

Genital Herpes Education and Counselling: Testing a One-page 'FAQ' Intervention

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KEY WORDS

■ GENITAL HERPES ■ HEALTH EDUCATION ■ PUBLIC HEALTH
■ HEALTH COMMUNICATION

SUMMARY

Approximately 17% of adults in the USA have antibodies to herpes simplex virus type 2 (HSV-2), 85–90% of whom are unaware of their infection. Diagnosed patients are more likely to detect HSV reactivation, disclose infection status to partner(s) and employ risk-reduction strategies; therefore, diagnosing more cases may reduce herpes transmission rates. Providers are reluctant to identify genital herpes because of potentially lengthy counselling visits or discomfort in dealing with patients' emotional reactions. This study tested the efficacy of a one-page frequently-asked-questions (FAQ) sheet regarding length of initial diagnostic visit, patient satisfaction with topics covered, provider's coverage of topics and resources/referrals provided to patients. Data from 147 patients and 26 providers were analysed. When pre- and post-FAQ sheet data were compared, diagnostic visit time was not substantially reduced but there were favourable trends in patient satisfaction levels on some topics, and providers covered more topics and offered more resources. This FAQ was useful in simplifying topics, providing prompts for providers and resources for patients. While this FAQ sheet appears favourable in this exploratory study, more investigation is needed to measure the degree to which patients use and understand the FAQ sheet, and find it to be a helpful tool.

Introduction

WORLDWIDE, GENITAL HERPES is a common infection. In the reported literature, approximately 17% of adults in the USA have antibodies to herpes simplex virus type 2 (HSV-2), of whom 85–90% may be unaware of their infection.^{1,2} Those who are diagnosed with HSV-2 infection are more likely to detect reactivation, disclose their seropositivity to partner(s) and use antiviral medications and/or condoms to prevent transmission.^{3–5} Thus, diagnosing more cases may reduce transmission rates.

Yet barriers exist that prevent adequate detection rates. The advent of type-specific HSV serological testing has enhanced our ability (at the clinical level) to diagnose genital herpes more accurately, but many clinicians are reluctant to screen or test for HSV, for a variety of reasons. Much of the literature suggests that, among asymptomatic patients, the psychological impact of diagnosis from serological screening is minimal.^{6–10} Among clinicians who are reluctant to perform HSV-2 screening, however, one obstacle appears to be the perception that asymptomatic patients will mirror the (often strong) negative reaction

to genital herpes that is found among symptomatic patients. While the psychological effects of a positive diagnosis vary, some have suggested that all diagnoses require a discussion about transmission and prevention, regardless of whether or not the patient is symptomatic.¹¹ This in turn requires additional time and skill in patient education and counselling. Additionally, clinicians' perceptions of genital herpes as a treatable disease with minimal health impact can also deter screening, testing, counselling and preventive education strategies.¹² Finally, some providers believe that diagnosing patients with asymptomatic HSV-2 infection does not lead to behavioural change.⁶ Among patients, additional barriers exist: they report that embarrassment, lack of empathy by providers and perceived judgement inhibit the counselling process.^{13,14} Such constraints on the patient–provider dialogue represent squandered opportunities to diagnose, treat, discuss risk-reduction strategies, encourage preventive behaviours and, ultimately, to reduce transmission of genital herpes to others.

To address these issues, we undertook a small exploratory study to test the effectiveness of a one-page frequently-asked-questions (FAQ) sheet. Designed to simplify the education and counselling messages recommended by the Centers for Disease Control and Prevention (CDC) for both providers and patients,¹⁵ the FAQ sheet consisted of nine topics and several resource listings for patients who have additional questions or want emotional support after the first diagnostic visit.¹⁵ Our first hypothesis was that providers could reduce the duration of the initial diagnostic visit if they used the FAQ sheet, based on our theory that providing them with brief and succinct talking points would focus the discussion and allow essential topics to be covered quickly. Our second hypothesis was that providers would cover more topics if they used the FAQ sheet (also based on an assumption that talking points would remind the providers to cover all of the recommended topics). The third hypothesis was that patient satisfaction would improve if the FAQ sheet were used. Finally, our fourth hypothesis was that both patients and providers would report that more resources were provided as a result of distributing the FAQ sheet, which included referrals and resource information.

In theory, improving patient and provider satisfaction and comfort with the diagnostic visit could improve rates of genital herpes testing, diagnosis, treatment and other prevention activities (such as condom use and disclosure, which have been associated with reducing HSV-2 transmission).^{3,4,16}

Frequently Asked Questions about Genital Herpes



1. What is genital herpes?

Genital herpes is caused by a virus called the herpes simplex virus (HSV) that travels from the skin to the nervous system where it stays in the body. There are two types: HSV-1 and HSV-2. Some people do not have any symptoms, some do not recognize symptoms and some have symptoms anywhere below the waist or above the thigh. Symptoms might include tingling, itching, sores, blisters, splits, cuts, bumps, pimples, redness, aches and pains in the genital area, or flu-like symptoms. These symptoms can reappear (called "a recurrence") weeks, months, or years later. Anything that could weaken your immune system (such as illness, poor diet or sleep, emotional or physical stress) could allow a recurrent outbreak. Symptoms usually heal within two to 12 days, but can last longer.

2. How did I get genital herpes?

Genital herpes is a sexually transmitted infection that is spread from skin-to-skin contact in one of two ways: by receiving oral sex from someone who has oral HSV infection or by having genital-to-genital or genital-to-anal contact with someone who has genital herpes. Although genital herpes can be spread by an infected person who has symptoms ("an outbreak"), it can be spread between outbreaks or when there are no symptoms (called "asymptomatic viral shedding"). In most cases, it is difficult to know how long you have had genital herpes, who gave it to you, and how long they may have had it.

3. How common is it?

Genital herpes is very common. In the U.S., about one in five adults have genital herpes (about 50 million) and most do not know they have it.

4. How can I reduce the risk of giving this to someone else?

If you have symptoms, abstain from all sexual activity until they are gone. Since most genital herpes is spread when no symptoms are present, using daily antiviral medication can reduce the risk of giving someone genital herpes whether you have symptoms or not. (Valtrex® is the one that has been FDA approved for this). Using latex condoms consistently and correctly will also reduce the risk of transmission.

5. Can medication prevent or reduce outbreaks?

Taking daily antiviral medication (called "suppressive therapy") can reduce the number and severity of outbreaks. Taking antiviral medication only when symptoms appear (called "episodic therapy") can shorten the length of the outbreak by one to two days.

6. What if I have emotional or social effects from having genital herpes?

Myths about the virus are common, and so getting accurate information and emotional support will help you overcome any potential anxiety or depression that some experience.* Herpes is a common, manageable virus that anyone who has ever had sex could have. Individuals with herpes can have the same loving relationships that anyone can.

7. How do I talk to a partner about genital herpes?

All persons with genital herpes are encouraged to inform their current sex partners that they have genital herpes and to inform future partners before initiating a sexual relationship. Being calm, confident, honest, and making it a two-way discussion are important. Encourage a partner to get facts and be tested for genital herpes to see if they already have it.

8. Are there pregnancy and childbirth risks?

It is uncommon for herpes to cause problems with pregnancy. Still, herpes can be passed to a baby during delivery causing Neonatal Herpes, so talking to your healthcare provider about it is important. The highest risk for the baby is when a woman first gets new herpes late in pregnancy. A pregnant woman who does not have herpes, and who has a sexual partner with genital or oral herpes is encouraged to avoid intercourse or receiving oral sex during the third trimester.

9. Where can I get emotional support and more information about herpes?

Contact ASHA's STI Resource Center:
1-888-411-4377

Send an e-mail to: info@ashastd.org

Visit: www.ASHAstd.org or
ASHA's STI Message Board at
www.ASHAstd.org/phppbb/index.php

Figure 1: One-page HSV FAQ for providers to use when counselling newly diagnosed genital HSV patients. The FAQ covers the nine topics identified by the American Social Health Association (ASHA) as being most important to patients.

Methods

Our study was designed to compare survey responses from providers and newly diagnosed patients before and after using a brief (one-page) sheet that addressed nine topics, following a question and answer format (FAQ sheet, Figure 1). Topics were developed from the CDC 2006 Treatment Guidelines and from prior research.¹⁵ In addition, the FAQ sheet was reviewed by three experts in herpes research and clinical practice.

Physicians, stratified by speciality (general practice, family practice, internal medicine, and obstetricians/gynaecologists [OB/GYNs]) and gender, were randomly selected from the American Medical Association (AMA)'s e-mail membership list. All members of the Nurse Practitioners in Women's Health

(NPWH) professional organization were also invited to participate. To recruit participants, e-mail invitations were sent by third parties. Interested healthcare providers were linked to a web page that contained study information, downloadable consent forms and instructions for participation.

On receipt of a signed informed consent form, providers were sent study packets with pre- and post-FAQ surveys, FAQ sheets, patient educational materials and instructions for study completion. Each provider was asked to recruit 10 eligible patients: five to complete pre-FAQ surveys and five to complete post-FAQ surveys. Providers were also asked to complete five surveys before and five after, using the

FAQ sheet. Eligibility criteria for patients included being ≥18 years of age, not being pregnant, and being diagnosed as HSV-2-positive through serological testing. Providers were asked to acquire patients' verbal informed consent. Providers were offered US\$300.00 for participating in the study and compensation was given *pro rata*, based on an individual's level of participation.

Each patient participant completed the survey and returned it, in a sealed envelope, to their provider. Each provider returned all pre-FAQ provider and patient surveys together; subsequently, all post-FAQ surveys were returned. Finally, all mailings went into postage-paid envelopes. Patients received no financial compensation but were given resource and referral information (including a DVD about genital herpes, and *The Helper* newsletter); those in the post-FAQ group also received a copy of the FAQ. Patient identification was completely anonymous, as only verbal consent was obtained by each provider and no identifying information was collected. Reminder e-mails were sent and telephone calls made as required, to encourage providers to complete the study. Provider names and addresses were collected for the sole purpose of sending compensation.

Two surveys were developed, which were largely identical, to collect basic demographic data (age, gender, race/ethnicity) and healthcare characteristics (clinic setting, date and type of diagnosis, time spent with provider). Patients were asked a global question about their overall satisfaction with the diagnostic visit. All participants were asked about the following topics: prevalence rates, natural history (including recurrence), symptoms/asymptomatic viral shedding, testing/diagnosis, transmission, suppressive and episodic treatment, condom use, disclosure to partner(s), neonatal herpes risk and psychosocial impact. Patients were asked how satisfied they were with their provider's coverage of each topic and providers were asked whether or not each topic was covered. Finally, all participants were asked about the resources provided (e.g., written information, referrals to support groups, hotlines). Survey data were coded and entered into Microsoft® Excel 2000 (version 9.0, Bellevue, WA, USA) by two independent research assistants, then analyzed using SPSS® software (version 16.0, Chicago, IL, USA). Descriptive statistical analyses were conducted to summarize demographic and health characteristic data; χ^2 analyses were conducted to compare pre-intervention and post-intervention categorical data. *P*-values <0.05 denoted statistical significance. The study was approved by an independent review board.

Results

In an effort to receive packets from 30 healthcare providers, 59 providers were recruited (all of whom completed consent forms). After numerous e-mail and telephone reminders, 26 providers returned surveys (44%). During the follow-up telephone reminder calls, providers indicated a reluctance to recruit patients who were emotional after receiving the diagnosis, adding that many patients refused to participate. While the study protocol requested that providers complete up to five surveys before using the FAQ, and up to five following the use of the FAQ, 197 provider surveys were returned – an average of seven from each provider. Of those, 148 were eligible for inclusion in the data analysis; 75 pre-FAQ and 73 post-FAQ surveys. Surveys

were deemed unusable if patients were not newly diagnosed, if the patient had been diagnosed through visual examination only, or if the answers appeared to have been collected by the healthcare provider rather than by the patient.

Eight of the providers were male (30.8%), and 18 were female (69.2%); four (17%) were 25–34 years of age, nine (39.1%) were 35–44 years of age and 10 (43.5%) were over 45 years of age; range of years since graduation was 4 to 27 (mean, 14 years); exactly 50% were medical doctors and 50% were nurse practitioners. Eighteen (78.3%) worked in private practice, three (13.0%) were based in public-health settings, and two (8.6%) worked in emergency room or other settings.

Of the 200 patient surveys returned, 147 (74 pre-FAQ, and 73 post-FAQ) were usable. Criteria for usability were the same for patients. There were no statistically significant differences between the age, gender and educational levels of the patients who completed pre- and post-FAQ surveys (demographics are aggregated in Table 1).

To test the first hypothesis, patients and providers

Table 1: Demographic characteristics of patients newly diagnosed with HSV-2 infection who completed pre- and post-FAQ surveys (n=147)

Characteristic	Number (%)
Age, years	
<24	52 (35.4)
25–34	48 (32.7)
35–44	32 (21.8)
45+	15 (10.2)
Gender (n=147)	
Male	20 (13.6)
Female	127 (86.4)
Education (n=146)	
Some high school	13 (8.9)
High school graduate	38 (26.0)
Some university	46 (31.5)
University graduate	36 (24.7)
Post-graduate	13 (8.9)

were asked to estimate the length of time that the provider spent educating and counselling the newly diagnosed patient. Time estimates were stratified into four categories: <5 min; 6–10 min; 11–15 min; and >15 min. The reported times did not differ between patient and provider groups, nor did they decrease from pre- to post-FAQ use. Most patients (46%) reported (before and after using the FAQ sheet) >15 min; 27% said 11–15 min, 20% said 6–10 min and 7% reported <5 min were spent on education and counselling.

To test the second hypothesis, providers were asked to report which of the topics they did and did not cover, as well as topics for which the patient did not want information or counselling. For this analysis, only the first two categories were compared. Topics fell into three general categories of results:

1. Most providers (>95%) already discussed the topics pre-FAQ, leaving no room for improvement
2. Topics were discussed considerably more after using the FAQ
3. No difference pre- or post-FAQ, despite using the fact sheet.

How genital herpes recurs, how it can be

transmitted (asymptotically or when symptoms are present), asymptomatic viral shedding and episodic treatment were discussed frequently, both before and after using the FAQ sheet, thus differences were undetectable. Some topics were covered more often after using the FAQ, including: how common genital herpes is, suppressive treatment, transmission prevention using medication, dealing with the psychological impact of genital herpes, partner disclosure and pregnancy. Discussion of several topics, including using condoms to prevent transmission and dealing with the social impact of genital herpes, did not change significantly after the FAQ sheet was used. Table 2 describes the results of all 13 topic categories.

The third hypothesis, which predicted patient satisfaction levels would increase after using the FAQ, was tested by two measures. First, a global measure of patient satisfaction increased significantly when pre- and post-FAQ scores were dichotomized into two categories (very satisfied and satisfied versus not sure, unsatisfied and very unsatisfied) and then compared

($\chi^2=9.07$; $P=0.008$). Secondly, patients rated a series of individual topics in terms of satisfaction with the education and counselling provided. Response categories were dichotomized into 'satisfied' (just right, received information and wanted it) and 'dissatisfied' (too little, too much, received information and did not want it, didn't receive information and wanted it). On all topics, patient satisfaction trends were toward the more positive following use of the FAQ; however, only the topic regarding how common herpes is reached statistical significance ($\chi^2=4.819$; $P=0.028$).

To test the fourth hypothesis, patients and providers were asked if they received/provided the following resources: fact sheet; booklet; DVD or brochure; website links to information; referrals to hotline or e-mail answering services; website links to patient/chat groups; or referrals to psychological counselling/support groups. Patients reported no statistically significant differences, whereas providers reported significant increases in resource provision (Table 3).

Table 2: Topics covered by providers before (and compared with after) using the 'FAQ' sheet

	Pre-FAQ n=75 (%)	Post-FAQ n=73 (%)	χ^2 test	P-value
How common genital herpes is	69 (94.5)	72 (98.6)	4.057	0.044
How it recurs	72 (100)	72 (98.6)	NS	NS
How it can be transmitted when symptoms are present	73 (100)	72 (98.6)	NS	NS
How it can be transmitted without symptoms	72 (98.6)	71 (97.3)	NS	NS
Asymptomatic genital herpes	72 (98.6)	71 (97.3)	NS	NS
Treatments that suppress outbreaks	68 (93.2)	73 (100)	5.177	0.023
Episodic treatments	70 (97.2)	73 (100)	NS	NS
How to prevent transmission with medication	65 (90.3)	72 (98.6)	4.851	0.028
How to prevent transmission by using condoms	65 (89.0)	69 (97.2)	NS	NS
How to deal with the psychological impact of genital herpes diagnosis	41 (61.2)	54 (81.8)	6.93	0.008
How to deal with the social impact of genital herpes	48 (69.6)	55 (80.9)	NS	NS
How to tell a partner	52 (74.3)	63 (90.0)	5.892	0.015
Pregnancy issues	47 (79.7)	49 (98.0)	8.665	0.003

NS, not significant

Table 3: Pre- and post-FAQ provider reports of resources and referrals

	Pre-FAQ n=75 (%)	Post-FAQ n=73 (%)	χ^2 test	P-value
Fact sheet, booklet, DVD or brochure	67 (89.3)	70 (95.9)	6.24	0.044
Website links to information	51 (68.0)	67 (84.9)	10.446	0.005
Referrals to hotline or e-mail answering services	29 (38.7)	45 (61.6)	17.561	<0.001
Website links to patient/chat groups	32 (42.7)	42 (57.5)	14.67	0.002
Referrals to psychological counselling/support groups	23 (30.7)	34 (46.6)	9.791	0.02

NS, not significant

Discussion

Many, if not most, patients newly diagnosed with genital herpes need immediate education and counselling, as well as referrals for inevitable future education and/or counselling needs. Providers may want a simplified method to ensure that they cover the wide range of topics associated with a new diagnosis comprehensively: this range of topics covers emotional, social and sexual aspects of herpes, as well as its physical aspects. Giving healthcare providers a one-page FAQ sheet was expected to reduce the amount of time needed for the initial diagnostic visit, increase the number of topics adequately addressed, increase patient satisfaction with the clinic visit and increase resources provided to newly diagnosed patients.

Our first hypothesis was not supported. Using the FAQ sheet did not significantly reduce the time spent educating and counselling newly diagnosed patients, perhaps because it encouraged providers to cover more topics and also may have prompted more discussion.

Regarding the second hypothesis, after using the FAQ sheet, providers were significantly more likely to address five topics: treatment to suppress outbreaks; preventing transmission with medication; dealing with the psychological impact; disclosing to a partner; and pregnancy issues. Because coverage of the remaining topics did not significantly change, improvements to the FAQ sheet may be needed or improved measures developed. Interestingly, three of the topics that were discussed least, both before and after using the FAQ sheet, were psychosocial in nature (the psychological and social impacts, and disclosing to a partner). While ratings improved on these measures there is still room for more improvement, and patients frequently need psychosocial reassurance, according to other studies.¹³ These topics warrant more emphasis on future iterations of this FAQ sheet.

The third hypothesis was partially supported. On a global measure of patient satisfaction, higher levels of satisfaction were reported after using the FAQ sheet, compared with before. While most the 13 individual topics indicated improvement, improvement was statistically significant for only one (how common genital herpes is) and the remaining topics ranged from 'approaching significance' (how herpes can be transmitted when symptoms are present or not present, treatment to suppress outbreaks, how to prevent transmission with medication or with condoms) to little if any improvement (recurrence, asymptomatic infection, episodic treatment, psychological and social impacts, disclosure, and pregnancy issues). Compared with other studies, patients in this sample reported high satisfaction levels on all items before and after the study that may indicate a ceiling effect, and may explain why patients did not report significant increases in satisfaction on many of the items. Conversely, perhaps the content associated with such items needs to be revised.

Perhaps more importantly, dissatisfaction with counselling was reported twice as much before using the FAQ compared with after (15.1% versus 7.5%). Other research has indicated that patients often experience emotional trauma with HSV diagnosis, and data from the American Social Health Association's contact centres report that many patients with genital herpes seek further support following the diagnostic clinic visit.¹⁷ Of note, patients did not report increased satisfaction with counselling regarding psychological issues. Compared with all topics, the psychosocial

topics were least likely to have been discussed, before and after using the FAQ sheet. Providers should be aware of the potential for psychosocial distress in newly diagnosed genital herpes patients and be proactive in offering resources and referrals.

As far as the fourth hypothesis is concerned, providers reported offering resources (such as fact sheets, booklets, DVDs, brochures with referrals to hotlines, e-mail and chat services, and psychological/support groups) significantly more often after using the FAQ sheet than before. Because patients often have questions after, rather than at the time of, diagnosis and it is known that addressing questions can improve satisfaction and adjustment and indirectly reduce transmission to partners, this was a positive finding. Curiously, patients did not report a corresponding increase in resource provision. Perhaps this is because all patients were given resources and the patients who were not given the FAQ sheet would be unaware of not receiving it, whereas providers would know the resources given to patients both pre-FAQ and post-FAQ.

During the study, a number of providers offered solicited and unsolicited feedback. In summary, although it was difficult to recruit and retain participants throughout the study, on the whole, physicians, nurse practitioners and their patients found the FAQ sheet to be valuable. Based on data from this pilot study, we recommend improving and retesting this FAQ sheet. Specifically, we recommend enhancing information given about psychosocial issues, using condoms for prevention and pregnancy concerns as a priority. In addition, an instruction sheet for providers may improve use. Asking patients to check off the boxes of information that they want prior to the counselling visit would also hasten the discussion. And finally, adding a non-threatening quiz or game to test comprehension and understanding of herpes facts may help providers know which topics may warrant further and/or future discussion.

These findings are limited by a variety of factors. First, the small patient and provider samples may lack the power to detect significant differences (such as satisfaction levels). Because of the self-selection of providers and their patients, it is not known how well these samples represent all US-based patients and providers; thus, the ability to generalize these findings to other groups is questionable. Demographic comparisons with prevalence data indicate a disproportionate number of participants of younger (compared with older) age groups, and the ratio of females to males was also disproportionate, even though females have higher HSV-2 seropositivity rates than males. Also, the self-reported nature of the data precludes verification. Furthermore, it is not known why patients were screened or tested (e.g., whether they were symptomatic, exposed to HSV-2 or worried). Neither the extent to which the FAQ sheet was actually used by patients or providers, nor the degree to which the information was understood, is known. Finally, informational needs may differ by medical practice speciality, geographic location or other factors that are not detectable by this small sample.

A more robust follow-up study is warranted. Such research would include larger sample sizes and in-depth structured interviews to determine actual use, and would collect patient and clinician recommendations for improving the FAQ sheet. Then, once the FAQ sheet is improved and revised, a study to test its longer-term impact on both patients and

providers is warranted. It would be useful to know if improving the initial diagnostic visit would actually encourage providers to test, diagnose and treat more patients in future. Finally, testing the theory that improving patient satisfaction and comfort with the diagnostic visit would lead to preventative activities, (use of antiviral medications, condoms, etc.) and ultimately reduce the number of additional genital herpes cases, will be essential.

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Conflicts of Interest

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