in Chapter 4. Subsequently, Chapter 5 discusses the results, how these results were applied to each research question, and how further research may contribute to what was found in the study.

## II. Literature Review

This study analyzed the types of supports found within genital herpes message boards. As such, it is helpful to review existing literature regarding the Internet as a support source for related concerns, and to operationalize the concepts involved. This review of relevant literature begins with the physical and psychological impact of genital herpes as well as the importance of education and counseling when faced with such a disease. Following will be the effectiveness of Internet message boards and the benefits and motivations for joining and participating in these online communities.

### *Physical Impact of Genital Herpes*

Herpes is one of the most common sexually transmitted diseases. At least 45 million people ages 12 and older have had a genital herpes infection in their lifetime, and from the late 1970s to the 1990s, the number of those infected has increased by 30 percent. This viral infection (caused by the *herpes simplex virus*, or HSV) has two types: herpes simplex 1 (HSV-1), which usually contributes to most infections around the mouth (where it causes cold sores) but can also be seen in the genital areas, and herpes simplex 2 (HSV-2), which causes most genital or anal infections. Symptoms of an HSV outbreak can be treated, but the infection cannot be cured (Marr, 1998).

For all sexually active individuals, genital herpes is a risk. In the past, it was thought that in order to transmit herpes, the infected person must have a noticeable sore, lesion, or symptom of an outbreak. Further research concluded that herpes could be transmitted when the infected person is not having an outbreak, which is known as “asymptomatic shedding”. Estimates suggest that 40 percent of people infected with genital herpes are symptom free with their first infection, and 20 percent of people

with genital herpes will never have an outbreak in their lifetime. For the other 80 percent, depending on the severity of the symptoms, most will never realize their symptoms are caused by genital herpes. For those who do have an initial occurrence, the person may experience blisters and ulcers in the genital or anal area, which may range from mild to extremely severe. They may also experience other symptoms which may vary from person to person, such as pain in the back of the leg, lymph node swelling, headache, back pain, stiff neck, sore throat, and sensitivity to the eyes to light, among others. Previous research has been unable to determine the specific cause and rate of recurrences. It is clear, however, that those newly infected with the virus have more shedding of the virus than those who have been infected for a longer period of time, and those who experience more symptomatic outbreaks tend to shed the virus more frequently during times without symptoms than those who have fewer outbreaks (Marr, 1998).

Because many of those with genital herpes are unable to determine when they are shedding the virus, it may be difficult to prevent transference. Genital and oral sex should be avoided when the individual is having a herpes outbreak, or has received the first symptoms of an outbreak. Condoms should be used, but do not necessarily protect a person from the virus because the virus may be shedding in an area not protected by the condom. Abstinence is another way to prevent the spread of herpes, but this must also include oral sex if a person is infected with HSV-1, because the virus may also be transmitted in this way as well (Marr, 1998).

## *Psychological Effects of Genital Herpes*

The primary outbreak of a genital herpes infection can be severe, and recurrent outbreaks may be without symptoms or short lived, depending on the person. Aside from the burden of these physical implications, the psychological effects may be even more challenging. Studies have shown that acquiring an STD, such as genital herpes, can result in varying levels of psychological and psychosexual morbidity.

Mindle & Marks (2005) reviewed several studies of people's responses to a genital herpes diagnosis and found that the emotional responses from these individuals ranged from depression, anger, distress, anguish, hostility toward the person believed to be the source of infection, as well as a decrease in self esteem. According to Alexander & Naisbett (2002), patients newly diagnosed with genital herpes often feel embarrassment, anxiety, anger, shock, guilt and depression. However, recent data on the psychological effects of such an illness has some limitations. It was first thought that stress and psychological effects caused recurrences of the infection. However, while it is true that higher stress levels and recurrences do appear simultaneously, this may instead suggest that it is the recurrences that cause the stress, and not the reverse (Mindle & Marks, 2005).

There are also factors that have been found to add to the psychological morbidity of a genital herpes patient. A study focused on the personal experiences of patients found that these factors include the site of the lesions, the number of reoccurrences, perceived lack of adequate treatment, press coverage (which is often inaccurate) and social stigma (Mindle & Marks, 2005).

Stigma is an important concept that affects both those uninfected and infected with genital herpes. “A 1982 *Time* magazine cover story was headlined, “Herpes: Today’s Scarlet H”- a title derived from Nathaniel Hawthorne’s novel *The Scarlet Letter*, in which scarlet A’s were sewn onto the clothing of adulterous Puritans to brand them as promiscuous.” (Marr, 1998, p. 200) This article is a good representation of the stigma that is often identified with having genital herpes. The article seemed to imply that if you are infected with herpes, you are promiscuous. Although this stigma is undeserved, it is still felt by many people diagnosed with genital herpes today (Marr, 1998).

According to Fortenberry (2004), stigma arises from three distinct sources: attitudes about sexual behavior, perceived contagiousness, and the treatment and curability of genital herpes. Stigma has been found to be caused by a sense of “personal responsibility” to one’s self, including one’s sexual behavior. Since sex is a personal choice, this can lead to social incrimination relating to the responsibility of the person choosing to have sex. In this case, sex is the cause of the stigmatized behavior and not the herpes itself (Fortenberry, 2004).

The perceived contagiousness of genital herpes is also a factor in herpes-related stigma (Fortenberry, 2004). The epidemiology of this disease is often poorly understood, and testing for herpes is generally not conducted unless specifically requested by a health care provider and many times not part of a routine STD screening. Most of the people that acquire HSV are unaware they are carrying the virus. A household national survey showed that less than 10 percent of those who tested positive for herpes knew they had the virus (Fleming et al., 1997). Since many

people do not have symptoms or are unaware they are infected with genital herpes, there is potential to spread the virus to sexual partners.

The treatability and curability of genital herpes also plays a factor in stigma-related behaviors, such as lack of proper treatment and inadequate information regarding treatment. Treatment may also be a factor in the disclosure of the disease to new partners. In a study conducted in the UK, it was found that participants who had access to proper treatment did not inform sex partners that they had herpes because they believed to have their condition “under control.” This shows that with or without proper treatment, stigma is a concept that can cause harm to those with genital herpes and may affect attitudes and actions relating to this condition (Fortenberry, 2004).

Fortenberry (2004) also found that deviance, shame, guilt, contamination, isolation and visibility are all components associated with stigma, some of which those with genital herpes may experience. Contamination is a concept found in the research of sexually transmitted diseases and refers to a sense of “dirtiness” or “being soiled.” People with genital herpes also often describe isolation from partners, potential partners, or friends and family members. For those dealing with genital herpes, this stigma may be a factor in the disclosure and comfort ability of those seeking information on the Internet, and could affect a person’s decision to seek care or disclose information about their condition (Fortenberry, 2004).

### ***Education and Counseling***

When faced with the challenges of such a disease, people may turn to different outlets of support. Those dealing with a genital herpes diagnosis may go through

psychological and social adjustment, and education and counseling is an important determinant in this adjustment period. Education efforts are essential in helping patients understand the emotional and social associations linked to a genital herpes diagnosis (Alexander and Naisbett, 2002).

Gilbert et al. (2001) found in a patient survey conducted by the American Social Health Association that the majority of patients stated that education and counseling were extremely important during the first six months of a genital herpes diagnosis. However, 23.4 percent of those recently diagnosed with genital herpes reported that no form of education or counseling was offered to them. Concerning the barriers to adequate education and counseling, more than half of the patients stated that embarrassment was a concern. A quarter considered time restraints or the ability to understand elements of their condition a concern. Others included providers offering “too little time” (the vast majority stating that their provider offered less than 11 minutes of education and counseling), “provider unsympathetic”, “provider not like me” as well as differences in the provider’s demographics compared to the patient. Patients also stated that health care providers typically reported on the clinical concerns of the diagnosis, rather than the emotional and psychological effects (Gilbert et al., 2001).

Concerning the patient’s own information seeking, 91.5 percent sought information aside from their provider. It was found that the highest percentage of patients, 53 percent, visited Internet websites for their own information. However, 95 percent stated that they would contact a trained health educator by phone or in person, if one were offered to them. This study focused primarily on what providers could do for genital herpes patients, but did not address the types of support that using Internet

message boards offer compared to support found outside of cyberspace (Gilbert et al., 2001).

Patients were also asked for suggestions on improving genital herpes education and counseling from health care providers. Some wanted more information (39) and resources (nine), as well as emotional support (nine) from their provider. Patients also expressed the need for health care providers to address issues of embarrassment and isolation, preventing transmission to partners, and non-judgmental communications with others (Gilbert et al., 2001).

It was found that patients were most satisfied with counseling they received on clinical topics, but dissatisfied with the emotional counseling and support, as well as the impact on sexual relationships. This study suggests further research focusing on the types of education and counseling best utilized by health care providers without unnecessarily burdening them, while at the same time meeting the needs of those coping with genital herpes (Gilbert et al., 2001).

Patrick et al. (2004), in their study of patient satisfaction for the care of genital herpes, asked participants to rate their satisfaction of the answers and attention they received regarding physical symptoms from health care providers, as well as social and emotional issues. For physical symptoms/treatment, 29 percent of participants were somewhat or very satisfied and 51 percent were somewhat or very dissatisfied. For social and emotional issues, 16 percent were somewhat or very satisfied and 63 percent were somewhat or very dissatisfied. Also 38 percent of participants found their physicians to be somewhat to very unsympathetic. Also, the amount of time provided by the health care provider at the time of diagnosis related to overall patient satisfaction. Other factors found to be related to patient satisfaction were the provision

of educational materials (such as web addresses, brochures, etc.) and receiving a prescription on the initial visit (Patrick et al., 2004). This study shows the importance of proper physical and psychosocial treatment at the time of diagnosis, as well as the dissatisfaction those with genital herpes may feel toward health care providers.

### ***Online Communities/Message Boards***

In the past few decades, the Internet has become widely accepted as a means of gathering information. People turn to it for interpersonal communication, consumer goods, and a multitude of services, including those of human services such as health care (Finn & Holden, 2000). Many times, an individual may not have the resources available to learn about their condition, talk to others in the same situation, and communicate with specialists concerning their condition. Lack of information can result in an increase in fear, anxiety and stress in the individual. Social support and the use of medical services seem to be important protective factors against stress (Haggerty, 1980). Health care websites offer such resources, while online communities of interest can also supply information and support.

Many websites offer information on specific diseases and conditions. Kalichman et al. (2003) found in their research of several studies that these sites can educate patients, motivate them to be involved in their own health care, and have access to treatment options and gain social support, as well as building coping strategies. Kalichman et al. (2003) surveyed HIV patients to study the health effects associated with the Internet. It was found that “health-related Internet use was associated with HIV disease knowledge, active coping, information-seeking coping,

and social support among persons who were using the Internet” (Kalichman et al. 2003, p.111). Those people more exposed to the Internet were better informed about HIV and reported greater use of social support and coping strategies. This also supports the notion of information- seeking coping, which states that those with serious medical conditions gain health benefits from information seeking as a coping style. The idea of “active coping” has been used as a way of dealing effectively with stress and refers to a problem solving strategy that involves taking responsibility for one’s life and doing what is necessary to deal with the situation, instead of denying or distancing themselves from the disease (MacArthur & MacArthur, 1998). Internet message boards are built on this kind of active behavior.

Interventions focusing on interactive computer technology, such as question and answer resources, health risks assessment, and personal stories and accounts from those with similar conditions have resulted in positive outcomes for those with health related problems. This research supports the idea that using the Internet for health related information can help people cope with illnesses and also allows for social support between members (Kalichman et al. 2003).

Within these health related websites, online message boards (commonly referred to as online forums) have become increasingly popular. These online communities have been described as people interacting in virtual environments. The characteristics may vary depending on the social interactions of the individuals and the policies that guide them, which may range from the focus of these groups to the size of the community, etc. (Preece et al., 2003). The various types of online groups may include a variety of topics; according to a study conducted by the Pew Internet

and American Life Project (2005), 28 percent of Internet users belonged to health-related groups.

Online communities are unique because most of the information on these sites is member-generated, as opposed to general websites where site administrators post the information. Online communities tend to focus on very specific topics, giving users opportunities to find communities directly related to their specific condition or concern (Horrigan et al., 2001).

Preece (2000) describes online communities using four concepts:

- 1) People who interact with one another socially
- 2) A shared purpose that all in the community shares
- 3) Policies that guide them
- 4) A computer system in which this is performed and supported

Although early online communities have existed since the 1970s and 1980s, the early 1990's has shown an increasingly large number of people have been using online self-help groups, such as online message boards, for health care information. They have reported that information, social support and empathy were all found by using these groups (Preece, 2000).

Online health communities can range from small groups of individuals focusing on a specific topic to large, commercial companies. Smaller sites, like the third website used in the study, are designed specifically for sexually transmitted diseases, with smaller groups focusing on individual conditions. At this site, members participate in a bulletin board where messages are posted and participants may interact and respond over a period of time. These online health communities help people to interact with others who are going through the same situations and

problems. Unlike static websites, where people can get information about certain diseases or conditions, online message boards allow users to communicate with others who have the same or similar concerns (Maloney-Krichmar & Preece, 2000).

### ***Benefits, motivations and Types of Support found in Online Message Boards***

Walther & Boyd (2002) found four primary benefits and/or reasons for using health related online communities that apply to this study:

- 1) Ability to access the community at any time/place
- 2) Management relating to expressiveness, stigma and obligations are improved by certain characteristics of online communities
- 3) Confidentiality (especially those of sensitive topics)
- 4) Potential stigma and honest behavior

People have found the Internet to be a valuable resource for sensitive topics. In research by Suzuki and Calzo (2004), which utilized a bulletin board on a popular health website to facilitate the discussion of adolescent health issues, results showed that the frequent posts and viewings of the posts reflected interests and concerns about changes in the adolescents physically, emotionally, and socially. Romantic relationships were the most common topic on the teen issues bulletin board, and sexual health was the most common topic on the sexuality bulletin board. Members found the board to be useful for these sensitive topics. (Suzuki & Calzo, 2004). During the course of the study, the bulletin boards proved to be a place for teens to go for emotional support, opinions, suggestions, and information.

Information exchange has been cited as the primary reason for those joining online communities (Ridings & Gefen, 2004; Reeves, 2001). Reeves (2001), found that HIV positive individuals use the Internet for “finding information, making social connections, advocating and escaping” and views social groups as a positive component of the Internet when dealing with health related concerns. All participants in this study said that finding information was the primary reason to use the Internet. Social support exchange is another; they made social connections in chat rooms and message boards with others that shared similar conditions. A participant described how one can “hook up with people that have gone through the same experiences, that *do* understand what you are talking about, and *have* been there” (Reeves, 2001, p. 713). This social support is found throughout message boards and may contribute to the individual motivations to join the sites. Studies have found that online communities offer a sense of belonging, emotional and social support, as well as encouragement from other members. Others include information and social support exchange, and recreation (Ridings & Gefen, 2004), as well as trust and empathy, group dynamics behavior, and the development of friendships (Preece et al., 2001).

A major reason people join virtual communities is for the development of friendships and personal relationships. Although many initially visit sites for information about a certain topic, such as genital herpes, friendships also may develop over time (Ridings & Gefen, 2004). The interactivity of message boards allows users to communicate directly with other users and may result in building and maintaining friendships.

Empathy may also be a contributing factor to the social support found in online communities. Preece and Ghazati (1997), in their exploration of 100 online

communities, explains empathy as “knowing what another person is feeling, feeling what another person is feeling, and responding compassionately to another person’s distress” (as cited in Levenson & Ruef, 1992, p. 234). Preece & Ghozati (1997) found that empathetic communication was present in 81 percent of the communities studied. Of these, empathy was strongest in the emotional support and patient communities. Past research on empathy shows that patients who are similar, or share common experiences or shared memories of previous events, seem to have more empathy for one another (Colvin et al., 1997). This could contribute to the motivations of those using Internet message boards for genital herpes support. Since many health communities are focused specifically on certain topics or conditions that everyone in the community shares, this could relate to a sense of empathy between members (Preece & Ghozati, 2001). This could also contribute to the types of supports desired by those turning to online environments for support.

### *Summary*

With the emergence of online communities and health care on the Internet, much is now available on the topic of genital herpes. For some, the psychological effects of a genital herpes diagnosis may be much more severe than the physical effects (Alexander & Naisbett, 2002). Recognizing the motivations of those people to visit the message boards and the types of support found within the boards may aid health care providers in understanding the needs of those with genital herpes and how to better treat these psychological issues. A deeper understanding of the motivations and supports gained will provide health care providers the tools to effectively deal

with the challenges of those affected by genital herpes. The following chapter focuses on the methods employed in this study to understand these motivations and supports.

### **III. Methodology**

#### ***Introduction***

The goal of this study is to better understand the types of supports gained from Internet message boards for people with genital herpes, thus, determining the best forms of education and counseling for health care providers. The following questions were asked to determine this:

- 1) What are the motivations of individuals who seek out support from Internet message boards for genital herpes?
- 2) What are the types of support these online message boards offer?
- 3) What are the advantages and disadvantages of these Internet message boards compared to other means of health care information?

#### ***Research Design***

This study employed a qualitative research design, which allowed for analysis and interpretation of the data from the perspectives of those using the message boards for genital herpes information (Charmaz, 2006). However, because this is an exploratory study, it does not go as in depth as most qualitative studies that use in-depth interviews and qualitative surveys do. Because of the characteristics of the

Internet as a medium and the lack of research in this specific area, an exploratory study was the logical choice.

The study utilized two instruments, non-participant observation of online message boards and qualitative in-depth surveys via email.

### ***Research Questions***

The first research question, “*What are the motivations of individuals who seek out support from Internet message boards for genital herpes?*” can best be found with qualitative research. Evaluating individual posts from the observations and responses from surveys can reveal the motivations of using the message boards that other methods might not. The second and third research questions, “*What are the types of support these online message boards offer?*” and “*What are the advantages and disadvantages of the Internet compared to other means of health care information?*” are best addressed with qualitative methods as well. To determine the advantages and disadvantages of the Internet with other forms of health care information, it is necessary to ask open-ended questions that allow for long, in depth responses. Using another method, such as a quantitative survey, would not allow participants to answer with thorough answers. The qualitative approach leaves the questions open for interpretation, and ultimately, more thoughtful responses.

## *Qualitative Research*

Creswell (1998) highlights several studies regarding the definition of qualitative research. In his findings, Denzin and Lincoln (1994) offered their perspective on what constitutes qualitative research:

Qualitative research is multimethod in focus, involving an interpretive, naturalistic approach to its subject matter. This means that qualitative researchers study things in their natural settings, attempting to make sense of or interpret phenomena in terms of the meanings people bring to them. Qualitative research involves the studied use and collection of a variety of empirical materials—case study, personal experience, introspective, life story, interview, observational, historical, interactional, and visual texts—that describe routine and problematic moments and meaning in individuals' lives (p.2)

This definition shows several elements to qualitative research found in the present study, such as the need for observational and interview-based methods. The methods used in this study, non-participant observation and qualitative email surveys, were then chosen for their qualitative nature. The interaction between members on the message boards is the natural research setting for members, and helps to define the context in which the phenomenon occurs. This contextual information is best addressed through observation of the message boards and is necessary to understand the research area (Professor Ruth Huard, class discussion, September 5<sup>th</sup>, 2006)

Acting as an outside observer helped to incorporate the members' own perspectives in the study. Because context is critical to qualitative research, observing the participants within their natural environment is essential. This made the results of the study more comprehensible by providing a baseline of meaning, as well as a way to reenter the field to explore the context for results that were unclear (Fetterman, 1998). Nosek et al. (2002), in their study of psychological research on the Internet stated, "Participant observation can yield rich data and is a method that can be beneficial to survey research." (p. 174)

Fetterman (1998) also explains how the most important element of fieldwork is being within the culture being studied: observing, asking questions, and documenting all that is seen or heard. According to Hoepfl (1997), qualitative methods can be used to gain new perspectives of research, or to gain more in depth information that is difficult to explain with quantitative methods.

After being exposed to the natural environment, qualitative email surveys were also needed to better address the research questions. According to Crabtree & Miller (1999), the goal of conducting interviews is "to seek deeper collective interpersonal understanding" (p. 101). Because of the nature of the Internet and lack of accessibility of participants in a face-to-face environment, to receive this deep understanding of the participants' world, email surveys were used as a form of interviews. These surveys focused on open-ended questions, such as "What is your overall impression of using the message board(s)?" (See Appendix C for the complete list of survey questions) These types of questions allow participants to interpret the question and respond with full, meaningful answers (Fetterman, 1998) that could not be found from observation alone. Using these approaches together, it is

possible to interpret the qualitative data and explain what was witnessed within the framework of the message boards.

The two remaining sections of this chapter explain these two methods in depth, while focusing on the qualitative aspects of each and the appropriateness for the study.

### ***Non-participant Observation***

Participant observation is an ethnographic approach that helps the role of researcher change from being a complete outsider to a complete insider (Creswell, 1998). However, non-participant observation, which was chosen for this study, involves observation at a distance, as opposed to active involvement with the group being studied. The significance of choosing this method relates to the significance of the context of the message boards to the participants being observed. Since the purpose of this study is to examine the interactions and activities within the message boards to give meaning to certain behaviors and responses from the participants, this method is a logical choice (Crabtree & Miller, 1998).

Specific advantages are gained by using this type of method. First, the members of the message boards are not aware they are being observed, and are less likely to alter their behavior. This also helps the researcher witness the “real” behavior and interactions within the boards. Also, rather than constructing questions in the form of a survey or interview, questions are asked between members in the language of the message board itself. Members respond freely and openly allowing for rich data. Moreover, the context is important to the interactions on the boards.

Rather than piecing together data from separate surveys or interviews, the sequence and connection of the data is witnessed in its natural setting (Crabtree & Miller, 1998).

### ***Procedures for Non-Participant Observation***

Non-participant observation was conducted prior to the research over a period of two months for the researcher's own interests, spanning across many sites and related links to the researchers' personal health concerns. After the specific topic was chosen for this study, more formal research was conducted over a two-week period on three websites, webmd.com, healthboards.com, and a third popular website which will not be identified for confidentiality purposes. These sites were chosen for this study because they are high traffic and well-respected websites, and were found to be user-friendly and easy to navigate.

Healthboards.com has over 300,000 registered members, and offers more than 150 different message boards focusing on different diseases, conditions, and health topics. Although WebMD.com is affiliated with healthboards.com, WebMD.com also has its own message board for genital herpes information and support that was also assessed. The third site was created by a woman who has genital herpes and has dedicated her website to those diagnosed or wanting to learn more about this disease. This site will not be identified because many of the participants that took part in the email surveys are involved in an "online mentoring program" on this site. Each individual involved in this program is listed by location, and members may reveal

personal information as well as photographs to the public. Keeping this site anonymous will reduce risk of exposure of these participants used in the study.

The observational population were members of the herpes related message boards, and those who posted specifically focusing on genital herpes infections (HSV-1 or HSV-2). At the beginning of this study, the three websites were observed roughly two hours a day. Posts were read and summarized directly from being observed on the boards, with important quotes transcribed directly into observational notes. All posts were then separated into categories of the three different websites. After observing the message boards for an extended period of time and developing an understanding of the relationships on the boards, the second method was then ready to be conducted.

### *Qualitative Email Surveys*

The second method of research was emailing qualitative email surveys to volunteers. Qualitative interviewing uses open-ended questions that allow for varying answers from participants (Hoepfl, 1997). Meho (2006), in his study of email interviewing in qualitative research, found that using email as an interviewing method allows for opportunities that may not be found outside of the Internet, such as access to those who would not otherwise be available in the physical world. Email interviewing is also explained as a reasonable method of research, especially when boundaries such as financial issues, time, and geographical complications are involved. According to Murray and Sixsmith (1998), interviews conducted via e-mail allow for better clarification of concepts, as well as a feeling of empowerment that

face-to-face interviews might not offer. Meho's (2006) exploration of several studies found that this feeling of empowerment is gained because participants are in better control of the flow of the interview, where interviewees may answer at a convenient time and location that is suitable to them. A clearer expression of thoughts and ideas may be manifested from the ability to revise and reflect on messages before sending them, as would otherwise not be possible in standard face-to-face interviews (Meho, 2006).

Because this study was conducted entirely online, qualitative interviewing will be referred to as qualitative email surveys. Although some participants were later contacted for further clarification of questions, the communication between researcher and participants was mostly asynchronous.

### ***Sampling Procedures for Email Survey Participants***

Participants for the email surveys were found by searching a member list on the third previously mentioned message board specifically geared toward herpes. The names on the list were those who had previously submitted a post on the herpes message board and would have been exposed to the qualifications of the study. Some of the members of the website had included an email address posted to the public, and were then contacted via email to participate in the study. Participation was limited to those individuals who were diagnosed with genital herpes (HSV-1 or HSV-2) and had been exposed to message boards relating to genital herpes. Some members contacted by email responded that they in fact, did not have genital herpes, but had come to the boards to ask a question regarding symptoms or other information. These members

were not included in the study. For the remaining respondents, all had been diagnosed with herpes and exposed to the message boards at one time or another, with varying durations of use. These members were thus asked to participate in the research.

For the other email addresses acquired for this research, email addresses were found through a program from the third popular website designed to give one-on-one support for those with herpes related concerns. All members had offered their service and email address to the public, and were contacted to participate in the survey. Thirteen of the participants came from this list of respondents. This program was convenient for acquiring such a sample, however, the researcher did not purposely choose people that were administrators or apt to help others for this study.

The other seven were selected from the email member list posted to the public. Potential respondents were then asked to participate via a short email outlining the scope of the project and their potential involvement (Appendix A). These sampling techniques are similar to those used in other research that used qualitative email surveys.

The survey (Appendix C) emailed to participants was developed from the researcher's own questions, and derived from past research as well as what was witnessed in the initial stage of observation on the boards. The final list of willing volunteers was emailed the survey (Appendix C) along with the informed consent form (Appendix B), and were advised that by typing their name at the end of the consent form, filling out the survey, and emailing it back to the researcher they were giving consent to have their responses used for the purpose of the study. The email also included a section for the participants to verify that they were at least 18 years of

age. While conducting interviews via email, confidentiality was guaranteed. No ID's, usernames, user-chosen pseudonyms, or identifying information were included in the research. Researcher-chosen pseudonyms were also used to protect the identity of the participants in the research discussions and publications (different than those pseudonyms the respondents may have used in their posts on the boards). All surveys and other research records were destroyed when the study was completed.

The final sample consisted of 20 participants, 3 males and 17 females, whose ages spanned from 19 to 61 years of age. Participants had been living with a genital herpes diagnosis from a range of 6 months to 15 years. Participants had also been using Internet message boards for genital herpes purposes for a range of 6 months to 10 years.

This list of questions was provided to the participants (Appendix C) via email. Data collection consisted of standardized open-ended qualitative surveys. According to Patton (2002), open-ended questions aim at obtaining the participants' experiences and perspectives from the point of view of the participants. The surveys thus contained open-ended questions to allow for rich data, focusing on the use of message boards for genital herpes information and support. The first five questions concerning age, location, gender, time of diagnosis, and the specific virus strain were asked to get a better understanding of the backgrounds of participants, as well as increase the comfort ability. Next were questions focused on what types of support found on the boards, as well as overall experiences using the message boards.

The questions that were aimed at answering the research questions specifically are as follows:

- Why do you visit these board(s)?
- Have you received emotional support from the boards? Please explain.
- Have you received informational support from the boards? Please explain.
- Have you used the message boards for direct support (to find face-to-face support in your community)? Please explain.
- What type(s) of support do you get online that you don't get from health service providers?

Participants were also asked to include “additional comments” as well as their “overall impression” of using the message boards. These open-ended nonjudgmental questions helped to ensure unanticipated responses and stories to emerge from the interviews (Charmaz, 2006). Nosek et al. (2002) explained that allowing participants to respond freely using open-ended questions provides information that preconfigured surveys and other methods might miss.

### ***Ethical and Privacy Issues***

In regards to human subject concerns for the email surveys, the researcher obtained approval from the University of Hawaii Institutional Review Board prior to the research. For the method of observation, the researcher had no access to demographics or personal information of any kind while observing, since the individuals were listed by screen name only. The sites themselves were anonymous

to protect the rights of the individuals. Each message board was composed of posts (or threads) written by members of the site. On all of the websites used for the purpose of this study, threads were posted in chronological order, and the sites allowed members to post to threads and start new threads. In order to access the sites, visitors registered to the boards with a username and password, and an email address for validation purposes.

Messages were posted to boards with specific health topics, and members had access to all messages as well as responses. All posts were considered regardless of topic, gender, or usernames. Since it was strictly observation without participation, the relationship between researcher and participant was objective. Observations were made from the three websites, which were geared solely toward “herpes” related questions and concerns.

### *Coding the Data*

Since this was an exploratory study, the researcher did not adopt one format for coding. Instead, past research was examined for certain styles of coding, such as Charmaz’ (2006) word-by-word, line-by-line, and incident-by-incident coding. The line-by-line coding seemed to apply to this study, categorizing each line of text into certain themes. Because the study was conducted online and all of the data was text-based, this was an appropriate way to look at the results and to remain open to what was found in the responses (Charmaz, 2006). Categories for coding were developed through the process of coding and observation, and what appeared from these two methods as well as previous research.

The data was then organized by taking what was learned from past research and information from other students about different ways to code data. Each concept of information from the observations were read and explained with a statement relating to what was found in the post, for example:

- (Grape8) asked a lot of questions because he's newly diagnosed. He asked if he can transmit genital herpes HSV 2 to his partner with oral sex. (fish78) wrote back and suggested he get blood work because it was a visual diagnosis only. (fish78) also said "This is a very common virus with a bad rap!" *Grape8 was looking for informational support.... received informational support. Also lack of knowledge of health care providers. Stigma.*

After exploring each post, the relationship between the concepts was then explored, such as those posts that were motivations as well as benefits. For example, a member may have come to the site with emotional support as motivation, or they may have found after being exposed to the site that emotional support was a benefit, or both.

After receiving the surveys, each individual survey was printed as a hard copy, and the data was broken down into different components as well. In order to analyze the data most effectively, triangulation was used to cross-examine observations and surveys with one another, while still focusing on the relationships between the concepts found in the data. Each survey was examined using highlighters to color-code the different themes, such as *empathy*, *friendships*, and *emotional support*, etc. Doing this, patterns continued to emerge and support previous themes. These themes were then transferred to a more comprehensive list of themes. This created a more thorough understanding of the data and an analytic framework to explain this.

The main themes that emerged during the coding of the responses are presented at the beginning of the next chapter. Following this is a presentation of the results from the two research instruments used.

## IV. Results

This chapter presents the raw data results of the two research instruments used in this study, observations and email surveys.

### Observations

To code the data within the observations, each observation was first summarized and split into categories incident by incident. Many themes that had appeared in the literature review were also seen while coding, such as empathy and friendships. These themes were then developed into categories, entitled *emotional support, informational support, friendships, empathy (or feeling “not alone”), privacy of information online, reliability and lack of knowledge/information from health care providers, stigma, and telling new partners*. After coding the data, different patterns were found within and between the two methods, as well as supporting past literature.

Following are the observations in raw data form accompanied by initial coding of the data. These observations were found on webmd.com, healthboards.com and a third independently managed website. Pseudonyms were used to protect the identity of members.

## Observations into Categories

### *Emotional Support*

Past research has found emotional support to be a common element among Internet message boards (Reeves, 2001). This was a pattern that also developed out of the observations. Aspects of emotional support were seen in many of the posts on the sites, relating to emotional aspects of the disease and advice. Certain posts specifically focused on the advice and support gained from using the boards, and how people *felt* about living with this disease. This started the “emotional” category and posts that contained such messages were labeled as a form of emotional support.

Summaries of the posts are as follows:

- (Move3) explained that she was diagnosed with herpes and devastated. She said that she finally met someone that she likes and needs to tell him but doesn't know how. She asked what's the best way to tell him, and how to present it. She also asks if there's a good website to go to get herpes information. (Rainbow8) consoles her and gives her advice and suggests she go to a search engine because on the site he cannot post commercial sites on healthboards.com.
- (Key89) was newly diagnosed and is "totally destroyed". (Rainbow8) tells her that 1 in every 100 people have one form or another. (Key89) wrote back and said she just found out that her best friend has it too! And thanks Rainbow8 for the reply.
- (Purple5) is "ashamed" because she is experiencing a breakout and doesn't want to tell her parents because she is only 17. (Light6) suggests seeing a doctor, or try to talk to parents about it, or to try Planned Parenthood.
- (Sky12) said “First let me just say, surprisingly I'm handling my diagnosis rather well...compared to when I first found this wonderful group of people! So thank you...the support and words of wisdom have helped tremendously!” Also conveyed that she is very confused and frustrated regarding different tests.
- (Stripe7) "I've only just got it and I'm a bit scared"... She just got herpes and is worried about passing it on.

- (Sky12) says "Some of the people here seem to be a tremendous source of strength, support and guidance."
- (Let66) says that she had sex a little over 24 hours ago and then her partner said he had herpes. She wants to know the chances of transmission because he said 1 in a 1000. (Page44) said that he's lying to her, (Sky12) says, "He indeed was not honest with you...though he may not even realize it himself. It seems so many Dr.'s say one thing against what you may have heard or have been told by another." "If you need a good group of people for support and such, this is a good place to be.... or so I've found it anyway....."
- (Yellow0) says "Hey guys, Thanks for all the help in the past" and was diagnosed with herpes last week and wondering about info. (Uni8) says, "The real problem with herpes is the stigma attached." She explains that there are a lot worse things than having herpes and many people have it their whole lives and have no clue. (Haven8) says she is
- (Bead2) said that she is newly divorced and terrified of telling new partners down the road. (Road7) talks about how they found their soul mate and it was not a big deal to them.  
in the same dilemma. (Cass9) wishing you strength to find the courage and the right words to tell your new partner and I hope we will hear good news from you soon.
- (Planet6) says "Hello everyone...I've just came across this board today, and thought maybe I'd give it a try. Everyone seems to be very helpful, and I really don't know where else to turn...." (Rock7) says that they've had it for 20 years and forgets she has it sometimes- and things get better with time. (Planet6) writes it's nice to hear from others, makes me feel less alone..."
- (Pip87) says she is newly diagnosed. (Road7) says "Sorry you have to go through this. Yeah, it's amazing that there is so little info out there on herpes" and gives her advice.
- (Space44-male) explains that she is newly diagnosed and wants to know how this is going to affect her. She says "I'd be nice to hear how everyone how everyone else felt now and then". (Overit22-female) says, "I will keep posting until it gets better. It's been 9 months and I told my first boyfriend since the dx. He left. Reading the posts, it will get better." (Feather1-female) says, "It's been a very rough month and the only thing that makes me feel a little better is reading everything I can on Hsv."
- (Monet3-female) talks about how she told her boyfriend about having herpes, and when they broke up, he told everyone about it. (Angel6-female) says she is sorry she had to go through that. (Monet3) says "thanks again for your responses, I don't talk about this to anyone and it's nice to have an outlet."
- (Olson0) expresses how lonely and depressed she feels after being raped and contracting herpes. (Wizard7) expresses sympathy and says that she took the first step in dealing with it, coming to the board and sharing her story. (Olson0) says "I

just wanted to thank you for taking the time to post a reply, it did make me feel better.” (Nich9) says “Listen... you always have friends here you can come to talk to.” (Olson0) says “Hi guys!! First of all, thank you so much for all of the support. Really, its so much more than I expected and it means so much to me.” and “From the bottom of my heart, thanks for all of the support! Although I still do not have the courage to tell anyone I know about what happened, I have been feeling better the last couple of days and I feel like maybe this isn’t the end of the world and I’ll survive...”

- (Rock4) was diagnosed with HSV-1 and needs information. (Nich9) gives a link to a website and answers his questions. (Rock4) says “This site is really an amazing thing, you guys are doing a great job by allowing us to get answers and know that others are going through the same things. It really shocked me to hear it earlier today, but now I’m feeling a lot better.”

### ***Informational Support***

Informational support has also been found to be an important benefit from using message boards. This type of support was first witnessed in the literature, which found informational support to be the primary reason for using the boards (Reeves, 2001; Ridings & Gefen, 2004). It was also found while observing the message boards and coding the data. Certain posts contained information on HSV and questions concerning initial outbreaks and symptoms, etc. This started the “informational” category and all posts related to this topic were labeled as such. This informational support was the most common type of support found; most members came to the boards initially for informational purposes. Summaries of the posts are as follows:

- (Red3) claimed that he tested for the virus but it came back negative, but he's still having symptoms. (Color2) said it took 3 tests and 6 months to finally be tested positive.

- (Blue6) asked if it's possible to transmit herpes from a razor on the face to the genital area. (Green4) said it's unlikely, but possible.

- (Star2) asked what it would look like after a genital outbreak has passed. (Rainbow8) said that there will be no symptoms and look normal.

- (Got6) asked if it's possible to transmit herpes when there weren't any symptoms. (Rainbow8) said that yes, it is. (Sky12) suggested getting tested for herpes before jumping to conclusions.
- (Move3) explained that she was diagnosed with herpes and devastated. She said that she finally met someone that she likes and needs to tell him but doesn't know how. She asked what's the best way to tell him, and how to present it. She also asks if there's a good website to go to get herpes information. (Rainbow8) consoles her and gives her advice and suggests she go to a search engine because on the site he cannot post commercial sites on healthboards.com.
- (Key89) was newly diagnosed and is "totally destroyed". (Rainbow8) tells her that 1 in every 5 people have one form or another. (Key89) wrote back and said she just found out that her best friend has it too! And thanks Rainbow8 for the reply.
- (Face13) says "I had no idea how common this was until I came to this board and read more information on the web".
- (Dark9) wrote "hey all, been reading this board lately because new gf informed me she has hsv2".
- (Tree2) only has lesion on leg, and wants to know what this means. (Rainbow8) says that it is still transmittable.
- (Shine2) asked about HSV2 and how it can be prevented (condoms, abstinence). (Farr78) tells her there is no cure, and it can be transmitted whether they have an outbreak or not.
- (Grape8) asked a lot of questions because he's newly diagnosed. He asked if he could transmit genital herpes HSV 2 to his partner with oral sex. (Fish78) wrote back and suggested he get blood work because it was a visual diagnosis only. (Fish78) also said "This is a very common virus with a bad rap!"
- (Let66) says that she had sex a little over 24 hours ago and then her partner said he had herpes. She wants to know the chances of transmission because he said 1 in a 1000. (Page44) said that he's lying to her, (Sky12) says "He indeed was not honest with you...though he may not even realize it himself. It seems so many Dr.'s say one thing against what you may have heard or have been told by another "If you need a good group of people for support and such, this is a good place to be....or so I've found it anyway....."
- (Yellow0) says "Hey guys, Thanks for all the help in the past" and was diagnosed with herpes last week and wondering about info. (Uni8) says, "The real problem with herpes is the stigma attached." She explains that there are a lot worse things than having herpes and many people have it their whole lives and have no clue.
- (Blue42) performed oral sex on a girl and then she told him that she has herpes. (Center8) says that he just should go get tested.

- (Orange9) discusses chances of transmission. She had sex with a partner who has genital herpes. (Rainbow8) says there's always a chance, and abstinence is best.
- (Speak8) was just newly diagnosed with herpes and is pregnant. She asks questions regarding the virus. (Maroon7) tells her that there are two types of herpes- HSV 1 and HSV 2. (Speak8) had no idea there were two types because her doctor never specified.
- (Court3-male) asks why herpes is not included in standard STD tests. (Viox5-senior veteran) says, "I read online yesterday that 50% of college students are infected with this virus." And doesn't know why doctors don't test for it.
- (Care98- male) says that he had his first outbreak and it was minor- wants opinions from others. (Femme-female) explains her story.
- (Artesian9-female senior member) asks if there are special physicians to treat herpes. (Apple9-female) suggests an Applied Kinesiologist for alternative medicine care.
- (Follow8-male) wants to know how fast a herpes sore can develop. (Ocean9-male) gives him the information and suggests he see a doctor.
- (Unit0) wants to know how well Valtrex works for outbreaks. (Bin9) says that the worst part is over and Valtrex will help.
- (pipi3) is scared and feels she may have herpes from her symptoms. (Mellow4) says not to get too upset without seeing a doctor first.
- (Hold4) says she is scared and needs information. She gave oral sex to her partner and now notices a sore. (Unit0) says the same thing happened to her and it was herpes. (Feelinblue80) agrees that her partner is at risk.
- (Faith9) needs advice about a sore she found. She says, "I have never par-taken in sexual intercourse. However when i was young i was subjected to something by a crowd of bullies, orally. But not with another person. As you can imagine it isn't something I would like to bring up with anyone face to face what happened to me. But in the Internet I am faceless". (Just9) suggests seeing a doctor. (Mellow4) says she thinks she doesn't have anything to worry about, but suggests seeing a doctor just in case.
- (Bot8) worries that his symptoms are genital herpes. (Just9) says to wait for the test results before worrying so much.
- (Only1) was just diagnosed with herpes, but is confused because she's only been with one man, her husband. (Nich9) says it is impossible to tell who gave it to who, and she should get tested to find out which form of herpes she has.

- (Hapin7) does not have herpes but is inquiring about a girl he just started seeing who has it. (Wizard7) answers his questions regarding transmission and suggests getting tested himself.
- (Rock4) was diagnosed with HSV-1 and needs information. (Nich9) gives a link to a website and answers his questions. (Rock4) says “This site is really an amazing thing, you guys are doing a great job by allowing us to get answers and know that others are going through the same things. It really shocked me to hear it earlier today, but now I’m feeling a lot better”
- (Nell5) is scared that she may have herpes, because she has been sleeping around. She was tested 6 months ago and it came back negative. (Mellow4) suggests getting tested again because herpes is not tested for in a standard STD screening.

### ***Friendships***

The idea of friendships emerging from communication within message boards was first witnessed in the literature, but became apparent while observing the boards as well. One post specifically expressed the development of friendships found on the message boards, and was labeled as such.

- (Olson0) expresses how lonely and depressed she feels after being raped and contracting herpes. (Wizard7) expresses sympathy and says that she took the first step in dealing with it, coming to the board and sharing her story. (Olson0) says “I just wanted to thank you for taking the time to post a reply, it did make me feel better.” (Nich9) says “Listen... you always have friends here you can come to talk to.” (Olson0) says “Hi guys!! First of all, thank you so much for all of the support. Really, its so much more than I expected and it means so much to me.” and “From the bottom of my heart, thanks for all of the support! Although I still do not have the courage to tell anyone I know about what happened, I have been feeling better the last couple of days and I feel like maybe this isn’t the end of the world and I’ll survive...”

### ***Feeling “Not Alone” or Empathy***

The concept of empathy or the feeling of being “not alone” was seen in some of the observations on the boards. This concept was mentioned in the literature, but also became clear in the observations. The desire for empathy manifested itself in

several ways, such as the need to feel “not alone” or to feel understood by others. The category of “empathy” was then created and any posts that contained this feeling of understanding from others were placed there.

- (Face13) says, "I had no idea how common this was until I came to this board and read more information on the web".

- (Space44-male) explains that she is newly diagnosed and wants to know how this is going to affect her. She says “I’d be nice to hear how everyone how everyone else felt now and then”. (Overit22-female) says, “I will keep posting until it gets better. It's been 9 months and I told my first boyfriend since the dx. He left. Reading the posts, it will get better.” (Feather1-female) says, “it's been a very rough month and the only thing that makes me feel a little better is reading everything I can on Hsv.”

- (Rock4) was diagnosed with HSV-1 and needs information. (Nich9) gives a link to a website and answers his questions. (Rock4) says “This site is really an amazing thing, you guys are doing a great job by allowing us to get answers and know that others are going through the same things. It really shocked me to hear it earlier today, but now I'm feeling a lot better”

- (Dixie2) is waiting for her tests results and is in extreme pain. She asks for advice from others. (Nich9) says that it sounds similar to his first experience (Wizard7) recommends a Herpes Handbook online. (Dixie2) says it's nice to know that she's not alone on this.

- (Overit22-female) asks how to tell future partners she has herpes. She explains how she told her a guy after 6 weeks and he left. (Monet3-female) says Maybe try an H dating website when you are ready. I haven't met the "one" that way yet but I have met some people I can talk to. They know exactly what you have been through and won't judge and make you feel worthless.” (Femme-female) says, “your boyfriend is scum”.

- (Lotus9) has questions about breakouts with HSV-1. (Jayb7) says, “I would love to hear from others who have genital HVS-1 so that I can have some actual stories, not just test studies and medical info.“

### ***Privacy of Information Online***

The private nature of the Internet has been found to be an important factor when relating to Internet message boards, especially when relating to sensitive

information (Suzuki and Calzo, 2004). This category was also witnessed in some of the observational posts, relating to issues of the privacy and accuracy of information online and the confidentiality of the Internet as a form of support.

- (Purple5) is "ashamed" because she is experiencing a breakout and doesn't want to tell her parents because she is only 17. (Light6) suggests seeing a doctor, or try to talk to parents about it, or to try Planned Parenthood.
- (Monet3-female) talks about how she told her boyfriend about having herpes, and when they broke up, he told everyone about it. (Angel6-female) says she is sorry she had to go through that. (Monet3) says "thanks again for your responses, I don't talk about this to anyone and it's nice to have an outlet."
- (Faith9) needs advice about a sore she found. She says, "I have never par-taken in sexual intercourse. However when I was young I was subjected to something by a crowd of bullies, orally. But not with another person. As you can imagine it isn't something I would like to bring up with anyone face to face what happened to me. But in the Internet I am faceless". (Just9) suggests seeing a doctor. (Mellow4) says she thinks she doesn't have anything to worry about, but suggests seeing a doctor just in case.

### ***Reliability and Lack of Knowledge/Information from Health Care Providers***

The reliability and lack of knowledge from health care providers was also witnessed in the posts. Some also concerned the reputation of health care providers. Some members spoke of the treatment from health care providers and this expressed concern. This category was seen in past literature regarding the dissatisfaction toward health care providers, and was witnessed in the observations as well. Any posts containing the negative treatment of health care providers (emotional or informative) were placed into this category.

- (Grape8) asked a lot of questions because he's newly diagnosed. He asked if he can transmit genital herpes HSV 2 to his partner with oral sex. (Fish78) wrote back

and suggested he get blood work because it was a visual diagnosis only. (Fish78) also said "This is a very common virus with a bad rap!"

- (Let66) says that she had sex a little over 24 hours ago and then her partner said he had herpes. She wants to know the chances of transmission because he said 1 in a 1000. (Page44) said that he's lying to her, (Sky12) says, "He indeed was not honest with you...though he may not even realize it himself. It seems so many Dr.'s say one thing against what you may have heard or have been told by another."  
"If you need a good group of people for support and such, this is a good place to be....or so I've found it anyway....."

- (Mar8) believes he may have herpes. (Bird2) says, "The first thing that I have to say is that the medical community is SO uneducated about herpes and I have no idea why this is". She recommends taking care of himself physically and emotionally, avoid stress and eat right.

- (Speak8) was just newly diagnosed with herpes and is pregnant. She asks questions regarding the virus. (Maroon7) tells her that there are two types of herpes- HSV 1 and HSV 2. (Speak8) had no idea there were two types because her doctor never specified.

- (Near7) said she developed a different kind of outbreak and she called her doctor and he was completely insensitive about it. No one replied.

- (Pip87) says she is newly diagnosed. (Road7) says "Sorry you have to go through this. Yeah, it's amazing that there is so little info out there on herpes" and gives her advice.

- (Court3-male) asks why herpes is not included in standard STD tests. (Viox5-senior veteran) says, "I read online yesterday that 50% of college students are infected with this virus." And doesn't know why doctors don't test for it.

### *Stigma*

Since stigma is a concept related to the comfort ability and disclosure of those with genital herpes (Fortenberry, 2004), it was an important concept to be aware of while observing. It was not surprising then, that stigma was found throughout the message boards in the following posts, relating to judgment and disgrace from others unfamiliar with genital herpes.

- (Grape8) asked a lot of questions because he's newly diagnosed. He asked if he could transmit genital herpes HSV 2 to his partner with oral sex. (Fish78) wrote back and suggested he get blood work because it was a visual diagnosis only. (Fish78) also said "This is a very common virus with a bad rap!"
- (Yellow0) says "Hey guys, Thanks for all the help in the past" and was diagnosed with herpes last week and wondering about info. (Uni8) says, the real problem with herpes is the stigma attached. She explains that there are a lot worse things than having herpes and many people have it their whole lives and have no clue.
- (Faith9) needs advice about a sore she found. She says, "I have never par-taken in sexual intercourse. However when I was young a crowd of bullies subjected me to something, orally. But not with another person. As you can imagine it isn't something I would like to bring up with anyone face to face what happened to me. But in the Internet I am faceless". (Just9) suggests seeing a doctor. (Mellow4) says she thinks she doesn't have anything to worry about, but suggests seeing a doctor just in case.
- (Overit22-female) asks how to tell future partners she has herpes. She explains how she told her a guy after 6 weeks and he left. (Monet3-female) says Maybe try an H dating website when you are ready. I haven't met the "one" that way yet but I have met some people I can talk to. They know exactly what you have been through and won't judge and make you feel worthless." (Femme-female) says, "your boyfriend is scum".

### ***Telling New Partners***

How to tell new partners about their condition was a common concern for some of those visiting the boards. Some members seemed to come to the boards for advice on how to tell potential sexual partners about their condition. This concept was not expected from the review of literature but was witnessed in some observations.

- (Move3) explained that she was diagnosed with herpes and devastated. She said that she finally met someone that she likes and needs to tell him but doesn't know how. She asked what's the best way to tell him, and how to present it. She also asks if there's a good website to go to get herpes information. (Rainbow8) consoles her and gives her advice and suggests she go to a search engine because on the site he cannot post commercial sites on healthboards.com.

- (Rainbow8) asks about other people's experiences with telling new partners they have herpes. He believes that men are more accepting from experience. (Bow199) agrees.
- (Heart55) talks about telling a new partner. Asks for thoughts on where and when to tell people.
- (Fly2) just found out she has herpes, and doesn't know how to tell her boyfriend, and doesn't know if she should. (Push3) recommends telling her boyfriend immediately.
- (Bead2) said that she is newly divorced and terrified of telling new partners down the road. (Road7) talks about how they found their soul mate and it was not a big deal to them. (Haven8) says she is in the same dilemma. (Cass9) wishing you strength to find the courage and the right words to tell your new partner and I hope we will hear good news from you soon.
- (Overit22-female) asks how to tell future partners she has herpes. She explains how she told her a guy after 6 weeks and he left. (Monet3-female) says Maybe try an H dating website when you are ready. I haven't met the "one" that way yet but I have met some people I can talk to. They know exactly what you have been through and won't judge and make you feel worthless." (Femme-female) says "your boyfriend is scum".

### Email Surveys

After receiving the initial observations, email surveys were conducted to better explore the research questions and themes found within the observations. To begin coding the email surveys, statements were compared within the same survey as well as with other surveys to find similarities and differences. Many themes emerged from the data. The different categories included:

- *Types of support (emotional, informational, direct, face-to-face)*
- *Motivations and/or benefits (including friendships, empathy, helping others, and anonymity, privacy and convenience of Internet)*
- *Source of information/support*

- *Reliability, lack of information, or treatment from health care providers*
- *Other important factors (stigma or judgment, telling new partners and sexual relationships, how long participants participated in boards following diagnosis or initial outbreak)*

### ***Participants***

To develop a better understanding of the survey participants used in the study, a short biography of each participant is provided below. Pseudonyms were used to protect the identity of survey participants.

**Adeline**- 33-year-old female residing in Texas, using the message boards since March 2004.

**Emily**- 28-year-old female from Canada, using the message boards a couple months after initial outbreak.

**Laurie**- 25-year-old female from Texas, using the message boards for 5-6 years.

**Alex**- 29-year-old male from Vermont, using the message boards since August of 2005.

**Jarrold**- 24-year-old male residing in Florida, using the message boards for about 6 months.

**Andrea**- 19-year-old female from New York, using the message boards since about a year.

**Tara**- 35-year-old female residing in North Carolina, using the message boards for about a year.

**Melissa**- 46-year-old female from Australia, using the message boards for about five years.

**Deborah**- 36-year-old female from Canada, using the message boards since September 2006.

**Rebecca**- 37-year-old female from Texas, using the message boards since 1997.

**Theresa**- 23-year-old female from New York, using the message boards for about a year.

**Violet**- 53-year-old female residing in Nebraska, using the message boards for one year.

**Shannon**- 21-year-old female from Pennsylvania, using the message boards for about 7-8 months.

**John**- 61-year-old male from Illinois, using the message boards since 1998.

**Kelly**- 22-year-old female from Pennsylvania, using the message boards since September, 2006.

**Bianca**- 23-year-old-female residing in Washington D.C., using the message boards since diagnosis at age 19.

**Gabrielle**- 45-year-old female from Michigan, using the message boards for five years.

**Holly**- 41-year-old female from Canada, using the message boards about a year.

**Sonja**- 39 year old female residing in Oklahoma, doesn't participate in the message boards very often.

**Cathy**- 26-year-old female from Pennsylvania, using the message boards for one year.

### ***Emotional support***

This question was asked in the surveys to touch on the emotional support found in the message boards: "*Have you received emotional support from the boards? Please explain.*" Other questions in the surveys also disclosed a response containing emotional support and are listed below. Eighteen out of 20 participants expressed that they received some form of emotional support by using the message boards, although many commented more than once regarding the emotional support found.

### Adeline

- “Helps you heal emotionally just by being there”
- *Have you received emotional support?* “It is because of the boards I am still alive. The night I posted at PUP, it was my final straw. I was reaching out and had no where else to turn I needed to hear from those who were like me, not someone who was ‘clean’.”
- “Message boards are good for emotional support.”

### Emily

- “I found everyone, the administrators and other members, were all extremely supportive. It didn’t matter how foolish your questions were, no embarrassment, or whether they had been asked and answered two billion times previously- someone took you and your concerns seriously and personally answered promptly. Thus, it felt to me like a safe-haven.”
- “Family like feeling of the site”
- “There is a great deal of- relief? Catharsis? In purging your frustrations, emotions, fears, sadness, anger and thoughts by writing them down/discussing them. Somehow releasing all the negativity truly helps.”
- *Have you received emotional support?* “When I was coming to terms with the disease I went through a number of emotional phases –disbelief, depression, frustration, low self esteem/feeling like damaged goods, anger and finally acceptance board – and it allowed me to vent I received a lot of support, understanding, positive energy from the board”.

### Laurie

- “They were great when I discovered I was pregnant and they could help me with the fear.”
- *Have you received emotional support?* “Very much so. They have been there from getting married to having a child. If you’re having a bad day or even if you’re having an outbreak, they are there to comfort you and they may have an idea for you to get more comfort.”

### Alex

- *What are the benefits?* “Emotional support.”
- *Have you received emotional support?* “In the beginning I did, I was confused and not sure why this happened to me.”

- *What type of support do you get online that you don't get from health providers?* “Emotional support.”

### **Jarrold**

- “They are a great place for people to share their experiences whether they are mental or just physical reactions.”
- *Have you received emotional support?* “Yes, it was just a relief to know that I was on the right track and helps reaffirm what I had been trying to do.”
- “When I first learned I had herpes the boards would have been a huge emotional support, I don't know if I would have used them then but I would have taken great comfort in the fact that other people have the same troubles and worries that comes with the virus.”

### **Andrea**

- *Have you received emotional support?* “Yes, when I first came to the site, I saw many people asking questions and didn't see too many go into depth about “what happened”. So I decided to tell my WHOLE story. And from that everyone gave me support and nice comments.”

### **Tara**

- *Why do you visit these boards?* “At first, I visited b/c I needed some emotional support from people who had herpes and HPV.”
- *Have you received emotional support?* “Yes. At times, I needed advice on how to handle situations with new boyfriends.”
- “Sometimes I have bad days and need some support and someone to remind me that all people won't be idiots about my herpes or that I can get through telling someone about my herpes and HPV.”

### **Melissa**

- “The owner of the group and the members were wonderfully supportive when I first joined.”
- “Seeing people actively support each other was wonderfully reassuring.”
- “If you need some emotional support all you need to do is post how you are feeling and people will offer sympathy, encouragement and advice.”
- *Have you received emotional support?* “Yes, I have. In the early stages when I was still struggling emotionally with the ‘relationship’ issues, people were encouraging.”

### **Deborah**

- *Have you received emotional support?* “I have because just reading and posting makes you feel better. Your questions are answered.”
- “I get more personal and emotional support from the boards.” (than informational)

### **Rebecca**

- “Message boards are GREAT therapy!”
- *Have you received emotional support?* “Absolutely! Being able to share my story and communicate with others was extremely beneficial in helping me to get over my herpes diagnosis.”

### **Theresa**

- “The group as a whole is very supportive.”
- “Honestly these groups were the only thing that kept me going on some days, and kept me sane. I realized I can be angry and depressed...but it’s still not going to change the fact that I have herpes.”
- “They are my saving grace.”

### **Violet**

- *Have you received emotional support?* “Yes, I have one person I talk to from time to time, and we have bearded our souls to each other...”
- “The people are very supportive, and they are there to help you understand what you are going through and what to expect...”

### **Shannon**

- *Have you received emotional support?* “I have received emotional support through people I’ve met on these boards. A person I was already talking to online and through text messages.”
- *What type of support do you get online that you don’t get from health providers?* “Able to talk about the feelings associated with being diagnosed. Fears, concerns, etc.”

### **John**

- *Have you received emotional support?* “Absolutely. I also got good advice about dealing with some of the emotional aspects as well...”

- *What type of support do you get online that you don't get from health care providers?* “Emotional peer support.”

### **Kelly**

- “I go to the boards just for support when I am having a hard time dealing with hsv”
- *Have you received emotional support?* “Yes, just reading other people's experiences helps you so much.”

### **Bianca**

- “I relied on the boards for emotional support for most of the first two years after diagnosis...I really liked hearing from people who had really positive attitudes about HSV. It showed me that there were a lot of paths I could go down in dealing with herpes and helped me decide how I wanted to handle things.”

### **Gabrielle**

- *Have you received emotional support?* “Yes, I did when I was first diagnosed. I found people who shared the same feelings I did and let me know there is life after herpes.”
- “Online support groups are there to help people with the transformation, emotional support, and to let them know they are not lepers and that HSV or HPV is a virus that is manageable and you will not die from it. And you can lead a normal happy life.”

### **Cathy**

- “I feel as though I'm connected to these people and as though I'm a part of a wonderful community who won't discriminate against me because we're all the same.”
- “I have received emotional support from the boards in that I have felt more emotionally connected to those I am communicating with.”

### ***Informational support***

This question was asked to inquire about the informational support found within the message boards: *“Have you received informational support from the boards? Please explain.”* Other questions in the surveys also exhibited responses containing informational support and are listed below. Seventeen out of 20 participants expressed that they received some form of informational support by using the message boards.

#### **Adeline**

- “I have received experience support from the boards. Things that have worked for others.”

#### **Emily**

- *Have you received informational support?* “Yes, initially I was full of questions that I was having difficulty finding answers for- my most pressing questions at the time was regarding outbreak frequency and severity- and they were all answered.”
- “Initially, the boards were more informative and supportive.”

#### **Laurie**

- “It’s helpful to see what has been used, discovered...”
- *Have you received informational support?* “Very much so, the owner of the forum (She) has her own site with excellent information and also some links for other sites that could be wonderful... very informative.”

#### **Alex**

- “It’s a great place for information...”
- *What are the benefits of using the boards?* “Learning the facts.”
- *Have you received informational support?* “Yes, most of my useful facts and information about HSV has come from one or both of the two sites I have mentioned.”

- “The message board has given me more education about HSV so I can handle it better myself.”

### **Jarrood**

- “I visit the different boards looking for information that anyone may have about herpes.”
- “I go to the different board to try and find out any information that anyone has about “home remedies” to medical studies. Any information that I can arm myself with...”

### **Tara**

- *Have you received information support?* “I found some books to order helpful as were the true stories about other people living with herpes and HPV. I also learned about the herpes select blood test which I never even knew existed.”

### **Melissa**

- “On a forum you can ask anything about herpes or any aspect of having herpes and someone can answer your question or refer you to one of the best sites for answers.”

### **Sonja**

- *Why do you visit the boards?* “Only for information for a question that’s asked of me.”
- “After almost 15 years since diagnosis, I never knew about the phenomenon called “shedding.”
- “In the beginning, I needed the information.”

### **Rebecca**

- *Have you received informational support?* “Absolutely!”

### **Theresa**

- *Have you received informational support?* “A lady from the pup group has a medical background...and she has been very helpful to me with the medical questions.”

### **Shannon**

- *Have you received informational support?* “Yes, I have. Had received links to various sites.”

### **John**

- *What are the benefits of using the boards?* “I also learned a lot about the virus and how it functions.”
- *Have you received informational support?* “In the beginning, I learned A LOT about all aspects of the virus via the discussion on the boards. The great thing about the boards versus strictly informational sites is that it’s interactive so you can ask questions.”

### **Kelly**

- “The Shut up and post message board has given me a lot of information.”
- *What are the benefits of using the boards?* “They provide a lot of useful info.”

### **Holly**

- *Why do you visit the boards?* “Source of information, and understanding the virus.”
- *Have you received informational support?* “Yes, I have. Descriptions, symptoms, definitions, very helpful.”
- *What effect has it had on you?* “It was a source of info. Much appreciated.”

### **Bianca**

- “Talking to the old pros is great because you learn tricks for managing outbreaks that the doctor may not have told you.”
- “I feel like I learned a lot about managing outbreaks.”
- “I also learned a lot about pregnancy.”

### **Gabrielle**

- *Have you received informational support?* “Yes, the boards I mentioned have several links to great information, transmission, outbreaks, the works. If it’s not listed then just ask and they will find an answer for your question.”
- “I believe they are a great avenue of information.”

### **Cathy**

- “I receive information about genital herpes through the Internet.”
- “I have received information support from message boards regarding ways to suppress outbreaks without the use of pharmaceuticals.”

### ***Direct Support***

A question was asked regarding direct support (or face-to-face support outside of the Internet): “*Have you used the message boards for direct support (to find face-to-face support in your community)? Please explain.*” Only five out of 20 participants commented that direct support was a factor in their use of online message boards.

#### **Melissa**

- “I have used the message boards to arrange social and support meetings.”

#### **Rebecca**

- *Have you used the boards for direct support?* “Absolutely!”

#### **Theresa**

- *Have you used the boards for direct support?* “Yes, I actually started a group for people in my area.”

#### **Shannon**

- “I have one person I talk to on the phone, thru text messaging, through instant message and emails.”

#### **Gabrielle**

- “*Have you used the boards for direct support?* “Yes, I have. I searched online and found a group in my area and attend their monthly meetings. It was a great help to see people face to face and to know I was not alone on this.”

### ***Face-to-Face Support***

A question was asked regarding participation in face-to-face support in general: “*Have you participated in a face-to-face support group? What was your overall impression?*” Four participants said that they participated in face-to-face support. Three participants said there were no face-to-face groups in their area.

### **Rebecca**

- *Have you participated in face-to-face groups?* “Yes, I run the Omaha Help herpes support group. Meeting people face-to-face is just as important.”

### **Bianca**

- *Have you participated in face-to-face groups?* “I absolutely loved the support groups. I really liked the face-to-face interaction and found it very helpful. Real time conversations are better than a string of posts.”

### **Gabrielle**

- *Have you participated in face-to-face groups?* “Yes, I have. It is awesome to know that you are not alone and others felt the same as I did when I was diagnosed.”

### **Motivations and Benefits**

It was unclear on some answers of the email surveys when distinguishing between motivations and benefits. These concepts seemed to overlap across surveys, thus, difficult to differentiate. The following question was asked to specifically aim at the motivations of using the message boards, “*Why do you visit these board(s)?*” The following are the answers to this question:

### **Motivations**

- **Bianca**

“Well, to be honest these days I don’t really look at them that much. I used them a lot when I was first diagnosed for the support. I had no idea about where to go or what to do and none of my friends had it. I needed the instant community the message board provided to feel like I was not alone and that my life was not over (haha, sadly, I went through that dramatic stage at first! But at least the boards helped me know that it was normal and would pass). These days I mostly go on them when I

need a refresher course on HSV or when I am getting close to telling someone and want a little extra support and advice.”

- **Rebecca**

“When I first began looking for support in the form of a message board on the Internet it was probably because the idea that I was going to have the opportunity to reach out to others that were going through some of the same things that I was going through in a private setting. Well, that was very appealing to me because these individuals and/or strangers didn't know me and could not judge me the same way that a personal face-to-face friend or family member might do.”

- **Violet**

“It gives me an insight to what I can expect, and someone to talk to who understands what I am going through. I can't talk to my family or friends, because they just wouldn't understand.”

- **Theresa**

“When I was first diagnosed I was an emotional wreck, I cried all day and just was very angry at the world and the person who passed this virus to me. And honestly these groups were the only thing that kept me going on some days, and kept me sane.”

- **Jarrold**

“I visit the different boards looking for information that anyone may have about herpes. The disease is a virus that there is so little known about, there has been a great deal of studies yet we still don't know very much about the virus. And currently the methods of treatment or so inefficient it is ridiculous! I refuse to take a pill a day for the rest of my life or even to take a bombardment of pills for each outbreak. I have started using essential oils directly on the site that an outbreak occurred/s on and have none of the sickness associated with the pills. (anything prescribed) And I still haven't had a full outbreak since I started using the Essential Oils, I go to the different board to try and find out any information that anyone has about "home remedies" to medical studies. Any information that I can arm myself with will help me cure myself of this virus.”

- **Shannon**

“Support that is given.”

- **Kelly**

“It gives people someone to relate to, I go to the boards just for support when I am having a hard time dealing with hsv.”

- **Holly**

“Source of information, and understanding the virus.”

- **John**

“I am the web master and moderator for the site and a lot of the people there are my friends now.”

- **Melissa**

“Initially I visited to find out more about what it was like to live with a lifelong virus – there was and is plenty of medical information available but it is not the same as hearing from real people about their own experiences. I am a member of a number of forums but I only continuously visit those where I feel I have become a part of the community (and the ones I own/moderate).”

- **Tara**

“As a school counselor, I am cursed to want to help people. This is a way for me to help people who aren’t able to seek support elsewhere and make sure they get to reliable sources of information. I am a moderator and h-pal for the yoshi2me.com website. At first, I visited b/c I needed some emotional support from people who had herpes and HPV. You don’t just go around asking people if they have it, especially when you are in my profession. Reading the stories about others who live with herpes also helped tremendously with me and to show to potential partners. I now use my h-pal bio as an opening for the “talk”.”

- **Andrea**

“My mom first thought I should go to a group session, but I wasn’t ready for such a big step...so she thought that maybe I could look at a forum.”

- **Adeline**

“I continue to visit the boards because I hope that I can help at least one person like I was helped.”

- **Sonja**

“Only for information for a question that’s asked of me.”

- **Gabrielle**

“I don’t really need the support for myself anymore, But I go because others newly diagnosed benefit from my help.”

- **Deborah**

“To see other people have the same questions, concerns and emotions.”

- **Laurie**

“I like the site because you have everyone from new to people that were diagnosed 20 yrs ago. It’s helpful to see what has been used, discovered and just anything that someone may have to offer you in general for support. They were great when I discovered that I was pregnant and they could help me with the fear.”

- **Alex**

“I visit the boards to stay in touch with the HSV community, and to help other people cope with the initial effects of having HSV. It’s also a great place to just chat and make friends.”

- **Cathy**

“for socializing and support.”

- **Emily**

“Although I no longer have questions regarding this ailment, I still continue to frequent the site. Besides from the reasons I stated in question #8 – the family-like feeling of the site, I find I like being able to give-back to the site – answer questions and provide support and empathy for new members. I realize how important that support was for me while I was coming to terms with having a disease in which there is very little control and no cure for...it’s a long, slow process, and I want to help others through those stages.”

### ***Benefits***

The following are the answers to the question, “*What do you feel are the benefits of using these message board(s)?*”

- **Bianca**

“As I said earlier, the boards give you an instant sense of community. You immediately find a group of people with the same problem and issues as you. It is extremely comforting to see the large number of people out there dealing with HSV, especially since most of us feel so alone and isolated when diagnosed. It’s a great place to find support and understanding. Talking to the old pros is great because you learn tricks for managing outbreaks that the doctor may not have told you. The boards are also a great place to vent, since a lot of the time, you don’t want to talk with your friends about your herpes. Or if they do know, you don’t want to sound like a broken record in bringing it up all the time. The boards are a place where you can feel free to talk about your HSV as much as you want to.”

- **Rebecca**

“It allows people to express what is on their mind when it's convenient for them to do so. You don't have to get in your car to drive to a support group meeting if you don't want to and you can really be yourself knowing that it won't matter what others think. Eventually people hopefully realize that it's ok to be yourself, herpes doesn't define who you are as a person, and it doesn't matter what other people think about you as long as you are good to yourself and can do the right thing and make good choices for yourself.”

- **Violet**

“a closely net friendship, that cannot be compared with friends you see everyday, because you are sharing something personal with someone who is also dealing with the same problem.”

- **Theresa**

“What do you feel are the benefits of using these message board(s)? it helps to see that your not alone. youre not judged because you have H (herpes), unlike society. it's like you always have someone to talk to. and a different perspective on questions that you have.”

- **Jarrold**

“They are a great place for people to share their experiences whether they are mental or just physical reactions and the comfort of knowing that there are other people experiencing the same hardship as yourself.”

- **Shannon**

“Getting feedback from all types of people.”

- **Kelly**

“You realize that you are not the only one out there. And they provide a lot of useful information.”

- **Holly**

“Enlightenment.”

- **John**

“The primary benefit to me right away was that I no longer felt alone in having GHSV. I also learned a lot about the virus and how it functions. As a side benefit, I’ve made a great many friends through the years there. Some of whom I’ve met in real life.”

- **Melissa**

“The benefits are many:

a) Support – if you need some emotional support all you need to do is post how you are feeling and people will offer sympathy, encouragement and advice.

b) Information – there’s a million plus websites out there with info on herpes – a lot of it conflicting or aimed at the medical profession. On a forum you can ask anything about herpes or any aspect of having herpes and someone can answer your question or refer you to one of the best sites for an answer. (Occasionally you may get some crackpot answers or incorrect information splashed about on forums, however, there are usually plenty of knowledgeable members to point you in the right direction.)

c) Social – a lot of groups provide opportunities for members to arrange and attend social functions. The idea of ‘socialising’ with others who have herpes may seem a little bizarre at first, but it helps people to feel normal again and to ‘get back out there’ socially as many do go through that ‘herpes hermit’ stage of withdrawing from family, friends and society.

d) Dating / Love / Romance – some groups are purely social and aimed at providing opportunities for herpes singles to meet up with a view to a relationship. There are different views on ‘dating’ post herpes. Some people think you should only date within the herpes community so as not to contribute to the spread of the virus; some people actually believe that they no longer have the right to have a loving relationship; others are in denial and continue on as if they don’t have herpes. With time, I believe most do come to the realization that one does not have to become celibate or date solely within the herpes community – that we all ‘deserve’ to be happy and that having herpes should not limit who we may love, or who may love us.”

- **Tara**

“The anonymous nature and the fact that people don’t stigmatize you. People still don’t like to talk about STD’s, and I find that my students don’t know as much as they think either. I’m adamant about being an advocate in any way I can without jeopardizing my place in the community as an educator. I’ve found that many doctors still give out incorrect information about herpes and other STD’s or make the patients feel horrible and dirty b/c of their non-verbal communication or tone of voice. ON the boards, we often have to tell people to find a doctor that makes them feel better and knows the correct information. I’m glad to see some teens seeking out the correct information as well and having people on the boards tell them about places such as the health department and planned parenthood where they can get tested and treated. Many of the moderators know where to get help with the cost of meds as well. Something doctors really don’t do quite often...they just prescribe the most expensive meds.”

- **Andrea**

“The benefits are that you can express your feelings to someone at anytime of the day, and know one would be able to point you out and say “ hey look...there’s so – and-so and she has herpes”. You become free and relax and ask questions without feeling embarrassed.”

- **Adeline**

“There is a sense of privacy when revealing your innermost thoughts to a group of people. No one knows you. No one sees your face. The information that the people know about you is what you choose to give to them.”

- **Emily**

“You are anonymous and surrounded (virtually) by people that understand what you are feeling and going through; you’re not suffering alone. It is informative – as in, what works best from personal experience rather than a statistically significant clinical trial. There is a great deal of – relief? catharsis? – in purging your frustrations, emotions, fears, sadness, anger and thoughts by writing them down/discussing them. Somehow releasing all the negativity truly helps. Furthermore, replying to someone else and helping them feels - empowering? – like you are able to make a genuine difference in someone else’s life. Furthermore, you can interact with the site at your own convenience – around your work schedule (as opposed to being present at a meeting at a particular time) and you have a global perspective (people from all over the world have HSV and therefore you are not alone).”

- **Sonja**

“Non-biased, precise information.”

- **Gabrielle**

“To spread the word, and let people know they are not alone in this.”

- **Deborah**

“Just to have a better understanding of things and to realize we are not alone.”

- **Laurie**

“Being able to get several prospective and experiences other than mine alone.”

- **Alex**

“Learning the facts, emotional support, and educating others about HSV.”

- **Cathy**

“The benefit of using these message boards is the ability to communicate with others who are in your exact situation so far as body and health are concerned. They aren’t doctors or people who have no clue what you’re going through because they went through it at some time and they’re willing to share their experiences with you. I feel as though I’m connected to these people and as though I’m a part of a wonderful community who won’t discriminate against me because we’re all the same.”

### ***Friendships***

Although the development of friendships was not mentioned in one post of the observations, this is a concept that emerged from the data of the email surveys. This concept was first seen in past literature, and was reflected in the email surveys as a feeling of “being there for one another”, as well as many posts that specifically stated “friendship.” Seven participants spoke of friendships that developed through their use of the message boards.

### **Emily**

- “They have become a site where I check back and talk to faceless people I consider friends.”

### **Alex**

- “It’s a great place for...friendship.”
- “It’s also a great place to just chat and make friends.”

### **Tara**

- “I also made cyber friends with someone from my home state.”

### **Violet**

- *What are the benefits of using the boards?* “Closely net friendship.”
- “I have one person that I talk to.... when I get an outbreak, I know she will be there for me.”

### **Shannon**

- “A person who I was already talking to online became a really close friend.”

### **John**

- “A lot of people are my friends now.”
- “As a side benefit, I’ve made a great many friends through the years there.”
- “It is truly a community. I know some of the people for as long as I’ve been participating online.”

### **Gabrielle**

- “I believe they are a great avenue of information, support, and even friendships with people who understand how you’re feeling, and you can be open and honest with them without being judged.”
- “I have built some very good friendships with these people (face-to-face). When asked most people if they could give their HSV back including all the friends they have made online and off in the message groups would they? Most would tell you no way. The friendships they have made has made it all worthwhile.”

### ***Empathy, feeling “not alone”***

Empathy was not a concept included in the email surveys, but this idea of being “not alone” developed out of the data from many responses, as also seen in the observations. Fourteen out of 20 participants commented on feelings of empathy gained from using the boards, and many mentioned this concept more than once.

#### **Emily**

- “Everyone had gone (or was going through) was I was experiencing.”
- “surrounded (virtually) by people that understand what you are feeling and going through; you’re not suffering alone.”
- “you are not alone.”

#### **Adeline**

- “Message boards give you the chance to talk to people who have the same disease.”
- “I needed to hear it from those who were like me, not someone who was ‘clean’.”

#### **Jarrold**

- “The comfort of knowing that there are other people experiencing the same hardship as yourself.”
- “Online a person can find and talk with people that understand that the virus isn’t like a headache there is a whole lot to it.”
- “Other people have the same troubles and worries that come with the virus.”

#### **Andrea**

- “I found people who were feeling what I was feeling. I was really able to relate to their frustration and pain.”

#### **Tara**

- “Reading the stories about others who live with herpes also helped tremendously with me.”

### **Melissa**

- “There were many stories that made my ‘tale of woe’ seem very insignificant. Reading all the messages made it clear that I was not alone, and not the only who had a hard time coming to terms with having herpes.”
- “Unless you have a doctor who has herpes themselves, they don’t really know what it is like, they can only imagine, sympathize or empathize, but not know.”

### **Deborah**

- “to see other people have the same questions, concerns and emotions.”
- “and to realize we are not alone.”
- “Reading the boards makes me feel better realizing other people are going through similar situations!”

### **Theresa**

- “PUP helped me to realize that I wasn’t alone.”
- “it helps you to see you are not alone.”
- “People online in those groups have H, and they kinda know what your going through.”

### **Violet**

- “It gives me an insight to what I can expect, and someone to talk to who understands what I can expect, and someone to talk to who understands what I am going through. I can’t talk to my family or friends, because they just wouldn’t understand.”
- “you are sharing something personal with someone who is dealing with the same problem.”
- “because they are going through the same thing you are.”
- “It has let me know that I am not alone, there are more people out there who have genital herpes than you would think.”

### **John**

- “The primary benefit to me right away was that I no longer felt alone.”
- “The first level is that of not feeling alone anymore.”

- “In other words, it’s support from people who have similar experiences as yourself.”

### **Kelly**

- “It gives people someone to relate to.”
- “You realize you are not the only one out there.”
- “it has gotten easier to deal with having HSV, seeing all of the other people that have it and that have had similar experiences as I have.”

### **Bianca**

- “It is nice because you have a chance to hear so many stories and experiences. It is rare to feel like you are alone in your issue, even if you have something not quite textbook going on. You can always find someone with similar problems or a solution.”
- “I needed the instant community the message board provided, to feel like I was not alone.”
- “you immediately find a group of people with the same problem and issues as you. It is extremely comforting to see the large number of people out there dealing with HSV, especially since most of us feel so alone and isolated when diagnosed.”
- “It was really nice to know I was not alone.”

### **Gabrielle**

- *What are the benefits of the message boards?* “To spread the word, and let people know they are not alone on this.”
- *Have you received emotional support?* “I found people who shared the same feelings I did...”
- *What is your overall impression?* “people who understand how you’re feeling...”
- “Just know that you are not alone.”

### **Cathy**

- *What are the benefits of the message boards?* “the ability to communicate with others who are in your exact situation so far as body and health are concerned....they went through it at some time and they’re willing to share their experiences with you....who won’t discriminate against me because we’re all the same.”

- *What type(s) of support do you get online that you don't get from health service providers?* “the ability to communicate with others in my situation.”
- “On the message boards, if we joke about herpes I feel more comfortable about it because we all have it and we know what each other is going through.”

### ***Helping others helps them***

Thirteen out of 20 participants serve as online “mentors” through the third independently managed website to those seeking advice or help regarding herpes. It was not surprising then, that 11 of the participants responded that helping others was an important part of their experience with message boards. Many of the members spoke of coming initially to the boards for support, but eventually becoming givers of such support. This developed the category of “helping others”, and posts that contained such concepts were placed among this category.

### **Adeline**

- “I continue to visit the boards because I hope I can help at least one person like I was helped.”
- “Over time, I have progressed from fear and self loathing to a mind set of helping others...”

### **Emily (not a mentor)**

- “I find I like being able to give back to the site- answer questions and provide support and empathy for new members...I want to help others through those stages.”
- “Replying to someone else and helping them feels empowering...like you are able to make a genuine difference in someone else's life.”

### **Laurie**

- “I’m also a moderator there as well as an [title omitted]. The position is to help others that are in need and might need another’s view point, but in their area”.
- “I’m able to help others as they’ve helped me out in the past.”

### **Alex**

- Why do you visit? “And to help other people cope with the initial effects of having HSV.”
- “I became the supporter.”
- “It began with me searching for support, and now I am giving support.”

### **Tara**

- “Helping others, helps me”
- “This is a way for me to help people who aren’t able to seek support elsewhere and make sure they get to reliable sources of information.”

### **Melissa**

- “My main participation on the boards now is as an owner/moderator and peer support provider.”
- “giving support and advice.”
- “Being able to help people, encourage them and support them and educate them has been an incredibly satisfying and rewarding experience.”

### **Rebecca**

- “When I first began looking for support in the form of a message board on the Internet it was probably because the idea that I was going to have the opportunity to reach out to others that were going through some of the same things.”
- “Anything I was not able to find information on I have gone to great lengths to make sure that I have made it available on my own site.”

### **John**

- “The change with time was that, over the first few months I became a giver of support rather than a seeker of support.”
- “I am web master and moderator for the site.”

### **Andrea (not a mentor)**

- “I found out that through helping other people, I helped myself as well.”

### **Gabrielle**

- “I don’t really need the support for myself anymore. But I go because others newly diagnosed benefit from my help.”
- “The key is to arm yourself with as much knowledge as possible. Before you know it you will be helping others.”

### **Cathy**

- “[website omitted] allows me the opportunity to be a helper for those who seek it.”

### ***Anonymity, privacy, convenience***

Six out of 20 participants expressed different reasons for using the Internet for herpes related information, relating to anonymity, privacy and convenience.

### **Emily**

- “You are anonymous.”
- “You can interact with the site at your own convenience.”

### **Adeline**

- “There is a sense of privacy when revealing your innermost thoughts to a group of people. No one knows you. No one sees your face. The information that the people know about you is what you choose to give to them.”

### **Andrea**

- “The benefits are that you can express your feelings to someone at anytime of the day and no one would be able to point to you and say “hey look...there’s so and so and she has herpes.”
- “I get time. With online, you can go at 2am till whenever, and sooner or later someone will respond...”

### **Tara**

- *What are the benefits?* “the anonymous nature”

### **Rebecca**

- “private setting.”
- “it allows people to express what is on their mind when it’s convenient for them to do so...you don’t have to get in your car and drive to a support group meeting if you don’t want to.”
- “message boards are great therapy. When you find the right ones to participate on and they are mostly free.”
- “A message board is always there.”

### **Kelly**

- “Online it is easier to talk, for me anyways, because there are just some things that are really hard to talk about in person.”

### ***Source of information/support***

A survey question was asked regarding the source of information and support found regarding genital herpes: “*Where do you get information about genital herpes (for example... books, Internet, physicians, etc.)?*” The most common response was the Internet, with half of the participants stating that the majority or all of their information was found online.

### **Emily**

- “the bulk of my information was derived from medical sites and the herpes message board (website omitted). A few of my colleagues that also share this affliction were extremely supportive.”

### **Adeline**

- “I use the internet for all my research needs lately. I also question people who know more like [names of members omitted].”

### **Laurie**

- “I got some information from my OB, but mostly I went online and had to search. I am not involved in a few yahoo groups and one forum online.”

### **Alex**

- “Planned Parenthood, Internet”
- “Medhelp.org is owned by real doctors with great advice.”

### **Jarrold**

- “Books, Internet, Medical Textbook and Manuals, trial and error.”

### **Andrea**

- “from my doctor and doing a little bit of research on the internet.”

### **Tara**

- “Books recommended from a list on the yoshi2me website, reliable internet sources (webmd.com, ashastd.org, mayocliic.com, CDC, Planned Parenthood), my family doctor. However, the first website where I learned about a herpes blood test was the yoshi2me.com website.”

### **Melissa**

- “Primarily the Internet, but have also been given or sought out various brochures and leaflets, and borrowed books from the public library.”
- “I did speak with my GP when I was diagnosed.”

### **Sonja**

- “Internet only.”
- “My ob/gyn in St. Louis was amazing about information and support about this condition.”

### **Deborah**

- “Physicians but mostly internet.”

### **Rebecca**

- “I initially had info. sent to me through the American Social Health Association. Once I realized there were resources on the Internet that I could see out in the privacy of my own home, I purchased my first computer. Herpes message boards have been a tremendous resource as well as the books that I have in my own home library.”

### **Theresa**

- “Internet, doctor’s office, public health.”

### **Violet**

- “Internet.”

### **Shannon**

- “Internet, friends who have been diagnosed with HSV2, message boards, a little from an ER physician.”

### **John**

- “books, internet, physicians, but mostly internet.”

### **Kelly**

- “I got some from my doctor and some from books before and shortly after my diagnosis...but I found the most useful information on the Internet.”

### **Holly**

- “Doctor, books and internet.”

### **Bianca**

- “I got my info. from a combination of places. When I was still in school, I got a lot of info. from the student health center. The nurse practitioners there were very helpful and there was also a sexual health educator who was very helpful. Besides that I used the Internet. When I was first diagnosed mostly google searches. I also used message boards....”

### **Gabrielle**

- “Internet, Doctor, Support Groups.”

### **Cathy**

- “I receive information about genital herpes through the Internet, the ASHA quarterly publication *The Helper*, and books purchased online. Fortunately, my gynecologist has been very helpful in answering any and all questions I have approached him with.”

### ***Reliability, Lack of Information, or Treatment from Health Care Providers***

Two questions were aimed at experiences and support from health care providers outside of the Internet: “*Have you had any negative experiences with message boards? Have you had any negative experiences outside of the Internet (regarding genital herpes)? Please explain.*” “*What type(s) of support do you get online that you don't get from health service providers?*” Half of the 20 participants expressed some form of concern or poor treatment from health care providers.

### **Emily**

- “I should mention that my physician (University health clinic) was not helpful at all- his reaction was disgust (perhaps harsh, but it was obvious he was uncomfortable and wanted me out of the office as soon as possible).”
- “It has been my experience that health service providers are not supportive, nor particularly informative.”
- “doctor’s body language was horrible and he was not helpful or supportive. That was also when I was the most scared, confused, hurt, and his reaction caused me to lock myself in my house for the majority of the 2 week duration because I was ashamed.”

### **Adeline**

- “I have found doctors do not want to talk about herpes in general, so I tend not to talk to them.”
- “I received a phone call from my local mental health center after she called my doctor. No one was able to answer my questions...”

- “My doctors are able to give me direct information, medical information, but not experience information. They do not have HPV or HSV and are unable to tell me what comes next as far as how to proceed in my life.”

### **Jarrold**

- “currently the methods of treatment are so inefficient it is ridiculous!”
- “ha! I only wish that I hadn’t gone to a doctor to diagnose the damn thing and spent all the money on the prescriptions to start with. What a bloody waste of time the so called health providers are.”

### **Andrea**

- “Most doctors just want to tell you what you have and leave. They are always in a big rush as if they don’t care.”

### **Tara**

- “I’ve found that many doctors still give out incorrect information about herpes and other STD’s or make the patients feel horrible and dirty because of their non-verbal communication or tone of voice.”
- “they just prescribe the most expensive meds.”
- “I’ve had issues in the past where doctors don’t listen.”
- “Even doctors are ignorant nowadays.”

### **Melissa**

- “he did not give me very much information and I felt unprepared for the impact which having herpes can have on your life.”
- “many health professionals are not that well informed about STI’s in general and herpes specifically. The stories of doctors giving incorrect information are countless.”
- “personally I have found doctors at sexual health clinics far better informed than regular GPs (as they should be since they are specializing in this field).”
- “there are countless stories about medical professionals who have been not only ill-informed but also unsympathetic and even accusatory towards people who have STI’s, quite obviously displaying the attitude that you must obviously be the type of person who deserves to catch an STI.”
- “Unless you have a doctor who has herpes themselves, they don’t really know what it is like, they can only imagine, sympathize or empathize, but not know.”

### **Rebecca**

- “Health care providers don’t always have the time to sit down and really talk to their patients...sometimes people feel as though they have been pushed in and out quite quickly.”

### **Theresa**

- “There are still many health care providers that don’t know a whole lot about this virus, and they don’t seem to have any compassion. The day I got diagnosed the exact phrase my dr told me was, this isn’t a really big deal, and it’s not really serious” and that just blew my mind. Finding out you have H is a really big blow, it changes your life.”

### **Bianca**

- “Doctors and nurses are great, but due to the way health care is these days, they don’t always have enough time to sit down with their patients and really explain things.”

### **Gabrielle**

- “Most health care providers looks at you like a number. Hand you a pamphlet and send you on your way to dwell on your diagnosis without thinking of the impact this will have on your life.”

### ***Stigma, Judgment***

Stigma was another concept that emerged from the email surveys, as well as from the observations. Nine out the 20 participants mentioned stigma or judgment from other people or society as a concern.

### **Kelly**

- “there is a lot of good information out there and I just wish that it was more of an open subject.”

### **Theresa**

- “you’re not judged because you have H, unlike society.”
- “Once people find out you have H, it feels like you’re shunned.... people just fear what they don’t understand.”

### **Rebecca**

- “squash the negative stigma that is associated with this STD.”

### **Deborah**

- “There should really be more info available to the general public so genital herpes is not so taboo!”

### **Melissa**

- “there isn’t this feeling of being stigmatized when you are amongst your peers.”
- “I am completely open about having herpes because I believe that is the only way to combat the stigma.”
- “hiding herpes behind closed doors and anonymity will not break down the barriers or reduce the stigma.”

### **Tara**

- “You don’t just go around asking people if they have it, especially when you are in my profession.”
- *What are the benefits?* “the fact that people don’t stigmatize you”

### **Emily**

- “I’ve found periodically people are ignorant of herpes and how it is transmitted, so I will get little comments that aren’t intended to be hurtful but are negative.”

### **Gabrielle**

- “you can be open and honest with them without being judged.”

### **Cathy**

- “I have had some negative experiences outside of the Internet in that those who do not know about my situation have made “jokes” about STDs and herpes at different times.”
- “I wish there was a way we could talk about this publicly without the fear of the negative stereotype surrounding us.”

- “we’re not very open about who we are because I believe that deep down inside even the smallest part of us is still afraid of being judged by those we meet if and when we tell them.”

### ***Telling new partners, dating and sexual relationships***

One question was asked regarding information the participants may be seeking: “*Are there any areas you would you like more information about? (transmission, sexual behavior, symptoms, etc.)*” Five out of 20 participants expressed that issues relating to dating and sexual relationships (telling new partners) was important when visiting online message boards.

#### **Bianca**

- “I mostly go on them when I need a refresher course in HSV or when I am getting close to telling someone and want a little extra support and advice.”
- “I also felt like I learned a lot about how best to deal with a relationship in which your partner is uninfected.”
- “They were also great when I started to date again. It helped me not worry as much.”

#### **Violet**

- *Any issues you would like more info about?* “yes, sexual behavior.”

#### **Melissa**

- *What are the benefits?* “Dating/love/romance”.

#### **Andrea**

- *Any issues you would like more info about?* “Yes, I would like to know more about information about what to do, if you plan on having a sexual relationship with our spouse or boyfriend. And even if they know and still want to have sex with you, how can you protect them?”

### **Laurie**

- *Any issues you would like more info about?* “Sexual behavior is interesting. I know when I was first diagnosed that I was very scared to have sex and also worried about future relationships; that there wouldn’t be one.”

### ***How long after they went to the message boards after diagnosis***

Participants were asked questions concerning the length of time they have been using message boards for genital herpes information: “*At what age were you diagnosed with genital herpes?*” “*How long have you been participating in message boards for genital herpes information?*” “*When did you start participating in the message board(s)?*” Some answers were calculated using the participant’s date of birth, time of diagnosis and length of time using the boards. Eleven out of 20 participants stated that they used the message boards immediately following diagnosis, with two of the 11 participants using them within the first six months of diagnosis.

### **Adeline**

- unknown

### **Emily**

- a couple months after initial outbreak

### **Laurie**

- 2 years after diagnosis

### **Alex**

- Immediately after diagnosis

**Jarrold**

- 6 months using message boards, diagnosed 2 years

**Andrea**

- immediately after diagnosis

**Tara**

- immediately following diagnosis

**Melissa**

- started using boards 2 years after diagnosis

**Sonja**

- does not participate in message boards very often

**Deborah**

- immediately following diagnosis

**Rebecca**

- 2 years after diagnosis

**Theresa**

- immediately after diagnosis

**Violet**

- immediately after diagnosis

**Shannon**

- diagnosed 1 year, using boards for 7-8 months

**John**

- calculation doesn't make sense to diagnosis time

**Kelly**

- immediately after diagnosis

### **Holly**

- immediately after diagnosis

### **Bianca**

- immediately after diagnosis

### **Gabrielle**

- immediately after diagnosis

### **Cathy**

- immediately after diagnosis

### ***Summary***

There were many themes that emerged from both the observations and email surveys. This created a better understanding of the motivations and supports those with genital herpes seek by using the message boards. The final chapter interprets and evaluates these findings, explaining the relationships found in the data and how the results can be used to understand the needs of those with genital herpes. Limitations will also be discussed, as well as suggestions for further research.

## V. Discussion and Conclusions

The two approaches, non-participant observation and email surveys, provided complementary information, which helps to answer the three research questions of this study. This chapter discusses the results of these research methods. At the end of the chapter, the limitations of the study and possibilities for future research are considered.

### ***Research Question #1***

*What are the motivations of individuals who seek out support from Internet message boards for genital herpes?*

After extensively reviewing the observations and email surveys, several specific motivations seem apparent. It is important to note that in many of the answers, it was difficult to distinguish between “motivations” and “benefits.” Many of these same themes were overlapped or repeated throughout the surveys and could be considered either a motivating factor and/or benefit from using the sites. For example, some members may have received emotional support from the boards, whether they were looking for it or not. In the same respect, some may have been motivated to go the boards looking for emotional support, but did not receive it. To better identify the motivations versus benefits, the answers specifically aimed at motivations and benefits were reviewed as well. The following motivations were found within the data from the observations and email surveys.

## *Empathy*

One theme found in the data was *empathy*, or commonly expressed by participants as feeling “*not alone*”. Fourteen out of the 20 email survey participants stated that empathy was sought and gained on the message boards, and many expressed this more than once in their responses. This concept was found in the observations as well, and supported by past research regarding empathy found in online communities (Preece & Ghazati, 2001; Colvin et al., 1997). Rock4 explained this feeling well “This site is really an amazing thing, you guys are doing a great job by allowing us to get answers and know that others are going through the same things. It really shocked me to hear it earlier today, but now I'm feeling a lot better.”

Melissa explained the effect of the message boards when relating to empathy, “There were many stories that made my ‘tale of woe’ seem very insignificant. Reading all the messages made it clear that I was not alone, and not the only who had a hard time coming to terms with having herpes.” Many others felt the same way. Bianca spoke of the feeling of isolation and the benefits of using the message boards “you immediately find a group of people with the same problem and issues as you. It is extremely comforting to see the large number of people out there dealing with HSV, especially since most of us feel so alone and isolated when diagnosed.”

Empathy may be a concept that health care providers are not able to provide. Because all of the members on the message boards are diagnosed or dealing with genital herpes on some level, there is an understanding between individuals that cannot be found elsewhere. Melissa describes this lack of understanding well “Unless you have a doctor who has herpes themselves, they don't really know what it is like,

they can only imagine, sympathize or empathize, but not ‘know’.” This shows the need for social support among those dealing with genital herpes, and what health care providers can recommend for patients, as well as recognizing certain limitations that can never be provided.

### ***Helping others***

Another concept that developed out of the email surveys was the idea of “helping others.” This was seen in 11 responses from the survey participants that helping others was a motivation for visiting the message boards. Considering that more than half of the participants of the study serve as “online mentors” for a herpes-related website, this was not surprising. Many of these mentors have needed this support in the past and may feel that giving back to the site helps them, even if they are no longer in need of support. Gabrielle described this well; “I don’t really need the support for myself anymore. But I go because others newly diagnosed benefit from my help.” Individuals initially came to the boards for support (emotional, informational) but many ended up being the givers of such support. One possible reason for this may be the message board environment, and the open and friendly people that frequent these boards. This idea of helping others is not a common experience available in the mainstream Western health care system, and the message boards can provide such an experience.

In the observations, although most of the posts were from new members seeking information, most of the replies were from those members who had been diagnosed in the past, and many were site administrators who had a great deal of

experience in helping others on the boards. After observing the boards for some time, it was apparent who were the experienced and most frequent members. This shows what seems to be a generally higher level of comfort and emotional stability for those living with genital herpes for a longer period of time compared to those who are newly diagnosed. This may help to understand the behavior of those with genital herpes and how this changes over time, with the use of Internet message boards.

### ***Anonymity, Privacy and Convenience of the Internet***

In the observations, some responses focused on the privacy of the Internet as a medium. Six out of 20 participants in the surveys mentioned the anonymous, private and convenient nature of the Internet as a motivation. Adeline spoke of the privacy and disclosure of using the message boards, “There is a sense of privacy when revealing your innermost thoughts to a group of people. No one knows you. No one sees your face. The information that the people know about you is what you choose to give to them.” Andrea expressed time as a benefit of using the boards, “I get time. With online, you can go at 2am till whenever, and sooner or later someone will respond...” and Rebecca noted the convenience of using the Internet for support, “it allows people to express what is on their mind when it’s convenient for them to do so...you don’t have to get in your car and drive to a support group meeting if you don’t want to.” The private nature of the Internet allows for a certain comfort and anonymity that cannot be found in the physical world. Being “faceless” can ensure privacy for sensitive issues such as genital herpes, thus allowing for strong relationships and social support.

## *Friendships*

Friendships were also noted in the email surveys as a motivation (as well as a benefit) from using the boards. Seven out of 20 participants in the surveys commented on the development of friendships that resulted from using the message boards. This finding supports past research regarding the development of friendships on the Internet (Ridings and Gefen, 2004). In the observations, there was one post that spoke specifically toward the development of friendships. This lack of findings could be due to the environment and nature of the message boards and the topics discussed. Friendship is a concept that develops over time and may not be determined with observation alone. Many of those being observed did not discuss in depth about their experiences of the message boards as they did in the email surveys. One survey participant, Gabrielle, explained the development of friendships and the impact it has had on her life “When asked most people if they could give their HSV back including all the friends they have made online and off in the message groups would they? Most would tell you no way. The friendships they have made has made it all worthwhile.”

The development of friendships is not surprising on the message boards. Many of these people communicate with other members on a daily basis, communicating very deep and sensitive issues of their lives. A certain trust may develop over time, and the message boards become not only a place for support, but for maintaining relationships as well.

## ***Telling New Partners***

Gilbert et al. (2001) found that patients expressed the need for information on preventing transmission to partners. This motivation and benefit was also found in the current study of the message boards, and could be an important factor for health care providers to recognize. In the observations, some expressed concern for telling new partners, regarding where, when and how to tell future partners. One member, Bead2, who was newly divorced and terrified of telling new partners, came to the boards for advice. Other members responded with encouraging words and emotional support. This need for advice for telling new partners was also seen in the email surveys; five of the 20 participants stated that issues relating to sexual behavior and telling new partners was important to them. As Bianca explained, “I mostly go on them when I need a refresher course in HSV or when I am getting close to telling someone and want a little extra support and advice.”

Telling future partners about genital herpes can be difficult, especially concerning the stigma usually related to this disease. For many, the physical implications of genital herpes do not impact people as much as the psychological. Dating and starting new relationships can be difficult *without* genital herpes, and having this disease can make it even more difficult. Getting advice and learning new ways to tell future sexual partners about their condition seems to be an important concern of those visiting the boards. Specific knowledge of the types of information being requested, such as telling new partners and sexual behavior, could be beneficial to health care providers or those working with those seeking support for genital herpes.

### ***Research Question #2-***

*What are the types of support these online message boards offer?*

Aside from these motivations, several types of supports are evident in the research results. It is important to recognize that these supports can also be viewed as a motivation (as well as benefit gained) to participate in the message boards but have been separated from the motivations to focus on the types of supports that the message boards offer.

### ***Emotional Support***

The first of these types of supports is emotional support, which was first witnessed throughout the observations. As one member, Sky12 expressed in a message board post “First let me just say, surprisingly I'm handling my diagnosis rather well...compared to when I first found this wonderful group of people! So thank you...the support and words of wisdom have helped tremendously!” Many members also expressed thanks to others for their support and guidance. Olson0 stated “Thank you so much for all of the support, really, its so much more than I expected and it means so much to me.”

Eighteen out of 20 participants who received the email survey also expressed that they were initially motivated to visit the message boards looking for emotional support. Tara expressed her primary motivation for coming to the boards “At first, I visited b/c I needed some emotional support from people who had herpes and HPV.”

Not only was emotional support an important motivational factor, but also a benefit gained from visiting the sites. As Adeline revealed, “It is because of the boards I am still alive. The night I posted at PUP, it was my final straw. I was reaching out and had nowhere else to turn. I needed to hear from those who were like me.”

This study, as well as others, found that health care providers do not offer the emotional support most needed by those with genital herpes. The message boards do provide this type of support, by allowing relationships to develop between members who empathize and truly understand what others are experiencing. This shows the effectiveness of the message boards and the possibilities of this peer-to-peer support to help those with genital herpes.

### ***Informational Support***

The second type of support found within the observations was informational support. This was the most common type of support among the observations, which is supported by past research as well (Ridings & Gefen, 2004, Reeves, 2001).

Informational posts focused on symptoms, where to get more information, prevention, transmission, testing, medications, and others.

In the email surveys, informational support was also found in 17 of the 20 participants’ responses. John described this informational support on message boards relating to other standard websites, “I learned A LOT about all aspects of the virus via the discussion on the boards. The great thing about the boards versus strictly informational sites is that it’s interactive so you can ask questions.”

According to past literature conducted on online message boards (Reeves, 2001), informational support was the most common type of support found on the message boards. For the observations, this seemed accurate. Informational support was found to be an important benefit, with almost all of the new posts focusing on questions relating to symptoms, transmission, etc. Many of these members were not given correct information at the time of diagnosis, and sought out the Internet to answer their questions.

However, after analyzing the responses in the email surveys, it was found that emotional support was a more important form of support than informational for this small sample of board users. Although nearly all of the participants stated that emotional *and* informational support was gained by using the boards, the emotional support was seen across individual surveys multiple times.

### ***Direct and Face-to-Face Support***

The use of Internet message boards for finding direct support or face-to-face support in one's community was not observed in the first phase of this study. In the email surveys, direct support was also not found. Five participants in the surveys expressed that the message boards led them to some type of direct support outside of cyberspace. This included one participant who used the message boards to connect with a friend via text message, email, phone, etc. When asked how many had participated in a face-to-face support group at any time, there was only four. Additionally, three of the 19 participants expressed that face-to-face support was not offered in their area. Possible reasons for the lack of face-to-face support sought

could be because of issues of privacy, convenience, accessibility, or the participants' comfort levels working in online environments as opposed to outside influences.

### ***Research Question #3***

*What are the advantages and disadvantages of the Internet compared to other means of health care information, as well as concerns?*

Although this research question seems to suggest a comparison of the advantages and disadvantages of the Internet and the medical field, this study only looked at the online community but did not research or talk to those working in the medical field. Therefore, this research question could not fully be answered by the focus of the study and the methods used.

However, it is important to note that many of the email surveys and observations focused on the *reliability, lack of information, or treatment from health care providers*. Observing the message boards over just a few days' revealed examples of the reputation of health care providers within this genital herpes community. Some posts focused on specific events in which they were given incorrect or little information. Speak8 came to the message board seeking informational support from others, and was told about the two types of herpes viruses, which was never conveyed by the health care professional. Others spoke in general about the overall lack of knowledge. (Bird2) said "The first thing that I have to say is that the medical community is SO uneducated about herpes and I have no idea why this is."

This lack of knowledge among health care providers was also seen within the email surveys, as well as the lack of emotional support offered by health care providers. Half of the participants expressed some concern about the quality of care from health care providers, and many of them commented more than once in their survey. Tara, an online mentor, explained this lack of information and stigmatized behavior well “I’ve found that many doctors still give out incorrect information about herpes and other STD’s or make the patients feel horrible and dirty because of their non-verbal communication or tone of voice.” Other views expressed relating to health care providers include a lack of time spent with patients, as well as a lack of empathy and compassion from health care providers.

### ***Other Important Factors***

Because of the nature of this research and the ability to ask open-ended questions, it is possible to discover other themes that were not expected from the observations and email surveys, as well as related to the research questions. The following themes were important elements that appeared in the data.

### ***Stigma***

Past research has found stigma to be an important factor in the disclosure and comfort ability of a genital herpes diagnosis (Fortenberry, 2004). This need for non-judgmental communications with others (Gilbert et. al, 2001) was also seen within the message boards, and could be important factors for health care providers to focus on when caring for patients with genital herpes.

This concept is seen throughout the observations, when referring to judgment and lack of public knowledge. Uni8 refers to the stigma associated with genital herpes: "The real problem with herpes is the stigma attached. There are a lot worse things than having herpes and many people have it their whole lives and have no clue." Fish78 also expresses "This is a very common virus with a bad rap!"

In the email surveys, almost half of the participants expressed concern regarding the stigma attached to genital herpes. As Theresa stated, "Once people find out you have H, it feels like you're shunned.... people just fear what they don't understand." This stigma is commonly felt by those with genital herpes and may affect the types supports and outlets people will go to when faced with such a disease (Fortenberry, 2004). The Internet allows for privacy, and members may feel that this atmosphere will alleviate some of this stigma often felt outside of the Internet.

### *Source of information/support*

It was also beneficial to look at where participants were getting their information and support. This may help health care providers to effectively plan intervention strategies geared toward the most popular sources for genital herpes information. For the observations, it was difficult to determine the source of information and support, thus email surveys were necessary. The surveys showed that the Internet was the most common source among participants, with half of the participants stating that they used the Internet for the majority or all of their information about genital herpes. It was unclear, however, from the email surveys as to why these participants used the Internet more than other sources.

### *When participants started using the message boards after diagnosis*

Another concept important to the study was how long after diagnosis participants went to the message boards. It is important to recognize that those coming to the sites and answering the survey come from different stages of the virus; some with their first symptoms or diagnosis of a genital herpes infection, and others, who have had knowledge of their condition for quite some time.

In the observations, many of the posts were from new members seeking information (usually involving their first outbreak, initial symptoms, etc.). The third message board showed the month and year that the member had joined the site, and their status (“newbie”, “veteran”, “site administrator”). Almost all of the new threads posted on the boards were posted by those newly diagnosed with genital herpes. It was seen in the observations that immediately following diagnosis is an important time for those with genital herpes. Many of the posts focused on primary outbreaks, or questions concerning a recent diagnosis. Stripe7 was newly diagnosed and explains, “I’ve only just got it and I’m a bit scared.” It is within the message boards that many of the members are exposed to genital herpes issues for the first time, talking with others who are knowledgeable about the condition and willing to help.

It was also found in the surveys that more than half of the participants used the message boards within the first six months of diagnosis, with 11 using the boards immediately following their diagnosis. This can be used as a tool to understanding the needs of those with genital herpes and the best time for helping those diagnosed with genital herpes.

Since many studies have found that the psychological effects are most prominent immediately learning of infection, the participants involved in the study may vary in psychological pain. It is also true that depending on the severity and reoccurrences of the outbreaks; this may affect the patient's psychological status as well (Mindle & Marks, 2005).

It is also important to note that accessibility to the Internet can also be a contributing factor to the use of the message boards. Some of the participants may not have had the option (or accessibility) to come to the Internet as an information or support source at the time of diagnosis. Many of those diagnosed today have this option, which changes the "source of information" considerably depending on the participant's age and accessibility of the Internet.

### *Summary*

The Internet has become an important resource in our society for finding quick information on a variety of topics. So it is not surprising that after being diagnosed, the boards became a place that offered information and emotional support without judgment from others. Observing the message boards as well as interacting with the survey participants via email were useful ways to explore the types of supports and identifying the motivations gained by using genital herpes message boards.

Supporting past research, the email surveys reported that the message boards are highly useful in emotional and informational support. This was also supported by the non-participant observation phase of the study. This study also identifies the types of motivations and/or benefits that inspired members to visit the message boards.

Empathy was a major motivating factor for visiting the boards, both through observations and the email surveys, which was also supported by previous studies (Colvin et al., 1997, Preece & Ghozati, 2001, Preece et al., 2003). The anonymity, privacy and convenience of the Internet were also mentioned as motivations throughout surveys, although this same issue of confidentiality was also expressed as a concern from some members. Friendships were found as well, supporting past research regarding friendships on online communities (Ridings & Gefen, 2004). Sexual behavior, focusing on sexual practices with future partners, was also found to be a motivating factor of visiting the message boards. Some members spoke of the need for better information on sexual behavior, as well as telling new partners of their condition.

Another concept that emerged from the data was that of *helping others*. This is a concept not explored in past research but may explain certain motivations of those visiting the message boards. Since most of the email participants had been frequenting the message boards for an extended period of time, this shows that those using the boards find themselves becoming givers of help rather than seekers as time goes on. John explained this transition well: “The change with time was that, over the first few months I became a giver of support rather than a seeker of support.” Alex also expressed, “In the beginning I did [receive emotional support], I was confused and not sure why this happened to me. This phase passed rather quickly, and I became the supporter.” This need to help others was an idea found in many of the email surveys, and shows the willingness to help others in need. As mentioned, 13 of the 20 survey participants are involved with the online mentoring program offered on

the website, after being exposed to the message boards for their own health concerns and deciding to offer their services.

When relating to the advantages and disadvantages of using the Internet compared other sources of health care information, there were a few factors that played into this. First, stigma is an important concept that may be linked to a person's decision to seek care or disclose information (Fortenberry, 2004). Stigma was mentioned throughout the observations and surveys, and explained as a motivation for joining and visiting the message boards. As Erin eloquently stated, "With a disease with this social stigmatism associated with it, where initially people are going to want to hide the fact they have it because they are embarrassed/ashamed but at the same time are scared and need support and information- the Internet message boards are a perfect medium." Compared to information sought and acquired outside of the Internet, the message boards allow for the privacy and confidentiality that minimizes this stigma, because they are among others who know what they are going through, but are still able to preserve some aspects of anonymity.

The reliability, lack of information, and treatment from health care providers was also a major concern of those with genital herpes. Many of the participants were unhappy with their clinical experiences and with the lack of emotional support from health care providers, but seem comfortable on the Internet message boards. Seen throughout the observations and the email surveys as well, this should be looked at as a serious concern by health care providers. The participants were motivated to come to the message boards to seek emotional and informational support and empathy, and many of these members did not receive this from their health care providers. It was also found that the most important time for support from the message boards was

immediately following diagnosis. Health care providers should recognize this as the most crucial time for education and counseling.

### *Limitations*

There are limitations in this research that should be recognized. First, the observations and surveys were conducted entirely online. Conducting surveys via email allowed access to individuals that may not be able to be reached via telephone or face-to-face interviews. It is also possible that using an online approach is the only way to conduct this study, and to reach the appropriate population. However, if possible, future studies may try to use other research methods to gain a better understanding of the types of supports and motivations, such as utilizing focus groups or face-to-face interviews. Because the study was conducted online, the researcher was unable to interact directly with participants and observe nonverbal cues that may prompt further clarification or discussion (such as tone of voice, eye contact, facial expressions, etc.). It is possible that this narrowed the participants' interpretations of the data and limited their responses. Other methods that may also be employed are face-to-face interviews, as well as focus groups. Interviews in a face-to-face setting would allow interaction between researcher and participant, allowing for clarification not found through email. Also, focus groups may spark conversation and a deeper understanding of the benefits of the message boards.

When concerning the motivation to "help others" in the surveys, the length of time participants had been using the boards did not seem to have an effect on the motivation to help others. New and old users alike expressed this need to help others after a short time visiting the message boards. One possible reason is that those who

completed the surveys and new to the message boards may have become comfortable with the environment and immediately decided to help others. However, a larger sample may be necessary to determine this. A larger sample size is also needed to determine the lack of face-to-face and direct support sought by participants. The data used in the study did not reveal the motivations not to seek outside help.

Also, the snowball sampling procedure was effective for the purpose of this research. These selected participants were highly involved in the online communities and were well prepared to answer questions regarding use of the message boards. However, this may have also limited responses from those new to the message boards, or concerned about sharing experiences, and these are the people may benefit the most from the message boards. This study also limited responses to only three websites. There are other less popular websites that could also be assessed and may reach those who prefer to use less publicized or popular sites. Also, because of the smaller sample size of the study, the results of this study cannot be generalized to the general population of board users. Further studies may employ a quantitative method, now that more is understood within the message boards by using a qualitative approach.

This research was limited by the time scale of the researcher's degree program, as well as requirements made by the Institutional Review Board for studies involving human subjects. Because of the sensitive nature of the topic, increased scrutiny and examination of the research proposal were made several times, even though the suggested changes were very minor and revised in a timely fashion. The study was sent to full review, instead of qualifying for expedited study, which is common for Masters level theses. This was due to the sensitive nature of the topic and this loss of time affected the researcher's ability to review the observations and

interviews as much as desired. With more time allowance, more interviews and observations would have been conducted to get a better understanding of the experiences of the individuals using the message boards.

In retrospect, a more synchronous approach to the email surveys might have been more effective, asking for more clarification and deeper understanding of the research questions. A chat session, where the participants are invited to join a group chat, could also be employed to probe respondents and receive better data. Also, comparing the message boards to face-to-face support groups would also be beneficial. For the participants that expressed their involvement in face-to-face groups, these participants may have been contacted further regarding their experiences both online and outside of the Internet, and the advantages and disadvantages of both. Furthermore, the literature review might benefit by focusing more on the idea of *helping others*, and the effect this has for those dealing with a genital herpes diagnosis online. However, this did not emerge as an important issue until the results of the research was analyzed.

Ultimately, the goal of this research is to better inform health care providers of the types of supports gained from using Internet message boards, thus helping providers to effectively deal with the challenges of a genital herpes diagnosis, therapy and support. This study found a lack of reliability and information from health care providers. However, more than half of the email participants were online mentors and may have turned to the Internet because of their resistance to health care providers in the first place. It is expected that these mentors would find the boards as a support system and mention their willingness to help others. Further research is needed to determine what the medical community and medical websites are doing to address

education, as well as interventions and strategies. Without this comparison of the medical field compared to online communities, it is impossible to determine the advantages and disadvantages that one form of support may offer over another. Another recommendation would be to study a particular community involved in both online message boards *and* face-to-face and compare this to the information and support they are getting from health care providers.

The empathetic communication, friendships, and supports that were observed in the data shows that message boards can be beneficial to those dealing with genital herpes, and for some maybe, the only types of supports offered to them. Some reported an apparent lack support and information from health care providers, especially immediately following diagnosis. Knowledge of how the Internet helps those with genital herpes may help health care providers outside of the Internet, especially immediately following diagnosis. This also shows the need for accessibility of the Internet for everyone, especially those with geographical barriers or the economically disadvantaged. The results of this study should encourage health care providers to inform newly diagnosed patients about these online resources, so they can receive the types of supports reported and observed.

Previous research also found that participants expressed the need for information on preventing transmission to partners and non-judgmental communications (stigma) with others, as supported in previous literature (Gilbert et. al, 2001). These were motivations and benefits found from using the message boards, and could be important factors for health care providers to focus on when caring for patients with genital herpes.

The results of this study may also be beneficial to webmasters and online support leaders, etc. By understanding the types of supports, motivations, and benefits gained by using the boards, it may be possible to design websites focusing on these topics, as well as combining the knowledge of health care providers with those working online.

The Internet has opened many doors for health care providers and patients alike. Recognizing the motivations and types of support gained by using Internet message boards may provide tools for health care providers when dealing with the physical and psychological implications of such a disease.

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## Appendix A

### Email Invitation Sent to Recruit Survey Respondents

Hi [name], my name is Christin Russman and I am a Master's student of Communications at the University of Hawaii. I am currently working on my thesis focusing on the types of support offered by message boards for people with genital herpes. The purpose of my research is to help health care providers to understand the needs of those with genital herpes, and to better understand why people and how people use the Internet for support.

I found your email address through [source of email address] and was wondering if you would be willing to answer a few questions for me. The survey will be completely anonymous. Please let me know if this is something you would be interested in- I really appreciate it! If you are willing to take the survey, I will email it to you, and you can take your time filling out the questions before emailing the completed survey back to me. The survey could take 15 minutes or more, and will include a consent form that will review the procedures I will take to insure your confidentiality and privacy.☺ Thank you so much- Christin

## Appendix B

### Agreement to Participate in Online Support Group Study

Christin Russman  
Primary Investigator  
808-741-3335  
hawaiigirl7000@yahoo.com

This research project is being conducted as a component of a thesis for a Master's degree at the University of Hawai'i at Manoa. The main objectives of this study is to better understand the motivations of individuals who seek out support from Internet message boards for genital herpes, to study the types of support these online message boards offer, and to identify the advantages and disadvantages of the Internet compared to other means of health care information, as well as concerns.

Participation in the project will consist of completing an email survey. Interview questions will focus on people's experiences with online support groups. Data from the surveys will be used to shed light on the questions outlined above. No personal identifying information will be included with the research results. Completion of the survey should take around 30 minutes. Approximately 15 people will participate in the study.

The investigator believes there is little risk to participating in this research project, since no identifying information will be disclosed. However, there may be a small risk that you will experience psychological pain when thinking in depth about personal issues. Moreover, there could be social risk of your personal information or your participation in the study becoming public knowledge. Therefore, the primary investigator will take steps to keep the information and your particular privacy confidential.

Participating in this research may be of no direct benefit to you, although you might benefit from discussing your experiences. It is believed, however, the results from this project will help health care professionals to better identify and address the publics' needs regarding support for those affected by genital herpes.

Research data will be confidential to the extent allowed by law. Agencies with research oversight, such as the UH Committee on Human Studies, have the authority to review research data. All research records will be stored in a locked file in the primary investigator's office for the duration of the research project. Digital files (including email addresses) will be kept on a password-protected computer in the investigator's possession and removed after the completion of the project. Email surveys and all other research records will be destroyed upon completion of the project.

Participation in this research project is completely voluntary. You are free to withdraw from participation at any time during the duration of the project with no penalty, or loss of benefit to which you would otherwise be entitled.

If you have any questions regarding this research project, please contact the researcher, Christin Russman, at 808-741-3335.

If you have any questions regarding your rights as a research participant, please contact the UH Committee on Human Studies at (808) 956-5007.

**Participant:**

I have read and understand the above information, and agree to participate in this research project. Please type your name to consent to be a participant in this study, and to verify that you are at least 18 years of age.

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

## Appendix C

### Online Support Group Study Survey

- 1) What is your age?
- 2) Where are you from?
- 3) What is your gender?
- 4) At what age were you diagnosed with genital herpes?
- 5) Have you been diagnosed with HSV-1, HSV-2, both or unknown?
- 6) Where do you get information about genital herpes (for example... books, Internet, physicians, etc.)?
- 7) How long have you been participating in message boards for genital herpes information? When did you start participating in the message board(s)?
- 8) Which site(s) do you prefer and why?
- 9) Why do you visit these board(s)?
- 10) What do you feel are the benefits of using these message board(s)?
- 11) What are some concerns you have about using these message board(s)?
- 12) Are there any areas you would like more information about? (transmission, sexual behavior, symptoms, etc.)
- 13) Have you received emotional support from the boards? Please explain.
- 14) Have you received informational support (regarding aspects of the virus, transmission, outbreaks, etc.) from the boards? Please explain.
- 15) What type(s) of support do you get online that you don't get from health service providers?
- 16) Have you had any negative experiences with message boards? Have you had any negative experiences outside of the Internet (regarding genital herpes)? Please explain.
- 17) What is your overall impression of using the message board(s)?

18) Have you used the message boards for direct support (to find face-to-face support in your community)? Please explain.

19) Have you participated in a face-to-face support group? What was your overall impression?

20) What effect has using the message board(s) had for you in dealing with genital herpes? Has this changed over time?

21) Do you have any additional comments?