



How herpes got its stigma

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“It is easier to fool people than to convince them that they have been fooled.” – Mark Twain

For anyone in the twenty first century it is hard to believe that there was a time when ‘herpes’ was not a stigmatised and feared condition. But this is true. Less than forty years ago genital herpes was largely ignored. Newly diagnosed patients were not made to feel that a common skin condition had just ended their chance of having future relationships. Doctors knew that they were simply dealing with the manifestation of the common facial cold sore on a different site and they treated it appropriately. In the early 1980s things changed. How and why did this happen?

The history of the genital herpes stigma dates back a mere 30 years. Before then, the condition, which was first named by the Ancient Greeks, was well known to doctors – but it was not invested with the terror it commands today and the word herpes barely registered with the public.

Two viruses are responsible for genital herpes and facial cold sores. They are called herpes simplex type 1 (HSV-1) and herpes simplex type 2 (HSV-2). Either virus may be caught in either place.

The start of modern sexual health services

The modern era of sexual health treatment in the UK began in 1917, with the passing of the Venereal Disease Act as millions of soldiers who had been mobilised during the First World War returned home and began to infect their partners with the ‘social diseases’ they had acquired. This led to a public-health crisis that terrified the government of the day, so a network of publicly funded clinics was set up. The Venereal Diseases Act of 1917 named syphilis, gonorrhoea and soft chancre (or chancroid) as dangerous diseases for which

free treatment was to become compulsory. Genital herpes did not get a look in. It was known to be a common and self-limiting and was rightly considered to be no more significant than a facial cold sore.

Little changed in the intervening 60 years. Public health films were shown in cinemas to encourage fidelity and abstinence, and these films highlighted the horrors of syphilis and gonorrhoea while herpes was ignored. Indeed, genital herpes was so far below the radar that, as recently as 1975, the standard textbook for obstetric and gynaecological nursing did not even have the word herpes in the index. This omission would be unimaginable today.

The role of antiviral drugs

Meanwhile, antibiotics had succeeded in vanquishing previously feared bacterial infections like syphilis and gonorrhoea. Pharmaceutical research moved on to the next holy grail: antiviral drugs.

Finally in the late 1970s, one company, Burroughs Wellcome, succeeded, but the drug it developed only had an impact on some viruses in the herpes family – mainly chickenpox and herpes simplex. At the time, these were not usually considered serious enough to require treatment at all in most cases and there was no pent-up demand for expensive new drugs. Almost everyone who caught these common infections recovered without treatment. So most patients were only offered palliatives. Herpes simplex may recur in a milder form before symptoms heal again. Chickenpox is a common childhood ailment that scarcely affects healthy children and causes no further problems unless it recurs as shingles, which mainly occurs in the elderly.

So having developed aciclovir, the drug company required a return on investment. But its marketing men had a problem: none of the conditions the drug might be used for required treatment except in extreme cases.

The herpes stigma is born

The answer was to pitch the drug at genital herpes patients. The trick would be to persuade them that the condition was serious enough to warrant expensive drug treatment. A disease-awareness campaign was organised to alert doctors and patients to the benefits of the new drug. The case was made by 'marketing' genital herpes so that it acquired the status of an important disease.

The strategy was spectacularly successful. Articles began to appear in newspapers. In the US, herpes became the cover story for *Time* magazine twice. Anything negative about the condition was highlighted in order to raise public concern. The masterstroke was to use the word 'incurable' to make genital cold sores seem serious. More than any other single thing, this created the stigma that has never gone away. Thrush, chickenpox and glandular fever are among a host of infections that stay in the body, but most people would be pushed to name any apart from 'herpes'.

Disease-mongering had gone mainstream. The trick had been to market herpes, not aciclovir. Once herpes hit the big time, the success of aciclovir was assured. This echoed the marketing of the antiseptic mouthwash Listerine in the 1920s, which turned a floor cleaner into a cure for 'chronic halitosis'. In the words of advertising scholar James B. Twitchell, 'Listerine did not make mouthwash as much as it made halitosis'.

For genital herpes, the American company Burroughs Wellcome sponsored support groups to advise 'sufferers' of the benefits of the new drug. In the UK, a charity emerged, the Herpes Viruses Association (HVA). It was oblivious to the fact that its appearance had been prompted by a drug-marketing campaign. A helpline was set up and was immediately besieged by newly distraught patients. One said, 'I wish I had cancer, then at least people would feel sorry for me. As it is, I can't even tell them what I've got.' The HVA's first director believed that if he spent two or three years setting the record straight, the charity could then be wound up. Thirty years later, it is still going strong and is needed more than ever.

Genital herpes is now accepted as one of the most stigmatised of all medical conditions. A Harris Interactive poll in the US in 2007 found that 39 per cent of patients were troubled by social stigma and 38 per cent made up excuses to avoid sex during an outbreak, rather than tell a partner. Only HIV was ranked higher for

stigma, a truly bizarre finding for an infection that is carried by at least three quarters of the population.

Herpes: common and largely undiagnosed

Herpes simplex is a largely hidden condition because most people get mild symptoms or none at all, so they are not diagnosed. Prevalence is high and one recent study of women between the ages of 35 and 44 found that 85 per cent have HSV-1 and 22 per cent have HSV-2. The HVA divides its time between advising a relatively small number of people who experience recurrent symptoms and reassuring a much larger number about transmission. Symptoms can usually be treated or prevented once people know what to do about them.

A more difficult task is explaining the origin of the stigma and the reasons why it is unnecessary. Marian Nicholson, the HVA's director said, 'Over and over again, callers to our helpline say, "*I can deal with my symptoms, they don't bother me, but I am terrified of passing this on to a new partner.*"' Sufferers fear rejection, although an HVA survey has shown that this usually doesn't happen. The artificially created stigma has caused the problem that has given this charity its raison d'être. Genital herpes is now perceived as a social and sexual death sentence.

The problem is that few sexual health experts believe that genital herpes has serious consequences. The British Association for Sexual Health and HIV (BASHH) has an expert group for herpes simplex. If herpes simplex is serious in any sense at all it is because of the stigma, not the condition itself. As a comparison, influenza is not generally considered to be serious, although it kills thousands of people every year in the UK, so it is a far more serious problem than herpes. Over 90 per cent of people with flu or herpes simplex do not have a serious condition. Those with severe symptoms deserve and usually get more support, but their experience is atypical.

Thirty years on from the great marketing campaign, the stigma remains and is now bolstered by jokes, internet chat rooms, dating services and purveyors of fake 'cures'. Is there a dating service for 'sufferers' from facial cold sores? No. Why not? The lack of joined-up thinking is clearer than ever. A hundred years ago, the Royal Commission that led to the setting up of our sexual health services was clear when it named the three infections that required treating and contact tracing and recommended that legal compulsion be adopted to ensure that they were contained. Genital herpes was not among them for sound medical reasons. But back then, nobody had tried to fool people about it.

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