

# Common Questions about Herpes: Analysis of Chat-room Transcripts

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## KEY WORDS

■ HERPES SIMPLEX VIRUS ■ COUNSELLING ■ PATIENT EDUCATION  
■ HEALTH COMMUNICATION

## SUMMARY

Patients diagnosed with genital herpes typically undergo a period of psychological adjustment. Although healthcare providers can play a key role in this adjustment, in several patient surveys patients have expressed dissatisfaction with the information and counselling offered by professionals. To address this gap, providers must first identify the common questions and myths that are not addressed, or are addressed inadequately. This article is that first step. Through a content analysis of herpes chat-room transcripts captured on their website from autumn 2001 to spring 2006, researchers from the American Social Health Association identified common herpes questions and myths. The 1968 chat passages were coded into 12 themes and 50 sub-themes. Frequently, visitors' questions concerned transmission, symptoms and diagnosis followed by natural history, psychosocial issues and treatment options. The results of this analysis will aid in the creation of tailored messages to address common factual questions and provide psychosocial support.

## Introduction

GENITAL HERPES SIMPLEX virus (HSV) infection is one of the most prevalent sexually transmitted infections (STIs) found in the USA. According to the most recently published data from the National Health and Nutrition Examination Survey (NHANES), approximately 17% of individuals aged 14–49 years living in the USA are seropositive for HSV-2, the primary cause of genital herpes.<sup>1</sup> As a stigmatized infection with chronic recurrences and no cure, genital herpes can present challenges in patient management and care. The psychosocial impact of this diagnosis has been well documented and while a number of studies indicate that there is no significant, long-term psychological morbidity associated with diagnosis (particularly among individuals with asymptomatic or unrecognized infection), patients typically experience a period of psychological adjustment.<sup>2–5</sup> Factors that assist in this period of adjustment include time and social support, as well as education and counselling from providers.<sup>6–9</sup>

Yet while providers can play a key role in patient education and adjustment, data from several patient surveys reveal essential gaps in care, including dissatisfaction with the information and counselling offered.<sup>9–12</sup> In one recent international survey of 2075 patients, 51% of respondents were somewhat or very dissatisfied with provider care on physical/medical issues, while 63% indicated dissatisfaction with the treatment of emotional/psychological issues.<sup>12</sup> HSV transmission is another topic that is often covered inadequately.<sup>11</sup> For their part, physicians surveyed cite time constraints as a barrier to appropriate patient

counselling, and also highlight inadequate training and education about STIs.<sup>9,13,14</sup>

Indeed, patients surveyed indicate the need for additional information, often seeking resources on their own.<sup>9</sup> One factor that has been associated with greater patient satisfaction is the provision of written information and website referrals,<sup>12</sup> including resources such as health-related website chat-rooms. Chat-rooms allow individuals to communicate simultaneously, sending and receiving real-time text messages through computer networks that are hosted by organizations or individuals. Publicly accessible chat-rooms typically use client-server software and the 'chatters' log in to a chat-server computer, registering with an anonymous name.

Several studies have investigated the value of interactive website tools (e.g., virtual communities, electronic support groups, message boards, social networking sites) for seeking health information. These studies have found many user benefits, including: the opportunity to gain, seek, confirm and discuss information; experience sharing; and giving and receiving emotional and social support in a non-threatening and confidential way.<sup>15–18</sup> However, few studies have specifically investigated chat-rooms. One study investigated the efficacy of using a chat-room to promote HIV prevention for men who have sex with men, and found it to be a promising vehicle for health educators.<sup>16</sup> Another study investigated a pancreatic cancer chat-room, and found that the chatters were more likely to be family members rather than patients, female rather than male, and offer support rather than ask for it.<sup>17</sup> A third study of adolescents found that chat-room users were more likely to report psychological distress, a difficult living environment and a higher likelihood of risky behaviours.<sup>18</sup> In addition to little being known about chat-rooms, few published studies examine and describe the common concerns of patients with genital herpes.<sup>11</sup> The present study was conducted to identify common questions regarding genital herpes through a content analysis of herpes chat-room transcripts. Defining the most frequently asked questions (FAQs) can improve the patient–provider relationship by giving healthcare providers information about what education and counselling messages are required. This in turn enables individuals to make better-informed decisions about risk reduction and personal health strategies. Indeed, appropriate education and counselling of patients and their partners may be effective strategies to assist in the adjustment process and potentially reduce HSV transmission risk.

## Methods

From autumn 2001 to spring 2006, the American Social Health Association (ASHA) hosted a real-time herpes chat-room, using iChat® software (Austin, TX, USA).

Although service levels varied over time, typically the chat-room was open for several hours every weekday afternoon and was moderated by a trained and experienced health communication specialist. Visitors found the chat-room through a link on ASHA's *Herpes Resource Center* web pages. Chatters would link to a web page, register by selecting an anonymous name and enter into an electronic, online discussion with others, including the moderator. Visitors would ask questions about herpes, and the moderator (and other visitors) would respond. All text was routed to the moderator before posting so that inappropriate comments could be removed. An electronic transcript was archived for some, but not all, of the months of service. Transcripts from 23 months over the course of several years (January 2004 to March 2006) were available for analysis.

This study used a qualitative and quantitative descriptive approach to summarize questions asked over this 2-year period for which transcripts were available. The unit of analysis was a passage, which was either an implicit or an explicit question about genital herpes. Initially, two trained research assistants reviewed 1 month of transcripts and independently developed themes and sub-themes. This coding strategy was reviewed, discrepancies were resolved, the codebook was revised and samples for each theme were added. As unique themes emerged, the codebook was revised iteratively, and more specificity was added regarding inclusion/exclusion rules. Once all of the transcripts had been coded by two research assistants and the codebook was finalized, all transcripts were coded a third and final time by one of the authors (FO), who then compared and reconciled all codes. Data were coded using Nvivo® (QSR International, Bundoora, Victoria, Australia) qualitative software. This allowed for overall themes (trees) and categories within those themes (branches) to be quantified individually (by theme or sub-theme) or aggregated (rolled up into the overall theme). If the same person asked a question more than once, or framed it in a slightly different way and it fell into the same theme or sub-theme, it was not coded more than once. Themes that were mentioned by fewer than three respondents were excluded in this analysis, as were those questions that were miscellaneous or inappropriate. This approach allowed for the categorization, summarization, quantification and description of questions posed in the chat-room. The study protocol was reviewed and approved by an independent Institutional Review Board as qualifying for exemption from a full board review, because it met the criteria set forth in the Code of Federal Regulations (CFR), in 45 CFR 46.101 (b) (4).<sup>19</sup>

## Results

While the final codebook consisted of 13 themes and 82 sub-themes, only 12 themes and 50 sub-themes were used for this analysis. Any theme or sub-theme with fewer than three passages was recoded into a more general theme. All totalled, 1968 passages were coded from 592 unique login names. Six of the 12 themes accounted for 1774 passages, or 90% of the total number of questions coded. Thus, the following analysis considers only the six main themes, the most common sub-themes and relevant sample passages from these themes. Table 1 describes the themes with their respective sub-themes, frequencies and percentages.

### THEME ONE: TRANSMISSION

Transmission was by far the most frequent topic theme

**Table 1: Themes, sub-themes and frequencies of herpes-related questions reported by chat-room visitors**

Theme/sub-theme	Number (%)
Transmission	560 (28.5)
Risks from exposure	92 (4.7)
General/miscellaneous	86 (4.4)
Without symptoms	50 (2.5)
Prevention	48 (2.4)
Misconceptions	40 (2.0)
Non-genital areas	40 (2.0)
Reinfection	36 (1.8)
Symptoms	437 (22.2)
General/miscellaneous	116 (5.9)
Unsure of	64 (3.3)
Location	36 (1.8)
Frequency	31 (1.6)
Length	30 (1.5)
Cause	28 (1.4)
Diagnosis	259 (13.2)
Serology/blood tests	97 (4.9)
Screening/testing	50 (2.5)
General	48 (2.4)
Culture/swab	42 (2.1)
Natural history	235 (11.9)
General/miscellaneous	52 (2.6)
Asymptomatic viral shedding	38 (1.9)
Dormant-reactivation	31 (1.6)
Psychosocial impact	218 (11.1)
Social	97 (4.9)
Psychological	81 (4.1)
Dealing with it	35 (1.8)
Treatment	190 (9.7)
General/miscellaneous	99 (5.0)
Suppressive	41 (2.1)
Alternate	27 (1.4)
Seeking referral <sup>a</sup>	56 (2.8)
Miscellaneous <sup>a</sup>	46 (2.3)
Research issues <sup>a</sup>	33 (1.7)
Pregnancy issues <sup>a</sup>	32 (1.6)
Rates (incidence/prevalence) <sup>a</sup>	23 (1.2)
Legal issues <sup>a</sup>	4 (0.2)
Total passages coded	1968 (100)

<sup>a</sup>These are less frequent themes that were not analysed or reported.

(*n*=560), encompassing questions about risk from various exposures, transmission with and without symptoms, prevention (e.g., condoms, medication, sexual activity), misconceptions, transmission to non-genital areas, re-infection, HSV-1 and HSV-2 and acquisition. Within the transmission theme, the most frequent sub-theme was risk of acquisition or

transmission from specific exposures or situations. Questions frequently revolved around the likelihood of transmitting HSV-2 in specific scenarios: 'Do you have any idea, statistically, what the risk factor is for passing herpes through oral sex?' Next in frequency was the general sub-theme, which included questions about when a person is and is not contagious: 'If one has not had an outbreak in some time, transmission is still possible, but is it safer?' Many questions were asked about transmitting HSV-2 in the absence of symptoms: 'I have had this for 21 years now, I still feel like I get symptoms, but no outbreaks, can I still transmit it to my partner?' Although most of the prevention sub-theme questions were general in nature ('What are the ways of stopping transmission to an uninfected partner?'), some asked about the efficacy of specific methods such as using condoms. There were many questions concerning myths and misconceptions about transmission, including whether it is possible to acquire HSV-2 infection from mosquitoes, blood, menstrual blood, needle sticks, semen, saliva, nasal mucus, bodily fluids, clothes or linens. Others were concerned about auto-inoculation to non-genital areas (for example, touching or washing an infected area of their body, then touching another part of their body [e.g., face, mouth, eyes, hands]). Finally, questions about re-infection with the same type were common: 'Can two people who have it make it worse for each other?'

### THEME TWO: SYMPTOMS

Many questions were about symptoms (*n*=437), including general questions about what they might be, the location, frequency, length of time, severity and causes of outbreaks. First and foremost, general questions within this theme were about how soon an outbreak could occur after exposure, if the primary genital herpes outbreak is always the most severe, what the typical number of outbreaks is and if they decrease over time. Following this, the next most common sub-theme was whether or not certain symptoms could be caused by genital herpes, such as frequent urination, tingling or burning, bumps, sores or clusters of sores, blisters, pimples, cuts, white or red spots; swollen, itchy, dry, red skin or rash on skin or influenza-like symptoms. Women specifically asked about vaginal pain, soreness, swelling, itching and discharge, uterine cramping and yeast infections, while men specifically inquired about dry skin, pimples, white or clear bumps, red spots on penis or urethral irritation. Less frequent were questions about oral symptoms such as swelling or small bumps on the back of tongue or gum. There were many questions about the location of outbreaks and if they could occur internally, externally, or in multiple places simultaneously. Next, chatters wanted to know the average number of genital herpes outbreaks that they could expect, or if their situation was 'normal'. Others were interested in how long symptoms usually lasted and how one would know when an outbreak is over ('completely healed'). Similarly, others wanted to know what causes outbreaks including whether specific foods, a poor diet, lack of sleep, medications, stress, wearing tight clothing, weakened immune system, illness, sun, frequent sex, friction or alcohol could trigger outbreaks. Others wanted to know if an exercise regimen, eating/avoiding certain foods (coffee, nuts), or something unknown could reduce or prevent outbreaks: 'Has anyone discovered something other than prescriptions to slow down outbreaks?' asked one chatter.

### THEME THREE: DIAGNOSIS

The third prominent theme involved genital herpes diagnosis (*n*=259) with sub-themes that included, most often, inquiries about blood tests, general screening and testing, and culture/swab tests. While there were more specific questions about serological tests than culture/swab tests, the questions were similar. Chatters were interested in how the types of tests differ (differentiate HSV-1 from HSV-2, oral from genital and old from new infection). Questions regarding appropriate timing and testing – referring both to incubation period and timing of test results – were common: 'Generally, how long should a blood test and culture take to get results?' Chatters inquired about which type of test is most accurate and what to do about suspected false-positive, -negative, mixed or inconclusive results. Screening and testing queries centred around testing or screening locations, what types of providers, practices or health facilities test (e.g., dermatologists, obstetricians/gynaecologists), and why many healthcare providers and clinics do not test for HSV infection: 'Why don't they routinely test for herpes if it is so common?' General questions centred around whether or not a genital herpes test is typically included in STI screening and testing, and when testing is recommended. Others wanted to know how to be absolutely certain whether or not they had genital herpes. Many chatters wanted to know how to find affordable testing and how to ask for the test: 'What would I need to say to make this the least embarrassing for me when I go to them?'

### THEME FOUR: NATURAL HISTORY

Many chatters were interested in the natural history of herpes as evidenced by queries about the virus types in general, asymptomatic viral shedding, and dormancy/reactivation (*n*=235). The most frequent sub-theme within this category was general questions about the differences between HSV-1 and HSV-2: could one type cause or confer immunity from the other, could oral migrate to genital, or genital to oral? Others asked about consequences: 'Is it really as big of a deal as I am making it?' And there were numerous questions about consequences: 'Are there potential long-term effects of having this virus, other than being more susceptible to other STIs?' Of interest, several asked if genital herpes is hereditary. The second most common sub-theme was asymptomatic viral shedding, with questions about how one detects shedding, signs of shedding, contagiousness while shedding, the range and average number of days most people shed, and if shedding decreases over time. In addition, questions were raised regarding oral herpes and shedding and if shedding is the same with HSV-1 as it is with HSV-2. There were questions within the sub-theme of dormancy and reactivation about how long the virus could remain dormant, and how long one could have it and not transmit it: 'But how could I not have transmitted it to him in 45 years?'

### THEME FIVE: PSYCHOSOCIAL IMPACT

In contrast to the many factual questions, many asked explicitly or implicitly for emotional or social support. In terms of psychosocial impact, three sub-themes emerged: social ramifications, psychological impact and coping with psychosocial issues. Within this category, more people were concerned with the social consequences than the psychological aspects of genital herpes. Most often, questions were about how to tell a partner: 'My partner does not know I have herpes, how can I tell him?' Also, many asked about dating ('I want to know how people handle dating') and whom it is

necessary to tell (e.g., partners, physicians, parents). Regarding the psychological impact, more than 50 different words were used in describing the emotions associated with a genital herpes diagnosis. These fell into several broader categories: non-specific negative emotions (e.g., 'I'm having a hard time' or 'freaking out'), depression (isolation, crying), anger, disbelief, punished (guilty, ashamed, dirty, tarnished) and afraid. The range of emotion was notable, from mild to 'a death sentence.' And many sought support, including how to comfort a recently diagnosed partner or child, and how to 'get over', 'deal with', 'accept', 'find peace with' or 'cope with' the psychological and/or social issues.

#### THEME SIX: TREATMENT

Treatment was the final of the six most common themes ( $n=190$ ), and consisted of three main sub-themes: general questions, suppressive treatment and alternative therapies. Many chatters wanted general information about the various antiviral medications, including which compounds were indicated for which situations. Also, many wanted to know how to decide whether or not to take medication with their particular number of outbreaks, or if more medication was needed if outbreaks continued to recur. They were curious to know if outbreaks would recur once medication was stopped and about how long it would take to begin working: 'Would Zovirax® reduce symptoms pretty quickly?' Specific suppressive-medication questions usually related to treatment duration: 'Is it possible to become immune if you take it every day?' followed by what will prevent transmission: 'Does Valtrex® help to prevent spreading genital herpes?' Also common were questions about side-effects: 'Suppressive therapy – any downside?' Others wanted to know more about it: 'What exactly is suppressive therapy and what does it consist of?' The next most frequent sub-theme included queries about the effectiveness of alternative treatments including natural remedies, supplements and immune boosters. Finally, questions about episodic therapy included when to use it and how long to use it.

#### MISCELLANEOUS THEMES

The remaining six themes had a range of four to 56 passages within each. Referrals ( $n=56$ ) were sought for literature, chat-rooms, support groups and websites. Research issues ( $n=33$ ) included asking about a cure for genital herpes and vaccine information. The remaining three themes did not have sub-themes and so were general questions related to each theme. It is notable that only four visitors asked about legal issues. Table 1 lists the 12 themes, the most frequent sub-themes under the six most common themes and the frequency of questions coded to each.

#### Conclusions

This study was conducted to identify common questions presumably unanswered by other informational sources including healthcare providers, websites and hotlines. The findings point out common informational and emotional needs of people or their partners who suspect they have, or have confirmed, genital herpes. Content analyses of these transcripts indicated that factual questions predominantly concentrated around five themes: transmission (including acquisition), symptoms, diagnosis, natural history and treatment. For the sixth theme (psychosocial issues), emotional support was sought rather than factual information.

Common questions about transmission indicate a

need to provide very specific information about how genital herpes is (and is not) transmitted, and from which parts of the body. People want to know their statistical risks of acquiring or transmitting HSV from specific exposures and scenarios (e.g., oral sex, using condoms, using medications, when there is no outbreak). Preventing transmission is a common concern and many need assistance with decisions about taking antiviral medication, using condoms and discussing herpes with partners.

Symptoms covered the second most frequent overall theme. Because genital herpes symptoms can be absent or include various expressions, it is important for healthcare providers to educate all patients about the various manifestations of outbreaks, as well as the issue of viral shedding. Evidence suggests that once patients are educated about symptoms, they are better able to identify outbreaks.<sup>20</sup> Furthermore, explaining how people differ in what is 'normal' in terms of outbreak frequency, severity, location, migration and reduction over time may reassure patients. People want to know what behaviours and activities are associated with outbreaks and what are not.

In terms of diagnosing genital herpes, the third most common theme for chat-room questions, clearly the general public needs information about the appropriate uses of screening and testing. Of note, many chatters were incredulous that people are not more routinely screened for HSV-2, given the seroprevalence of this viral infection in the USA. Explaining recommendations for who should be screened and tested, when to be tested for the most accurate results, and the pros and cons of the various tests available to detect both HSV-1 and HSV-2 will help those at risk.

Healthcare providers can also educate patients about the natural history of HSV, simply describing the potential for reactivation, the two virus types and two locations of initial infection and the manageability of the virus through treatment and prevention strategies. Describing the true risks from infection, dispelling myths about severe long-term consequences, and reassuring patients that outbreaks generally are fewer and less severe over time, is also warranted.

Perhaps the most difficult topic is the psychosocial impact surrounding genital herpes. De-stigmatizing this condition is essential in stopping its spread. The most important message to relay is that genital herpes is exceptionally common and that most people do not have serious long-term physical consequences. In this analysis, many patients were seeking support and advice about how to disclose a genital herpes diagnosis to a partner. Chatters noted a great deal of embarrassment in asking for advice, even when their identity was completely anonymous. Healthcare providers may want to consider discussing whom to tell, how to tell, when to tell, and also reassuring patients to ask their partners to get tested also, as many may already be HSV-positive. Furthermore, some patients need additional reassurance that genital herpes is not the end of fulfilling romantic and sexual relationships. Finally, providing resources and referrals will allow each individual the full scope of options to address psychological and/or social issues when and if needed.

In terms of treatment, it is important to clarify and describe the different goals of selecting and taking daily or episodic antiviral medications to prevent (or shorten) outbreaks, or to prevent transmission. Patients want to know more about prescription medications, such as when they are needed, for how long, when to stop taking them, and potential side-effects or consequences

of short- or long-term use of therapy. Many patients also want to know if alternative products or natural remedies are effective for reducing outbreaks.

Several study limitations invite caution with interpretation and generalization. First, visitors were not asked any demographic questions when registering for the chat-room; anonymous usernames were required, therefore no information about the age, gender, racial, ethnic, economic, or regional make-up of visitors is available. Additionally, while many of the chatters suspected they had, or had been diagnosed with genital herpes, others were sexual partners or potential partners and this information was not collected. Therefore, more extensive analyses to detect associations between questions asked and other variables were not possible. In addition, it is possible that the same visitor returned on more than one occasion using a different login; thus, their concerns or questions were counted more than once.

Nonetheless, this information provides a valuable first step in developing themes for future data collection and analyses. This information is also useful for developing tailored responses that healthcare providers might use to address questions posed by those newly diagnosed or living with genital herpes and their partners. Developing messages that target patients' FAQs and concerns increases patients' knowledge, debunks myths and misconceptions, bolsters patient-provider relationships and allows patients to make informed decisions regarding health and risk-reduction strategies.

More research is needed in the following three areas: to monitor questions to detect changing trends over time; to assess the impact of messages developed; and to find dissemination avenues for messages to reach healthcare providers and the general public, including

patients and their partners. In future analyses, it would be interesting to know the demographic characteristics of visitors including gender, age group, region and HSV status. With this information, comparisons by group that yielded significant differences would assist educators with tailoring messages for specific populations.

Many resources now exist for patients and their partners. Since this analysis was conducted, the ASHA chat-room (which had limited hours of operation) has evolved into a moderated message board that is accessible online 24 h per day, 7 days a week.<sup>21</sup> Healthcare providers can refer patients to this and other sources of credible information and support, such as the Center for Disease Control and Prevention (CDC) website<sup>22</sup> or the main ASHA website.<sup>23</sup>

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#### Conflicts of Interest

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