Adolescents' Anticipated Experience of Screening for Genital Herpes

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z *GENITAL HERPES* z *HERPES SEROLOGICAL SCREENING*
z *ADOLESCENTS*

SUMMARY
Screening asymptomatic adolescents for genital herpes will require sensitivity to the adolescents' developmental needs. Twenty-four adolescents (age range 16–19) were interviewed to explore their perceptions of screening. In general, adolescents thought screening for genital herpes would be viewed as 'taking care of themselves', although there were concerns that their peers might view getting screened as implying that the adolescent was infected or sexually promiscuous. Most adolescents expected their parents to respond positively, but typically thought that younger adolescents should obtain parental consent for screening, and that adolescents should inform their parents of positive test results. Adolescents wanted to be screened in settings which provided confidentiality and by non-judgemental care providers, but they differed on the setting which they believed would accomplish this. Some recommended mass screening (for example, screening all of those in a certain year at school), presumably as a way to reduce embarrassment and/or stigma. Screening programmes which are adolescent-friendly and accessible, and address adolescents' specific concerns regarding managing the information, can be created.

Introduction

HERPES SIMPLEX VIRUS type 2 (HSV-2) seroprevalence studies, in samples which are representative of the USA, and in selected high-risk populations in the USA, have found the seroprevalence of HSV-2 among adolescents to range from 5.6 to 33%.[1–3] Globally, rates of HSV-2 seropositivity among adolescents vary depending on the country and the specific population within a country.[4,5] Rates are particularly high in developing countries, with studies of high-risk adolescents demonstrating rates ranging from 18 to 55%.[4] The majority of persons who are seropositive for HSV-2 do not report a history of symptoms or an awareness that they are infected and, as a result, can still transmit the infection both to a susceptible partner or a neonate. With the recent commercial availability of herpes serological screening tests, which distinguish between HSV-1 and HSV-2,[6] health professionals have struggled to decide with whom and in what settings to administer testing.[7–9] This dilemma becomes particularly challenging when one considers screening adolescents. Screening adolescents for sexually transmitted infections (STIs) requires paying special attention to their developmental context, including protection of their confidentiality, attention to other sexual health-related issues, and consideration of their cognitive developmental level.[7,10] Thus, the purpose of this study was to explore adolescents' perceptions of the benefits and barriers to screening for asymptomatic HSV-2 infection.

Methods

A convenience sample of adolescent males and females, aged 16–19 years, was recruited from local high schools and community colleges, and through snowball sampling, to participate in a study examining their attitudes and expectations regarding screening for HSV. In Texas, USA, adolescents in this age group have the legal right to receive confidential care for STIs.

The Institutional Review Board at the University of Texas Medical Branch in Galveston approved this study. In order to participate, adolescents had to provide written informed consent and, for those under the age of 18, written parental consent in addition to providing their own written assent was obtained. The investigators interviewed adolescents until the interviews ceased yielding new information.

Two female interviewers conducted all the interviews, which were designed to last under an hour and were taped, transcribed and reviewed for accuracy by the interviewer. Notes were taken by the interviewer in the event that the audiocassette player malfunctioned. The adolescent was provided with basic information (see Box) and then was asked a series of questions regarding the reasons someone would get screening, the positive and negative outcomes that could occur as a result of such screening, and their thoughts about the issues involved in making screening available to adolescents. The adolescents received US$30 for their time and transportation.

The transcripts were reviewed in order to identify key issues, concepts and themes, which were used to develop a coding system.[11] Then the authors coded each transcript, and disagreements were resolved by consensus. Revisions to the coding schema were made as necessary and noted in an ongoing record. Documents were then created for each theme and reviewed by the authors. From these documents, the authors derived the following key points:

- The attributions that might be associated with the screening process;
- Behavioural changes that might occur after screening;
- Involvement of parents; and
- The most adolescent-friendly location and process for screening.

Results

Twenty-four adolescents participated in the study. The tape recorder malfunctioned during one of the interviews, so this transcript was not available. The interviewer's notes indicated that this individual (an 18-year-old African–American female) did not provide any unique information. The remaining 23 adolescents had a mean age of 17.9 years: 61% were female, 43% Hispanic, 35% Caucasian/other and 22% African–American. Five females reported having been pregnant, and one male reported having impregnated

someone else. Eight subjects reported knowing someone with genital herpes. After the interviewer described genital herpes to the participants, they were asked what information they believed should be shared with other adolescents. Approximately half of the adolescents mentioned that genital herpes could be asymptomatic, suggesting that adolescents may have the cognitive abilities to understand some of the abstract concepts associated with this infection.

ATTRIBUTIONS ASSOCIATED WITH SCREENING

Across the interviews, adolescents characterized screening as part of 'trying to take care of themselves', although some also described screening as a response to symptoms or sexual behaviour. If others, including their parents, discovered that the adolescent had been screened, the adolescents thought that the parents and others would see this as a positive action. One female participant stated, 'Parents would think that their children are just doing what their parents usually want them to do. Parents usually want you to watch out for yourself, to be protected and stuff like that.' There were some worries, however, that the act of getting screened would imply that they were infected (e.g., 'Other kids in school would probably think that it's kinda gross [that] you probably have it …') or that they had been sexually promiscuous (e.g., 'You probably had many partners, you probably slept with a guy who probably had many partners, you're not respectable …'). These potential perceptions were seen as most likely to be made by peers who were not their close friends. From an emotional perspective, embarrassment regarding the screening process represented a clear barrier to getting screened. However, the relief associated with 'knowing the test results' was frequently mentioned as one of the benefits of getting screened. One female participant commented, 'Just to know would be the best thing, to know that everything's okay …' Adolescents did mention the importance of getting screened to avoid transmission to partners, and a few described the desire to protect their future children.

BEHAVIOURAL CHANGES AFTER SCREENING

The adolescents wanted to believe that the anxiety associated with screening would serve as a reminder to engage in healthier sexual behaviours, such as using condoms more frequently or choosing sexual partners more wisely. However, some of the adolescents focused on the need to use condoms for the prevention of all STIs. For example, one male participant stated, 'It's always better to wear a condom because you are not just doing it for herpes but for other STDs [*sic*] , it's always better to protect yourself'. When queried about telling partners (about having been screened), adolescents seemed to make a distinction between established partners and new partners, and viewed new partners as harder to tell (e.g., 'I don't know I guess it just kinda depends if someone's in a steady relationship, then I think they would feel comfortable enough to tell him'.). Some mentioned fears of rejection and others conveyed a general sense of discomfort. Those adolescents who would plan to tell their partners anticipated that the partner would respond positively.

PARENTAL INVOLVEMENT AND CONFIDENTIALITY

For the most part, these adolescents believed that their parents would be supportive of their decision to get screened. Many stated explicitly that parents should be involved with younger adolescents. One female participant stated, 'Oh yeah, I think that if they are way young like, I don't know, under like 14 or under 15, then I think that they should have to tell their parents, but I think that it's your own choice if they're older, like above 16, but if they're not you should have to tell'. Some adolescents feared that the decision to undergo screening would suggest to the parent that the adolescent was sexually experienced and that this fact might upset parents (e.g., 'They would be hurt that their child is out having sex at such a young age'). However, when genital herpes was viewed primarily as a 'disease', adolescents uniformly thought parents would be supportive and should be informed. It may be this distinction, between being a sexual issue and a medical matter, that led some adolescents to distinguish between screening and the dissemination of positive results, i.e. more adolescents wanted to be able to be screened without parental involvement than thought positive results should be withheld from parents. Even those

Basic information given to adolescents prior to being questioned about herpes simplex virus (HSV) screening

There is now a test that could tell people whether they have the virus that causes cold sores and genital herpes. The test is not easily available yet, and people are not sure who should get it. The purpose of the current interview is to hear from teenagers, like yourself, what you think about genital herpes, and how teenagers would make a decision to get screened or not.

First, I am going to tell you some information about genital herpes.
Herpes simplex virus is a family of viruses which causes cold sores and genital herpes. There are two types – HSV-1 and HSV-2. Typically, HSV-1 causes cold sores, and HSV-2 causes genital herpes but not always. Sometimes HSV-1 causes genital herpes and sometimes HSV-2 causes cold sores.

Most people who have genital herpes never have symptoms, but some people have very painful sores. Other people have minor symptoms which they do not know are caused by herpes.

Herpes is transmitted by skin to skin contact. It can be given to someone even if you have never had symptoms or don't have them now. Girls can give it to their baby during pregnancy or birth. For a baby, it is a very serious infection.

There is no cure for genital herpes, but there are drugs which can make the symptoms better, and which might help you not give it to someone else. Telling your sexual partners that you are infected seems to be helpful in not giving it to them, and condoms used all the time can help you not give it to someone else and help keep you from getting it.

adolescents who believed that parents should be informed about positive results thought that adolescents should determine how the parent was told, and that the physicians should provide help only if needed.

LOCATION OF SCREENING

The adolescents had several concerns about obtaining screening which focused on confidentiality and minimizing potential embarrassment/discomfort or stigma. These included the potential interpretation of others if they saw the adolescent at the screening facility, the privacy of the space (for example, that the examination rooms were sufficiently soundproof), and the hope that healthcare providers would listen and not be judgemental: '… I wouldn't wanna feel like you were being judgemental. You know I would wanna feel like I could be able to talk to you.' Adolescents differed in what settings these objectives were mostly likely to be met and whether mass-screening (for example, screening all students at a certain age) would help. One female participant suggested, '… they call [you] like at a certain age, like a certain grade or something, so everybody gets tested, so it wouldn't be like, oh you're getting, you got tested, you think you got something, it'd be more comfortable'. For some adolescents, schools and school-based clinics provided easiest access and the least discomfort, but for others there was a lack of trust in privacy within a school setting. One male participant stated, '… some kids go to the teen clinic without their parents knowing because they can get out of class and say anything's wrong with them; go up to the nurse and she checks everything …'. Another participant possessed a different view regarding schools as possible screening sites: 'I don't really know. I mean I wouldn't choose to do it in school just because that's just a prone place to have rumours start. So, I wouldn't. I wouldn't choose to if they did'. Some believed that their regular healthcare provider would provide them with a sense of comfort, while others feared that their regular care provider might be judgemental. Regardless of the actual setting, adolescents thought that information encouraging screening should be disseminated through health classes or mass advertisements, and many felt that their healthcare provider should initiate the conversation regarding the possibility of screening. For example, one male participant stated, '... because the kids aren't gonna say nothing [*sic*], they [are] gonna be waiting for the doctor to say something'.

Discussion

As new type-specific serological tests become available for HSV, decisions will have to be made concerning how to screen susceptible individuals. Despite the increasing incidence of HSV-1 genital herpes, HSV-2 will remain the major clinical challenge because of its propensity to cause recurrent symptomatic and subclinical infections and hence there is a greater risk of spreading it to susceptible individuals. Sexually experienced adolescents are already screened regularly for other STIs. Although it is unlikely that widespread screening for adolescents will be recommended in the near future, decisions may have to be made as to whom to screen and in what context. For example, in the USA, one guideline of the Health Plan and Employer Data Information Set (Hedis) is to screen all sexually experienced adolescent girls for *Chlamydia trachomatis*.[12] These guidelines are used to evaluate the performance of managed care organizations. Others have found that many adult attendees of a genitourinary clinic in the USA expected HSV testing to be included in STI screening.[13] The results of this study suggest that most adolescents could view HSV-2 screening as an important part of taking care of one's health.

Despite these positive perceptions regarding the concept of screening for HSV-2, implementation for adolescents may be difficult. In a previous study, the following were given as reasons for a delay in seeking help for the treatment of STIs: the perception of barriers to care; the need to feel less self-efficacious; and the perception of a stigma attached to STIs.[14] Thus, in order to screen susceptible adolescents efficaciously, it will be important to address these perceived barriers to care, including stigma.[10,14,15] There are many ways to manage stigma, and the adolescents in the current study focused on 'secrecy' and 'covering'.[16] Secrecy was described by those who wanted to go to a place where no one would know them and they would not be seen. Covering is a strategy in which the person attempts to deflect the stigma, and combined with secrecy, may have been the strategy of those adolescents who advocated mass screening programmes. Although the adolescents did not explicitly describe mass screening as a way to reduce stigma, it seems likely to be one anticipated result. Similarly, adolescents who believed in universal immunization were more likely to accept the hepatitis B vaccine.[17] In fact, the hepatitis B vaccination was not successful until there were universal recommendations. This may present a difficulty for HSV-2 screening; although mass screening may be an effective strategy for fostering screening, it is unlikely to be seen as cost-effective, practical or appropriate to screen *all* adolescents for asymptomatic genital herpes.

The adolescents in this convenience sample obtained parental consent to participate if they were under 18, and as such these findings may not be the same as for those adolescents who would not be able to obtain consent from their parents to take part in a study on sexual issues. Despite this limitation, the findings of this study are consistent with other US research. For example, many parents are involved in the reproductive healthcare of the adolescents in their care[18,19] and, although adolescents may want to maintain control over their information, they view parents as likely to be supportive and helpful.[19,20] The fact that many adolescents involve parents, however, does not diminish the importance of having the legal right and access to confidential care. Concerns about potential lack of confidentiality can serve as a barrier to care for some adolescents.[21]

The results of this qualitative study suggest that adolescents would be receptive to asymptomatic genital herpes screening if such programmes were designed to be sensitive to their developmental needs. This is further supported by the fact that there is no evidence indicating that a positive test result leads to serious psychological morbidity, although individuals do possess a variety of emotional experiences and concerns, including the implications for romantic relationships and transmission.[20,22–25]

The nature of qualitative research allows one to identify issues of interest, but does not allow for broad generalization across populations. While it is likely that many of these adolescents' perceptions would be similar to the perceptions of adolescents from other industrialized countries, cultural context will play an important role in how adolescents view conversations with parents, stigma and the best ways for accomplishing screening. For example, school-based

screening for older adolescents may not even be feasible in developing countries in which adolescent girls do not remain in school. Thus, as screening programmes are considered and developed, it will be important to consider issues such as prevalence, healthcare systems and beliefs about adolescent sexuality in the particular country. Regardless of the country-specific issues, these results suggest that it will be possible to develop screening programmes that are adolescent-friendly and accessible, and to design appropriate ways to address adolescents' specific concerns regarding the management of information with partners and parents, and in schools.

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Conflicts of interest

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