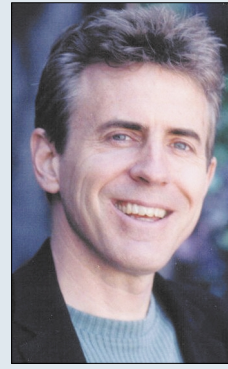


# A Clearer Perspective on Genital Herpes Stigma



Charles Ebel



Susan Rosenthal

Charles Ebel<sup>1</sup> and Susan Rosenthal<sup>2</sup>

<sup>1</sup>The American Social Health Association, NC, USA,

<sup>2</sup>Department of Pediatrics, UTMB Children's Hospital, Galveston, TX, USA.

GENITAL HERPES has long been characterized as a condition that carries with it a social stigma. Yet what does this term really mean when applied to genital herpes, and what, precisely, are the implications of stigma for patients and their healthcare providers? Further, how does stigma impact our public health efforts to reduce the risk of transmission and unnecessary psychological sequelae associated with this infection, which has a high prevalence rate in so many countries?

A recent colloquium to address these and related questions drew together 30 delegates from diverse fields, including behavioural science, public relations, marketing and clinical medicine. Two of the papers published in this edition of *Herpes* began as keynote presentations for this meeting, organized by the American Social Health Association (ASHA). Both illuminate key points of interest to those who have puzzled over the contradictions of genital herpes – a generally benign and extremely commonplace infection that nevertheless carries an emotional charge extending well beyond its physical manifestations.

Stigma, as Carmen Radecki Breitkopf details in her paper (pages 4–7), is an interactional process. It begins with a personal characteristic or condition that is viewed by society as abnormal, unsightly or indicative of undesirable behaviour. It flourishes with the 'acceptance of the stigma by the stigmatized', and is intensified where the condition is thought to be not merely an accident but rather the responsibility of the person affected. Readers of Radecki Breitkopf's review of the behavioural literature will find it quite relevant to the management of genital herpes. Worries about disclosure and fear of rejection are in some ways classic aspects of stigma as studied in relation to other conditions. This reinforces the importance of management strategies that directly address patient concerns regarding how they will be viewed by others, especially those with whom they might seek an intimate relationship.

Dennis Fortenberry has studied stigma as a barrier to care-seeking for persons with sexually transmitted infections (STIs). In his paper (pages 8–11) he argues persuasively that stigma, which might be interpreted by some as loose jargon, is 'a reality that affects both herpes-infected and uninfected people in the most intimate aspects of their daily lives.' Rooted in social norms regarding sexual behaviour, stigma is expressed explicitly in public health messages on the risks and dangers of sex. In this paradigm, stigma is used as a tool to influence the uninfected; it should be no surprise, then, that those who become infected feel its sting.

Jokes concerning STIs may be commonplace, yet for many of the millions of people diagnosed with genital herpes every year, such jokes simply reinforce their experience of the

dimensions of stigma, including self-blame, guilt and feelings of isolation.

As Fortenberry points out, addressing stigma is not merely of academic interest. Stigma complicates a number of proposed public health interventions designed to curb the spread of genital herpes — in particular the use of serological tests to identify asymptomatic or unrecognized carriers of herpes simplex virus (HSV). Many have argued against serological testing on the grounds that diagnosing asymptomatic individuals would be tantamount to doing harm, in part because of the expectation that those diagnosed will become stigmatized. A conclusion has yet to be reached on this issue; however, it is hoped that decisions about the appropriateness of using HSV serological testing would not be dictated by society's misinformation about herpes and discomfort with sexuality.

Stigmatizing perceptions of herpes – that it is a taboo subject, a mark of shameful behaviour and an infection that is restricted to marginal groups – potentially hinder the implementation of other interventions. As is clear in Cheryl Jones's and Tony Cunningham's review in this issue (pages 12–17) regarding vaccination strategies for herpes, there is progress in the development of prophylactic vaccines, and current trials may yield critical immunological insights about HSV. Yet, the stigma associated with herpes is a serious challenge faced in the recruitment of participants for vaccine trials now under way in the USA and other countries. Without adequate participation in trials, it will be difficult to assess efficacy.

Once a vaccine is developed and approved, stigma also may impact the development of policies that support the widespread implementation necessary to prevent the epidemic spreading even further. However, a successful licensed vaccine may represent the best opportunity to educate and reshape attitudes.

Efforts to address the stigma associated with herpes will necessitate coming to terms with deeply held attitudes about sexuality, which are not easily changed. The articles by Drs Radecki Brietkopf and Fortenberry, however, offer a clearer perspective on the underlying problem of stigma, as the authors outline a theoretical basis for developing and testing specific strategies against stigma. It is time to move beyond merely being saddened by the experiences of those individuals with herpes, towards the pursuit of measures that have already proved successful in reframing perceptions of other health conditions. Cancer, HIV and depression were among those cited in the recent colloquium, and it is clear that two decades have made a huge difference in each case. Finding strategies for changing the way the world perceives herpes would certainly be a worthwhile investment.