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Attitudes and Willingness to Assume Risk of Experimental Therapy to Eradicate Genital Herpes Simplex Virus Infection

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Abstract

Background—Current treatment of genital herpes is focused on ameliorating signs and symptoms but is not curative. However, as potential HSV cure approaches are tested in the laboratory, we aimed to assess the interest in such studies by persons with genital herpes, and the willingness to assume risks associated with experimental therapy.

Methods—We constructed an anonymous online questionnaire that was posted on websites that provide information regarding genital herpes. The questions collected demographic and clinical information on adults who self-reported as having genital herpes, and assessed attitudes toward and willingness to participate in HSV cure clinical research.

Results—711 participants provided sufficient responses to be included in the analysis. 66% were women; the median age was 37 years, and the median time since genital HSV diagnosis was 4.7 years. The willingness to participate in trials increased from 59.0% in Phase 1 to 68.5% in Phase 2 and 81.2% in Phase 3 trials, and 40% reported willingness to participate even in the absence of immediate, personal benefits. The most desirable outcome was the elimination of risk for transmission to sex partner or neonate. The mean perceived severity of receiving a diagnosis of genital HSV-2 was 4.2 on a scale of 1 to 5.

Conclusions—Despite suppressive therapy available, persons with genital herpes are interested in participating in clinical research aimed at curing HSV, especially in more advanced stages of development.

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Keywords

HSV; genital herpes; cure; clinical trials; experimental therapy

Introduction

Treatment of genital herpes relies on episodic or chronic use of antiviral therapy (1). While such therapy ameliorates the symptoms and lesions of HSV, the natural course of the disease is unaltered once antiviral therapy is stopped (2). In addition to the discomfort of the recurrent genital lesions, genital HSV is associated with stigma, which in many people is more burdensome than the clinical symptoms (3, 4). Such patients often request a curative intervention which would relieve them of the clinical disease as well as the need to disclose their status to sexual partners.

While cure of chronic viral infections seemed improbable several years ago, HIV cure is currently an active research area with several investigational approaches, and at least one patient has been cured following hematopoietic stem cell transplantation (5–9). An assessment in HIV-1 seropositive individuals in the United Kingdom showed high interest in HIV-1 cure studies, and willingness to take experimental therapies in the absence of personal benefit (10). Research activity toward an HSV cure has recently accelerated (11–14). The aim of this study was to assess whether persons with genital herpes are similarly willing to participate in cure studies, what risks they are willing to assume and what importance they place on such therapeutic approaches. Specifically, we aimed to: 1) ascertain whether people with genital herpes are willing to participate in HSV cure research; 2) understand the willingness to participate by phase of research and with varying time to implementation, 3) assess motivating factors that influence an individual's interest in participation, and 4) assess the tradeoff between perceived benefit and willingness to accept side effects.

METHODS

We constructed an online survey using RedCap to determine willingness to participate in HSV cure research, and assume potential risks associated with it. The survey contained 38 questions and was estimated to take 10–15 minutes. The questions were modeled on a similar HIV-1 cure survey and tailored for genital herpes infection; the content of the survey is provided in the Supplement (10). The survey opened with these statements: “HSV Cure studies are a new area of research that will attempt to remove the herpes simplex virus from the body, or to completely inactivate it. At this point, these studies are still being conducted in the laboratory. However, in the future, these studies may involve laboratory animals, and eventually, people. The goal of this survey is to understand whether people with genital herpes would be willing to participate in the early studies of new treatments that may result in a cure.” Phase I studies were defined for participants as studies to “test the safety of treatments to determine a safe amount of medicine to give people and to test for side effects.” Phase 2 were described as “studies that explore whether the treatment appears effective”, and Phase 3 as “studies that further measure whether the drugs are effective,

monitor the side effects and compare the drug to other commonly used treatments.” No other descriptions were provided.

The questions assessed the study participants’ socio-demographic characteristics, (e.g., age, gender, sexual preference, and country of residence) and clinical information about health status that was focused on history of genital herpes. Responses to statements regarding willingness to participate in HSV cure research in various phases of development, and to assume potential risks associated with it, were scored on a 5-point Likert scale from “strongly disagree” to “strongly agree”. The interest in participation was allowed to vary by the perceived time to cure and the perceived benefit. Participants were also asked to rank various hypothetical medical and social stressors, including genital herpes, a tool we have used in prior surveys (15). Several open-ended questions were included eliciting opinions about HSV cure as a goal for medical research and a priority for funding.

To be eligible, participants had to provide consent, be 18 years of age or older, and report having genital herpes. The link to the questionnaire was posted on four HSV-related websites: at the University of Washington Virology Research Clinic (<http://depts.washington.edu/herpes>), American Sexual Health Association (www.ashsexualhealth.org), Westover Heights Clinic in Portland, OR (www.westoverheights.com), and The Original Herpes website (www.racoon.com/herpes) between February 25th, 2015 and June 15th, 2015. These sites were selected because they provide reliable HSV-related information and are frequently accessed. The study was approved by the University of Washington Institutional Review Board, and participants provided consent by opening the survey instrument.

The data collected were anonymous without link to potential identifiers of participants; no compensation was given. Frequencies of responses were summarized using descriptive statistics.

RESULTS

During the study period, 1085 persons responded to the online survey, though 86 were ineligible: 42 did not consent, 2 were under 18, and 42 did not have herpes. The analysis included 711 participants who met the eligibility criteria and completed at least 85% of the questions. The threshold of 85% response rate was selected as it includes 71% of the 999 eligible persons and remaining persons completed no more than 70% of questions (median of 22% of questions each).

The median age was 37 (range 18–74). Most of the participants (66.3%) were women, Caucasian (75.7%), with at least 2 years of college (92.0%), and resident in North America (93.5%)(Table 1). The respondents came from 25 countries and 47 states within the US, and Washington, DC. Ninety percent of women and 88.0% of men were heterosexual; most participants reported one (37.5%) or 2 (20.3%) partners in the last year. Overall, 56.1% participants reported genital HSV-2 infection, 11.8% reported genital HSV-1 infection, 19.9% reported both genital HSV-1 and HSV-2 and the remaining 12.3% did not know their

type of genital herpes. The median duration of genital HSV infection was 4.7 years (range, 1 month – 47 years). No participant reported having HIV-1 infection.

Most participants (81.1%) had taken antiviral therapy for genital herpes, and considered themselves to be currently well (83.0%); in addition, most reported that they had a good general idea (44.1%) or understood a lot (21.1%) about the biology of genital herpes and mechanism of therapy (Table 2). Only 12.6% had previously participated in a clinical trial, including 4.4% who reported participating in a clinical trial of therapy for genital herpes.

Willingness to Participate in a Clinical Trial of HSV Cure

Respondents were interested in enrolling into genital herpes cure studies, with the interest increasing as the phase of testing became more advanced (Figure 1). Thus 59.0% of participants reported being “very likely” to take part in Phase 1 herpes cure studies, 68.5% in Phase 2 and 81.2% in Phase 3. Furthermore, the participants were more likely to join a cure study if the cure was 5 years away compared with 15 years away (78.8% vs 43.4%, respectively). Thirty-nine percent reported strong willingness to participate in a cure study even in the absence of immediate health benefits.

Participants were asked several questions to gauge their opinions surrounding herpes cure research participation and the risks and benefits they are willing to take on in relation to immediacy of a cure. Personal benefit was considered “extremely important” for 65.4% of participants in deciding to join a cure study (Table 3). Participants were willing to accept mild (40.6%) and moderate (36.3%) side effects in a cure study that had no immediate possibility of a cure for the participant. In contrast, if the cure study had an immediate possibility of a cure, participants were willing to take on moderate (39.7%) to severe (27.9%) side effects (Table 3).

If participation in HSV cure research necessitated interrupting antiviral therapy, strong concerns about potentially infecting the partner were more frequent compared to concerns for experiencing severe symptoms, 45.6% vs 24.3%, respectively.

Health Outcomes Genital Herpes

Participants were asked to rate the desirability of several health outcomes that may be possible with a cure (Figure 2). The participants were more motivated by protecting their partner than relieving their own symptoms, as eliminating the risk of transmitting genital herpes to a sexual partner or a neonate was the most desirable outcome for 96.6% of respondents compared to testing negative for HSV which was the most desirable outcome for 65.1%. In addition, not having anxiety about disclosing herpes to a sexual partner was rated as extremely desirable by the majority (79.0%) of responders.

Health Belief Model, Perceived Severity Subscale

As shown in Figure 3, the perceived severity on a scale of 1 to 5 of receiving a new HSV-2 diagnosis (mean 4.2, standard deviation 1.0) was somewhat higher to that associated with getting fired at work (mean 3.8), breaking up with someone you cared about (mean 3.9), or getting robbed (mean 4.0). Death of a close friend (mean 4.5), a prostate/breast cancer

(mean 4.5) or HIV/AIDS diagnosis (mean 4.9) were ranked as more traumatic than a new genital herpes diagnosis.

DISCUSSION

To our knowledge, this is the first assessment of attitudes toward HSV cure research in persons with genital herpes. We found a high degree of interest in such investigations, including willingness to assume risks potentially associated with experimental therapies. Not surprising, the potential for personal benefit was important in weighing the risk of participation, and people were more willing to volunteer for treatments at a more advanced stage and shorter timeline to market.

The motivation for this survey was our patients' own interest in cure research. Not infrequently, we receive inquiries from patients who are not interested in treatments for genital herpes, or in counseling regarding living with a chronic sexually transmitted disease, but who rather insist on HSV cure as the only viable option that will let them lead normal lives. In contrast, medical providers rarely consider HSV to be a life-changing diagnosis, and may trivialize its effect on patients' lives. While the impact of genital HSV on physical health is minor in most persons, psychological distress resulting from the stigma of genital herpes can be profound(4, 16–18).

Is HSV cure possible? Unlike HIV, HSV remains latent in a small number of cells and, in between reactivations, is detectable only in nerve cell bodies. However, while we associate HSV with dorsal root ganglia, autonomic ganglia can also be infected (19–21). The transmission of HSV infection via solid organ transplant suggests that other tissues may also harbor the virus (22). Unlike lymphopoietic cells, nerve cells cannot be replaced, and thus potential curative approaches that rely on destruction of the cells that contain the pathogen are unlikely to be feasible for HSV. For this reason, the most promising approach to date involves the use of targeted endonucleases, which offer the possibility of destroying latent HSV while leaving nerve cells intact (11, 13, 14).

We surveyed a convenience sample of people who frequent online sites that provide information about HSV, including information regarding clinical trials. As evidenced by the demographics of our population, the persons who chose to participate are not a representative sample of US population that is affected by HSV. However, they may be disproportionately affected by HSV clinical disease or stigma surrounding genital herpes. Support for this observation can be drawn from perceived severity scale, as in our prior clinic-based studies the diagnosis of genital herpes was ranked as less severe than in the current survey, average severity of 2.7 vs 4.2 (15, 23). Our study sample was self-selected, and thus not representative of population of people who have genital herpes. Therefore, we reported only associations demonstrated within the survey questions themselves, such as the questions asking about willingness to participate with varying levels of side-effects. We have not evaluated further associations between respondent characteristics and willingness to participate in cure studies, as such associations would subject to potential confounding and thus not possible to interpret. A limitation of our study is the self-reported nature of the survey and inability to confirm that an individual participated in the study only once.

Despite the lack of representativeness of the respondents with regard to all persons with genital herpes, these findings may still be representative of a population of potential cure study participants. While for some people genital herpes is a manageable infection, for others the severity of physical or psychological consequences merits potentially riskier therapeutic approaches. As with any investigational approach, the initial studies are likely performed on a subset of the affected population, and only generalized in later stages of research. Of note, the demographics of the survey participants mirror closely the demographics of participants in our clinical trials of new therapeutics or novel therapeutic vaccines and thus suggest that HSV cure studies will be able to find volunteers willing to assume risks with this novel approach (24–26).

In conclusion, in an online survey of persons with self-reported genital herpes, we found substantial interest in participating in HSV cure studies, especially if preliminary data are promising. Because HSV affects a large proportion of US, and global population, further research into curative therapies for HSV is warranted.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Summary

In an online survey we found that persons with genital herpes are willing to assume risks associated with experimental HSV cure therapy, especially in later stages of development.

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Figure 1.

Figure 2.

Figure 3.

Table 1

Demographics, Behavioral, and Clinical Characteristics of Study Population

Characteristics	N (%) or Median (Range)
Age (years)	37 (18–74)
Gender	
Men	235 (33.2%)
Women	470 (66.3%)
Other	4 (0.6%)
Race and Ethnicity *	
African American/Black	83 (11.7%)
Caucasian	538 (75.7%)
Asian	27 (3.8%)
Latino/Hispanic	37 (5.2%)
Native American/Indigenous/Pacific Islander	20 (2.8%)
Other	13 (1.8%)
Continent of Residence	
Europe	21 (3.0%)
North America	651 (93.5%)
Other	24 (3.4%)
Educational Level	
Up to high school	57 (8.0%)
Some college or 2-year degree	269 (37.8%)
4-year college graduate	197 (27.7%)
More than 4-year college degree	188 (26.4%)
Sexual Orientation	
Heterosexual	623 (88.8%)
Bisexual	52 (8.1%)
Homosexual	22 (3.1%)
No. of sexual partners in the past year	
0	97 (13.7%)
1	266 (37.5%)
2	144 (20.3%)
3–5	134 (18.9%)
6	68 (9.6%)
Type of Genital Herpes	
HSV-1	84 (11.8%)
HSV-2	398 (56.1%)
Both HSV-1 and HSV-2	141 (19.9%)

Characteristics	N (%) or Median (Range)
Don't Know	87 (12.3%)
Duration of genital herpes, years	4.7(0.1–47.0)
No. of recurrences in the most severe year	3 (0 – 365)
Recurrences in the last year	2 (0–365)
Ever told a new partner that you have genital herpes?	
No, no partners	129 (18.2%)
No, acquired from current partner	62 (8.8%)
No, have not told	41 (5.8%)
Yes, one	177 (25.0%)
Yes, more than one	299 (42.2%)
Ever transmitted genital herpes?	
Yes	101 (14.2%)
No	492 (69.2%)
Don't Know	118 (16.6%)
Ever taken genital herpes medications	576 (81.1%)
Current medication frequency	
Daily (suppressive therapy)	242 (42.2%)
Episodic (during outbreaks)	228 (39.7%)
None	104 (18.1%)

Percentages calculated based on those participants answering each specific question.

* Participants may check more than one category for race/ethnicity.

Table 2

Current Health, Willingness to Participate in Cure Studies and Knowledge about Genital Herpes

	N (%) or Median, (Range)
Current Health	
I am currently well.	589 (83.0%)
I am not well and this is due to genital herpes.	94 (13.2%)
I am not well and this is due to genital herpes medications.	3 (0.4%)
I am not well and this is not due to genital herpes, but it is due to another medical condition.	24 (3.4%)
Based on your current health, which of the following statements most closely matches your willingness to take part in a cure-related study?	
I am currently well and would NOT be willing to risk possible side effects	68 (9.6%)
I am currently well and would be willing to risk possible side effects	543 (76.5%)
I am currently unwell, so I would enter a study to see if it would improve my health	97 (13.7%)
I am currently unwell, so I would NOT be willing to enter a study	2 (0.3%)
Ever participated in a clinical trial	
Yes	89 (12.6%)
No	619 (87.4%)
Ever participated in a clinical trial for genital herpes	
Yes	31 (4.4%)
No	673 (95.6%)
Among those on suppressive therapy, willing to stop medication during cure study?	
Yes, definitely	122 (50.4%)
Probably	65 (26.9%)
Possibly	47 (19.4%)
Probably not	3 (1.2%)
No, definitely not	4 (1.7%)
How many years do you think it will take to find a cure for genital herpes?	10 (0–100)

Percentages calculated based on those participants answering each specific question.

Table 3

Potential risks and acceptable level of side effects from participating in a cure study

How important is your chance of a personal benefit (i.e. your health improving, no longer having genital herpes, etc.) in deciding to join a cure study?	Extremely important	Somewhat important	Slightly important	Not very important	Not at all important
If you were in a cure study, what level of side effects would you be prepared to accept					
With no immediate possibility of personal benefit	No side effects 100 (14.1%)	Mild side effects (e.g. headaches, backaches) 288 (40.6%)	Moderate side effects (e.g. flu like symptoms) 258 (36.3%)	Severe side effects (e.g. blisters that turn in to painful sores, too sick to go to work for 3 to 7 days) 44 (6.2%)	Extremely severe side effects (e.g. hospitalization) 20 (2.8%)
With an immediate possibility of personal benefit	25 (3.5%)	91 (12.8%)	282 (39.7%)	198 (27.9%)	114 (16.1%)
What is your concern about potential risks of stopping treatment for HSV	Very concerned	Moderately concerned	Slightly concerned	A little concerned	Not at all concerned
Experiencing more severe symptoms	172 (24.3%)	177 (25.0%)	127 (17.9%)	84 (11.9%)	148 (20.9%)
Become more infectious to sexual partners	323 (45.6%)	132 (18.6%)	79 (11.1%)	62 (8.7%)	113 (15.9%)

Percentages calculated based on those participants answering each specific question.