

The Effects of Stigma on Genital Herpes Care-seeking Behaviours

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KEY WORDS

■ GENITAL HERPES ■ STIGMA ■ SHAME ■ PUBLIC HEALTH
■ SEROLOGICAL TESTING ■ SEXUAL BEHAVIOUR

SUMMARY

Stigma affects both herpes-infected and uninfected people. The stigma associated with genital herpes may influence a person's decision to seek care or disclose the infection to others. For uninfected people, the threat of the stigma associated with sexually transmitted infections (STIs) is an integral tool of clinical and public health approaches to genital herpes prevention. This paper reviews concepts of stigma in relation to the prevention and treatment of genital herpes and other STIs, and calls for those involved in STI care to weigh the extent that public health response is altruistic, moral and effective against the substantial, although incomplete, evidence of harm caused by stigma.

Introduction

THIS PAPER REVIEWS various concepts of stigma in relation to the prevention and treatment of genital herpes and other sexually transmitted infections (STIs), in order to make two points. First, stigma is not an intangible metaphor that describes the consequences of sexual misconduct; rather, stigma is a reality that affects both herpes-infected and uninfected people in the most intimate aspects of their daily lives.

People with genital herpes usually endure recurrent disease episodes that alter day-to-day well-being.¹ Such recurrences are observable examples of the 'mark' or 'stain' that characterizes stigma, and they are a key source of psychological distress and reduced quality of life.² The stigma associated with genital herpes may also be important in influencing a person's decision to seek care, or make disclosures about the infection to others. For uninfected people, the threat of the stigma associated with sexual infection is an integral tool of current clinical and public health approaches to genital herpes prevention.³ Stigma may also be critical in the acceptance of type-specific herpes simplex virus (HSV) screening, especially for those who are asymptomatic and perceive themselves to be at lower risk of contracting the disease.⁴ From this perspective, the stigma associated with genital herpes harms people with and without the disease.

The second important point is that stigma is not a static, easily defined, entity. Stigma is associated with many conditions and issues, but little attention is given to variation in the experience of stigma in different people or during all phases of the condition.⁵ This article defines stigma by multiple aspects, and each may vary in importance when they are associated with herpes-related prevention and care-seeking.

The social and public health functions of herpes-related stigma suggest two additional questions that might profitably address the role of stigma in preventing and treating genital herpes. First, what aspects of stigma are relevant to herpes-related behaviours? Secondly, which herpes-related behaviours are affected by stigma? Herpes-related behaviours are the sexual, preventative and care-seeking behaviours that accompany herpes as a potential, or experienced, consequence of sex.

My argument here is that stigma does not have a monotonous relationship with herpes, or other STIs. Conversely, stigma has unequal effects on herpes-related behaviours, and some aspects of stigma may be more relevant than others in how they affect behaviour.

Origins of Herpes-related Stigma

Herpes-related stigma springs from three sources:

- Attitudes about personal responsibility for sexual behaviour;
- Perceived contagiousness;
- Perceived treatability and curability.⁶

ATTITUDES ABOUT SEXUAL BEHAVIOUR

In most discussions of herpes-related stigma, the causal association between sex and infection links genital herpes to the complex social codes that govern sexual behaviour. Many aspects of sexual behaviour are associated with stigma, the key one being the judgement that sexual behaviour is non-obligatory and volitional, and therefore subject to social attributions of cause and responsibility. For example, sex is considered to be a 'choice', and therefore responsibility for STIs such as genital herpes rests on the person who has chosen to have sex.⁷ Personal responsibility is often identified as an attribute of stigmatized conditions^{6,8} – genital herpes is viewed as the 'stain' that links a person to an undesirable characteristic (in this case, irresponsible sexual behaviour).⁹ Sex, not herpes itself, is a central aspect of herpes-related stigma – and the importance of sex in the stigma of herpes cannot be overstated.

PERCEIVED CONTAGIOUSNESS

How perceived contagiousness contributes to herpes-related stigma is poorly understood. From one perspective, we have no detailed knowledge of the global epidemiology of genital herpes, therefore we may substantially over-estimate its transmission risk.^{10,11} Conversely, many people are unaware that condoms and antiviral drugs can prevent HSV transmission^{12,13} – but these are both developments that could help to reduce herpes-related stigma.

PERCEIVED TREATABILITY AND CURABILITY

Perceived treatability or curability may also affect herpes-related stigma. Many people do not know that genital herpes can be treated effectively. Indeed, lack of treatment is sometimes cited as a reason to avoid testing,¹¹ and suppressive antiviral therapy may be under-utilized, even by patients with access to care.¹⁴ The treatability of herpes also appears to affect when, or whether, a person tells their sex partner that they have herpes, especially in established relationships;¹⁵ in this survey, undertaken in the UK, some respondents did not tell sex partners that they had herpes because antiviral therapy had helped them to 'control' the disease.

People who experience clinical outbreaks of herpes are not the only victims of herpes-related stigma. For most people with HSV-2, symptoms go unidentified; many do not realise they have the infection.¹⁶ Screening programmes enable HSV infections to be identified, but only 40–70% of at-risk persons are accepting

type-specific HSV screening in clinical settings.^{4,17} Even among those who agree to such screening, we found that only 71% returned to get the results;¹⁸ attitudes to herpes were significant predictors both of acceptance of testing and of return for results.

Even well-intentioned preventative efforts may contribute to herpes-related stigma. For example, the US Centers for Disease Control and Prevention 2002 treatment guidelines state that: 'Counseling that encourages abstinence from sexual intercourse is crucial for persons who are being treated for an STD or whose partners are undergoing treatment and for persons who wish to avoid the possible consequences of sexual intercourse (e.g. STIs/HIV and unintended pregnancy).'¹⁹ Stigma, of course, is another consequence of sex and STIs.

Aspects of Stigma and Herpes-related Behaviours

KEY DEFINITIONS

The phrase 'aspects of stigma' refers to a person's perceptions and feelings about genital herpes, emphasizing the person's internal reactions to the condition (*felt* stigma) rather than the overt responses of others (*enacted* stigma).²⁰ Although other schemata are possible, a literature review and consideration of clinical issues suggest that deviance, shame, self-blame (guilt), contamination, isolation and visibility are components of aspects of stigma (Table 1).^{2,9,15,21-25}

Deviance is the concept most closely related to traditional ideas of stigma, and implies some attribute that sets the person apart from others.⁹ Shame refers to a perceived failure in meeting social standards and

Table 1: The points that delineate between deviance, shame, guilt, contamination, isolation and visibility, which are all aspects of stigma

- **Deviance:** implies that herpes has some attribute that sets the person apart from others⁹
- **Shame:** an individual's perceived failure in meeting social standards and acceptance of responsibility for that failure²¹
- **Guilt:** a negative, even punitive, emotion somewhat distinct from shame²²
- **Contamination:** a sense of dirtiness or being soiled, referred to in several qualitative studies on STI experiences^{23,24}
- **Isolation:** people with herpes frequently describe isolation from partners and potential partners or from friends and family²
- **Visibility:** whether (or not) information about a condition is easily available in public or social settings. For example, obtaining treatment for an STI may make the condition public²⁵

STI, sexually transmitted infection.

acceptance of responsibility for that failure.²¹ A fair amount of writing on stigma is in fact referring to shame, but justification for a distinction between stigma and shame is provided below. Self-blame, and in particular guilt, is a negative and even punitive emotion, somewhat distinct from shame.²²

Contamination is a concept that emerges in qualitative studies about the experience of STIs.^{23,24} Isolation is another concept easily identified from descriptions of the experience of people with herpes: isolation from partners and potential partners, or from friends and family, are frequently described.² This concept is one that can emerge in the clinical setting – if appropriate

preventative measures are not emphasized, understanding of the role of asymptomatic shedding, combined with increased screening efforts, could enhance this aspect of herpes stigma.¹⁵ Visibility refers to whether or not information about a condition is easily available in public or social settings. To illustrate this practically, lesions of genital herpes and other STIs are seldom seen, but other types of visibility (including the receipt of care in STD clinics, or obtaining certain prescription medications) may make a person's condition public.²⁵

HERPES-RELATED BEHAVIOURS

With the above definitions in mind, how stigma is associated with herpes-related behaviours can be examined in greater detail. Herpes-related behaviours include not only sexual activity and condom use, but how sexual partners communicate or behave, depending on their perceived infection risk (Table 2). Herpes is not a static condition, and stigma may vary over time in response to treatment, experience, social support and coping. However, no studies have longitudinally assessed stigma, herpes-related behaviours and herpes, which is one of the shortcomings of existing research.

Table 2: Herpes-related behaviours that are associated with stigma

Behaviour type	Examples
Sexual behaviours	Abstinence during outbreaks
Prevention behaviours	Condom use
Partner communication	Disclosure of genital herpes
Symptom recognition	Self-treatment; use of alternative therapies
Provider choice	Avoidance of primary care provider
Acceptance of screening	Fear of diagnosis
Therapeutic adherence	Suppressive therapy to prevent transmission

GENDER DIFFERENCES

Several studies have examined the role of stigma in herpes or STI-related care-seeking. For example, among adolescents, young women take about three days longer than men to seek care. Most of the additional time is used to decide if care is needed, not because it takes longer for women to get a clinical appointment. In the women studied there was a statistically relevant association between 'stigma' and prolonging the interval between symptoms and care-seeking, regardless of their knowledge about (or perceived seriousness of) STIs, and controlling for socio-economic status and social support.²⁶ In a large, multi-site study in the USA, most patients with genital herpes infections sought care within 7 days of symptom onset. However, 20% of women and 16% of men took over a week to seek care, despite experiencing symptoms. These studies suggest that gender differences in social expectations for sexual behaviour negatively influence women's care-seeking behaviours.²⁷

A second study emphasizes the importance of gender in understanding aspects of stigma and herpes-related behaviour. In this study involving a relatively small sample of high-risk minority adolescents, stigma – but not shame – was associated with decreased disclosure to clinicians of sexual behaviour and past care-seeking

behaviour. However, this finding applied only to girls.²⁸ This study demonstrates that the traditional distinctions between 'good girls' and 'bad girls' are still relevant, and cause more negative effects on the care-seeking behaviours of women than those of men.²⁵

Gender differences in the relationships between stigma and STIs were somewhat replicated in a study in Kenya we conducted in 2003. In this study involving 160 men and women, higher levels of stigma – not shame – were associated with decreased STI testing in the previous year, as well as decreased perception of risk in the coming year. Stigma may make one less likely to seek services, and less likely to believe such services may be needed. In this study, contamination – another aspect of stigma – was associated with decreased likelihood of STI testing and decreased perception of STI risk.²⁹ Although thorough cross-cultural studies of herpes-related stigma have not been done, these data suggest the likelihood that stigma is important in a variety of societies and cultures.

STIGMA AND SHAME

Distinct effects of stigma and shame on herpes-related behaviours have not been studied. In a study of care-seeking for STIs, women and participants who used health services were more likely to get gonorrhoea testing, whereas younger participants and those with higher levels of stigma were less likely to have received such testing.³⁰ Similar findings have applied to receipt of an HIV test. Shame was associated with both gonorrhoea and HIV testing at bivariate but not multivariate levels.³⁰

The distinction between stigma and shame may be important. Shame reflects an individual's personal sense of failure and responsibility, consistent with the concept of 'felt stigma' introduced earlier.²¹ Shame figures heavily in reactions to genital herpes, and may contribute to the depression and sense of worthlessness that often accompany the diagnosis.^{14,24} As such, shame is amenable to clinical intervention. By contrast, stigma refers to social judgment and discrimination – and may be more difficult to change. For example, substantial stigma remains associated with HIV infection, despite many highly visible cases and a great deal of public health education.^{3,31} As type-specific HSV testing becomes more widely available, and the role of suppressive antiviral therapy is better understood, the distinction of stigma from shame may be an important element in the provision of clinical and counselling services.

Shame may be associated with one aspect of care seeking. We conducted post-visit telephone satisfaction surveys of STD clinic clients, 48 h post-visit, and satisfaction items related to the quality of interactions with the provider (care providers were mostly nurses and nurse practitioners). We found that higher levels of stigma were not significantly associated with lower levels of post-visit satisfaction. However, both shame and a related measure of guilt were each independently associated with lower levels of post-visit satisfaction. Satisfaction may be a key factor associated with subsequent care-seeking.

Conclusions

Stigma plays an important role in both the social and public health response to STIs, including herpes. We need to weigh the extent that public health response is altruistic, moral and effective against the substantial, although incomplete, evidence of harm caused by stigma. It is not entirely congruent to work against the stigma of herpes and other STIs while emphasizing the stigma of sex, all in the name of prevention.

In addition, stigma is more than one thing – and one or more aspects of stigma are associated with different types of adverse outcome in STIs. For example, the perceived social censure associated with the deviance aspect of stigma may deter people from timely care-seeking for herpes-related symptoms. Shame may be a more important element in communication with partners, and guilt may influence satisfaction with care and subsequent care-seeking. Research and intervention agendas may need to give greater attention to the aspects of stigma, and to specific types of behaviour affected by stigma, if our great progress in understanding the biology and epidemiology of genital herpes is to be matched by appropriate public health measures.

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