The Experience of Illness Series

Series Editors: Ray Fitzpatrick & Stanton Newman

herpes simplex

T. Natasha Posner

Herpes Simplex

Though medically minor and very common, herpes simplex is a condition which is capable of causing considerable distress, for psychological and social as much as physical reasons. *Herpes Simplex* contrasts the image of the condition presented in the media with the medical and epidemiological evidence, and discusses ways in which the distress associated with the condition can be alleviated.

The first part of the book examines the impact of diagnosis and then explains the roles of accurate information and empathic support, medical treatment and support groups in learning to live with recurrent symptoms. Other chapters use the experiences of people with the condition in different parts of their bodies to illustrate how the meaning of herpes simplex and response to the symptoms alters in association with life changes. The final chapters review psychosocial research, discuss the importance of the Herpes Viruses Association in acquiring a store of knowledge about people's experiences, and highlight the significance of herpes simplex as a public health problem.

Herpes Simplex demonstrates the importance of a biopsychosocial approach. It will be invaluable to doctors, nurses and other health professionals, as well as to people troubled by the condition.

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Herpes Simplex

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Editors' preface

The monographs in this series illustrate a fundamental theme. Physical illness needs to be understood at two quite different levels of reality. At one level the body is challenged by threats to biological processes. At another level illnesses have personal and social significance that cannot be reduced to biology. Natasha Posner's account of herpes simplex perfectly illustrates this twin dynamic. In many cases, infection with the herpes simplex virus is a mild event with few serious consequences for the body. However, to the individual who experiences infection, the diagnosis may be extremely distressing. How the virus can have these two very different kinds of impact, at the biological and psychosocial levels, is described by Natasha Posner with a persuasive and careful analysis of her materials and elegant narrative.

The book is based on a rich range of resources. She draws on up-to-date explanantions of herpes simplex from the medical literature. At the same time she has extensively examined the popular media's treatment of the subject. The media have created an image of a pervasive and threatening infection. It is often treated in moralistic terms as a by-product of the sexual revolution. Natasha Posner also sought the accounts of the lives of individuals who had experienced symptoms of the virus. They report shock, devastation and anger at the time of diagnosis. For some symptoms will be recurrent and individuals have to adjust to a chronic problem. Accurate information and support from others, particularly others with experience of the condition seems often to be far more beneficial than the response from the medical profession.

By challenging the negative cultural meanings of this virus Natasha Posner provides fundamental guidance towards more appropriate care for herpes simplex.

Ray Fitzpatrick, 1997

Author's preface

Much has been written about herpes simplex, both in the medical literature and in the popular press, often with a focus on rare medical complications of infection or worst case scenarios. This has left most of the usual experience of the condition out of the picture, since it was of little concern as a medical problem and of little interest as a story.

The challenge of this book has been to produce a more balanced presentation, and to accurately portray symptom recurrences as a chronic condition embedded in the complex interrelations of mind, body and social context. To try to do this, the book has drawn on a variety of data sources and a wide range of written material including newspaper and magazine articles, pamphlets and academic journal papers in the medical, epidemiological and psychosocial literature. It has been immensely enriched by all those people who have shared their experiences of herpes simplex on survey questionnaires, in interviews, or by writing about them. They have contributed to a growth in our understanding of the nature and impact of this condition and the different ways in which people respond to and live with herpes simplex. I am indebted to them for material presented in this book.

I would particularly like to acknowledge all that I have learnt during my association over a decade with the Herpes Association (now Herpes Viruses Association) in London, and from Mike Wolfe and Marian Nicholson especially. I first made contact with the association when I was carrying on research among self-help organisations in the health field, and was impressed by the association's role in supporting individuals, providing comprehensive information and representing people troubled by herpes simplex.

I want to thank my friends and colleagues in England and

Queensland who have borne my enthusiasms and frustrations during the writing process with equanimity. I have been very grateful for Ray Fitzpatrick's encouragement and editorial wisdom. I would also like to thank Jenny Berzins, Fred de Looze and Mandy Hudson from the Department of Social and Preventive Medicine at the University of Queensland for their help with typing the final version of the manuscript.

I am also grateful to the following: Sage Publications for permission to reproduce material from J. M. Swanson and W. C. Chenitz (1993) 'Regaining a valued self: the process of adaptation to living with genital herpes' *Qualitative Health Research* 3(3): 270–97; Baywood Publishing Co. for permission to reproduce material from David Longo and Kent Koehn (1993) 'Psychosocial factors and recurrent genital herpes: a review of prediction and psychiatric treatment studies' *International Journal of Psychiatry in Medicine* 23(2): 99–117; JAI Press for permission to reproduce material from Kathy Charmaz (1987) 'Struggling for self: identity levels of the chronically ill' *Research in the Sociology of Health Care* 6: 283–321; Cambridge University Press for permission to reproduce material from Nancy Waxler (1981) 'Learning to be a leper: a case study in the social construction of illness' in E. Mishler *et al.* (eds) *Social Contexts of Health, Illness and Patient Care*; Tavistock for permission to reproduce material from G. Scambler (1984) 'Perceiving and coping with stigmatizing illness' in R. Fitzpatrick *et al.* (eds) *The Experience of Illness*.

The book has been written in the hope that it may contribute in some way to our living more easily with this common condition which has coexisted so successfully with us.

Chapter 1

Introduction

The cultural, epidemiological and biomedical context

This book is not about a disease confined to a small minority of people but about a condition that most of the population have acquired, but do not suffer. Herpes simplex is a very common infection, but it rarely causes illness. Where it does cause suffering, the distress comes as much, if not more, from the image of the condition as from the physical symptoms. The psychosocial elements in the experience of herpes simplex are crucial. These elements are shaped by the personal and social context in which the condition is experienced.

Very different views of the condition exist. The medical profession's general view of herpes simplex is that it is not a significant medical problem except on very rare occasions, or when a patient is immunocompromised. Dr Adrian Mindel, an acknowledged expert on herpes simplex infection (and at that time GUM consultant at London's Middlesex Hospital), told the *Independent* (21 July 1987):

> For the majority of people herpes is a minor viral complaint; it is nothing more than an occasional nuisance.

Urologist Peter Gross spoke admiringly to *Time* magazine (2 August 1982) about the ability of herpes viruses to secrete themselves in the human bodily system:

> By any measure, herpes is an extraordinary bug . . . If you were doing a science fiction movie, you couldn't invent something better than herpes.

Professor Mike Adler, quoted in the *Daily Express* (7 February 1983) said:

> The disease is definitely sexually transmitted and so far there is

> no cure. But we need to see it for what it is, a minor non-life threatening complaint.

Levenson and co-workers (1987) wrote that:

> Genital herpes simplex infection is a major personal and public health problem affecting millions of patients.

Thus, among specialists, herpes simplex is 'a minor viral complaint', 'an extraordinary bug', a sexually-transmitted disease, and 'a major . . . public health problem' depending on which aspect of the condition is the focus of attention.

For one organisation representing people troubled by the condition, it is a 'natural part' of human life and one which has been with us for a long time:

> Herpes simplex itself is a natural part and fact of life – one we can live in harmony with if we can accept it in its true perspective.
>
> (Herpes Association 1993a: 10)

> The Herpes simplex virus has probably evolved and developed with humans since the dawn of time. It was certainly well known to the ancient Greeks from whom the virus acquired its name. The virus is found universally, knows no boundaries of class, creed or race and will infect any part of the body where it can gain access. Herpes simplex is a parasitic virus and is the most successful of all the herpes viruses, successful in that it has adapted itself so well to us, the hosts. At some time in their life almost everyone comes into contact with the virus and are infected – with or without symptoms.
>
> (ibid.: 9)

In the 1980s, herpes simplex received intense attention from the popular media. This both increased awareness of the condition, and created a very negative popular image of it. Herpes simplex became a problem in a way it had not been before. The nature of this problem needs to be considered against the background of its cultural, epidemiological and biomedical contexts.

THE CULTURAL CONTEXT

A *BMJ* editorial on 4 June 1983 was headlined 'Genital herpes: hype or hope?' and began:

> Genital herpes has received enormous attention by the media during the past year, and many of the articles have been sensational, inaccurate and of little help to patients.
>
> (Adler and Mindel 1983)

There was certainly little hope in the hype which presented the condition in the worst possible light, distorting the facts and exaggerating the significance of ill effects – in the process creating a monster out of a common and minor condition which had quietly co-existed with humans for a very long time. The meanings heaped on this condition were enough to take it to the top of the league of feared sexually transmitted infections, and in themselves, irrespective of the nature of any physical manifestations, to cause very significant psychosocial and psychosexual morbidity.

The condition was presented as sweeping through the ranks of the sexually active with an incidence reaching epidemic proportions.

> Today this viral infection has . . . established itself as an uncontrollable epidemic.
>
> (*Cosmopolitan*, July 1982)

> Herpes has emerged from relative obscurity and exploded into a full-fledged epidemic.
>
> (*Time*, 2 August 1982)

> A new and as yet incurable disease, spread through sex contact has reached epidemic proportions in parts of the Western world.
>
> (*Daily Mail*, 28 July 1982)

The *Daily Mail* article quoted above was in the 'Femail' section and headlined 'Nature's new threat to women' and, to emphasise the pervasiveness of the threat, suggested that you may be an ordinary woman in a typical role, but you only have to step outside the bounds of sexual propriety once to join the ranks of 'victims':

> Nor is the problem confined as is commonly supposed to women who make a habit of 'sleeping around'. Herpes is now so widespread that victims are often housewives, teachers and secretaries who may have been guilty of only one act of sexual indiscretion.

Joanna Day in the *Observer* (5 December 1982) attempting to put the claims into perspective, wrote:

> Statistics for England and Wales, meanwhile, show that *if* there is

> an epidemic on this side of the Atlantic, it is one of fear rather than fact.

Fear of the infection would certainly have been encouraged by the media presentations of its nature: 'Sexually transmitted herpes – highly contagious, incurable and unpredictably recurrent' (*Observer*, 2 May 1982); 'Herpes: the New Sexual Leprosy' (*Time*, 28 July 1980). The condition was presented as not only incurable, but having serious medical and psychosexual sequelae.

For a self-limiting condition which bodily defences normally deal with very adequately without medical intervention so that it is 'cured' every time it occurs, 'incurable' is clearly an emotionally loaded word. Many people who are infected with HSV do not appear to have recurrences and are unaware of symptoms. The infection produces antibodies while the virus lies dormant in the body, as do many others, for instance, varicella (chicken pox) which may in later life return to symptomatic mode as herpes zoster (shingles). Though HSV symptoms can now be suppressed by treatment with acyclovir, the antiviral drug was only just being introduced at this time. The unpredictable recurrence of symptom episodes is undoubtedly a difficult aspect of living with the condition, and has resulted in the attribution of negative anthropomorphic characteristics to the activity of the virus, and suggestions that it has 'a mind of its own' (*Time*, 2 August 1982) with which it chooses to play havoc with its victims' lives, leaving them at its mercy. A sufferer quoted in *Cosmopolitan* (July 1982) said:

> I felt like a victim. It's frustrating to be subject to a little tiny virus that messes things up.

Writing about the obscurity of the mechanisms which provoke re-emergence, Collee (1994) suggested that:

> at times the virus seems almost wilfully malicious . . . like having a tedious relation who unerringly chooses the most inappropriate moments to come and stay.

One of the scare stories which accompanied most articles about herpes in the early eighties related to the risk of cervical cancer, eg.:

> There is a strong suggestion of high risk of cervical cancer in women who have had herpes, especially HSV-2 of the cervix. They are recommended to have six-monthly smear tests.
>
> (*Spare Rib* 1980)

> Herpes has now been associated in many studies with another, extremely serious disease – cancer of the cervix . . . and it may well turn out to be the cause of it.
>
> (*Sunday Times*, 5 December 1982)

> In women, recurrent attacks are thought to increase the risk of cervical cancer between five and eightfold.
>
> (*Observer*, 2 May 1982)

> Herpes has been linked to cancer of the cervix, which afflicts an estimated 16,000 US women in its serious form and contributes to 7,400 deaths a year.
>
> (*Time*, 28 July 1980)

A most dramatic presentation of this postulated link was spelt out in *Cosmopolitan* (January 1984) in which an article suggested that there was 'evidence that . . . HSV-2 may be a trigger for cervical cancer', and that women with cervical cancer or pre-cancerous conditions of the cervix had been found to have 'high levels of antibodies to genital herpes in their blood and cervical mucus'.

> Laboratory tests have shown that if cells in a culture are exposed to the HSV-2 virus and then injected into hamsters, the animals develop tumours. While most viruses just kill the cell, the HSV-2 virus can turn the cell itself into a killer. Cells can become cancerous, yet the mechanism is so subtle that no trace of the deadly intruder is left behind – with no virus genetic material remaining to positively incriminate it. The herpes virus has the special ability to deliver a hit and run attack.

The negativity and metaphor of the language of this extract is typical of articles about herpes simplex around this time. The finding of a correlation between abnormal cervical cells and antibodies to HSV-2 was misinterpreted as a causal connection. In this case, the wrong virus was being implicated as a causal factor, and it was later found that certain versions of Human Papilloma Virus (HPV) were significant in the aetiology of cervical cancer and its precursors.

The *Cosmopolitan* article (January 1984) mentioned above contained several of the other scary warnings which were often reproduced in the media. One of these was the idea of self-inoculation, transference of the condition from one part of the body to another. The suggestion was that infection from the 'cold sore' version of the virus (HSV-1) could be transferred from the face to the person's own genitals: 'It's all too easy for this to happen during sleep through simple scratching'. The article went on to warn against the risk of using 'strange or unclean towels' as:

> towels can spread herpes, too, as the organism can survive on them for some time to provide a source of infection for anyone else using the same towel.

If the risk of transference of herpetic infection by self-inoculation or from towels was at all likely, one would expect many more instances of symptoms occurring on the hands or various other parts of the body than there are.

Another, highly emotive scare story which has been almost invariably mentioned in the media coverage of genital herpes simplex, relates to the neonatal risk of mothers passing on the condition to their babies. Again the facts were distorted and presented in the worst light:

> There is no doubt that herpes can be passed on to newborn babies if mothers have an active infection at the time of delivery. Each year several hundred babies are born with herpes simplex; more than half die, and survivors often suffer permanent neurological damage.
>
> (*Time*, 28 July 1980)

> In a British study of 302 babies born with herpes, 60% died; only 22% had no ill-effects . . . women who plan to have children face particularly frightening risks . . . babies can pick up the virus in the birth canal if the mother is suffering an outbreak at the time of delivery . . . The virus quickly spreads through the infants' bodies, killing more than half of them and leaving most of the survivors permanently brain-damaged.
>
> (*Cosmopolitan*, July 1982)

> A child who is delivered vaginally while the mother has an active attack of HSV-2 is likely to catch the virus through its eyes, skin or mouth. Two thirds of babies infected in this way die, and most who survive suffer severe damage to their brain or eyes.
>
> (*Spare Rib* 1980)

A cursory look at the prevalence of HSV-2 infection among adults, alongside the statistics for neonatal herpes simplex infection, would have raised doubts about the nature of the risk because of the large number of babies being born vaginally to women with HSV-2 antibodies who did not suffer herpetic symptoms (see discussion below).

The possible psychological and emotional sequelae of the condition were presented in equally lurid tones as if they were inevitable accompaniments. 'Not only is the disease dangerous physically – it also causes a great deal of psychological distress' *Cosmopolitan* (July 1982) suggested, before spelling out the nature of this suffering. Among the millions of Americans 'believed to suffer from herpes':

> Virtually all of them . . . must endure an emotional crisis so distinct in its assault on their sense of worth that psychologists speak of a 'herpes syndrome'. Herpes victims find themselves suddenly beset by new vulnerabilities and moral dilemmas. They feel tainted, fearful that no one will ever want to love them.

The article continued in the same tones, spelling out the author's interpretation of the 'herpes syndrome' postulated by Luby and Gillespie (1981): 'a pattern of anguish and isolation that may play havoc with a person's self-image and social life for years while he [*sic*] comes to terms with his disease'. And then there are the psychosexual consequences:

> For single people, herpes may shatter relationships or render a formerly fulfilling social life erratic and frustrating. For couples who are married or living together, herpes may strain the relationship to breaking point.

Doyle in the *Observer* (2 May 1982) wrote that much publicity had been given in the USA to 'the devastating emotional and psychological anguish of possessing an incurable sexually transmitted disease', suggesting that 'with herpes . . . the blow to a satisfactory sex life and to sexual self-esteem may be shattering'. An article in *Time* (28 July 1980) with the heading 'Herpes: The New Sexual Leprosy. "Viruses of love" infect millions with disease and despair' suggested that 'most will suffer shame, guilt and even depression, and a few will become suicidal', and quoted an informant who said:

> I regard myself as a carrier of an invisible, incurable disease. I have a guilt trip that won't quit.

Ten years later, the 'psychological effects' of the condition were still being written about as if they were a necessary accompaniment of the physical symptoms: