

## GENITAL HERPES: AN ETHNOGRAPHIC INQUIRY INTO BEING DISCREDITABLE IN AMERICAN SOCIETY

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### Introduction

In her widely acclaimed book *Illness As Metaphor*, Susan Sontag (1979) ruminates over Western society's use of illness as a symbol of corruption and decay and the subsequent social stigma attached to sufferers of those metaphorically manipulated afflictions. She states:

Leprosy in its heyday aroused a . . . disproportionate sense of horror. In the Middle Ages, the leper was a social text in which corruption was made visible; an exemplum, an emblem of decay. Nothing is more punitive than to give a disease a meaning—that meaning being invariably a moralistic one. Any important disease whose causality is murky, and for which treatment is ineffectual, tends to be awash in significance. (1979:57).

Writing in the late 1970s, she adds:

In the last two centuries, the diseases most often used as metaphors for evil were syphilis, tuberculosis, and cancer—all diseases imagined to be, preeminently, the diseases of individuals (1979:58).

Without question, if Sontag were to rewrite her thought-provoking treatise for the 1980s, two "diseases of individuals" would have to be added to the list of metaphorical maledictions in the United States. The diseases, of course, are genital herpes and, most recently, acquired immunodeficiency syndrome (AIDS).

This paper will deal with only the first of these two recent additions—the condition that has been dubbed by the popular media as "the new scarlet letter." Genital herpes is a sexually transmitted disease (STD) that tends to affect otherwise healthy, predominantly Caucasian, educated, well-employed, middle- to upper-middle-class men and women and, in so doing, may exert upon these never before-traumatized individuals a profound psychosocial impact out of proportion to the otherwise benign, non-life-threatening physical condition itself. The reason for the psychosocial ramifications, according to genital herpes patients,<sup>1</sup> is quite clear: namely, that the popular media have transformed genital herpes into a socially stigmatized condition of major proportions. This transformation, furthermore, has taken place only within the past five years, and its effects have diminished only slightly with the media's more current fascination over AIDS. Thus, to use Goffman's definition, the individual with genital herpes can now be seen as

possessing an attribute that makes him different from others in the category of persons available for him to be, and of a less desirable kind—in the extreme, a person who is quite thoroughly bad, or dangerous, or weak. He is thus reduced in our minds from a whole and usual person to a tainted, discounted one. Such an attribute is a stigma, especially when its discrediting effect is very extensive (1963:3).

### Questions and Methods

With this in mind, the question remains: What is it like to be an individual with genital herpes in the mid-1980s? This is the question to be addressed in this paper and is not unlike the one that other anthropologists, who have chosen to study so-called "marginal" members of their own societies, have asked in recent years.

This article represents the results of two months of fieldwork among a group of American adults of heterogeneous backgrounds and origins who have been brought together because of their "marginalized" status as genital herpes patients. All of the individuals who participated in this study are members (or, in some cases, are temporarily attending meetings) of HELP, a nationwide, volunteer-run, self-help organization for individuals with genital herpes. Through observation of three meetings (two for both men and women and one for women only) of a large metropolitan chapter of HELP, many of the concerns of individuals with newly diagnosed or recurrent genital herpes were recorded, and volunteers were recruited for follow-up, confidential telephone interviews. Eight individuals (four men and four women), ranging in age from the mid-20s to late-30s, agreed to be interviewed, each interview lasting from one to two hours. In addition, three sexually active individuals (two women and one man) of the same age group who do not have genital herpes were interviewed to elicit representative attitudes toward this disease from the so-called "normal" sector of the sexually active heterosexual population.

These data were supplemented by a thorough search of the recent medical (including nursing) literature on genital herpes; the "popular" literature (including recent articles in the press); and six years' worth of *The Helper*, the quarterly publication for HELP members, published by the sponsoring American Social Health Association (ASHA) in Palo Alto, California (ASHA 1979–84).

This paper integrates information from these varied sources as the key issues in the life experiences of individuals with genital herpes are discussed. These issues fall into two broad categories: (1) clinical concerns, revolving primarily around prevention of recurrence or of transmission of the disease to sexual partners; and (2) problems of "information management," as first defined by Goffman (1963). This paper will address only the second category: issues of information disclosure—to lovers, friends, and family—and the importance of "disclosure selectivity" in the lives of individuals with genital herpes.<sup>2</sup> This will be followed by a discussion of the role of self-help groups in information management counseling, and, finally, of the role of the media in the recent stigmatization of this condition and the impact of this stigmatization on the lives of genital herpes patients.

### To Tell or Not to Tell

For individuals with genital herpes, the greatest degree of discomfort often has very little to do with physical pain per

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se, but, rather, with the psychological suffering encumbered in the issue of "information management." In his now-classic book on stigma, Goffman (1963) explains the special problems of disclosure faced by those with a "discreditable" stigma, such as genital herpes. He states:

when his differentness is not immediately apparent, and is not known beforehand (or at least known by him to be known to the others), when in fact his is a discreditable, not a discredited person, then the second main possibility in his life is to be found. The issue is not that of managing tension generated during social contacts, but rather that of managing information about his failing. To display or not to display; to tell or not to tell; to let on or not to let on; to lie or not to lie; and in each case, to whom, how, when, and where (1963:42).

Indeed, Goffman's explication of the problems of the "discreditable" persona are quite germane to the discussion of genital herpes. Genital herpes is truly a discreditable condition—one that is essentially "invisible" (except, of course, when the individual is experiencing an outbreak and is having difficulty functioning), but, in certain instances, must be exposed with unpredictable outcomes to significant others. Indeed, this issue—more than anything else—seems to be *the* crucial variable in the lives of those with genital herpes; its importance cannot be underestimated.

*Sexual Partners* Many individuals who volunteered information at HELP meetings, and other respondents, did not know precisely from whom or how they had contracted genital herpes. In most cases, however, this was not attributable to sheer number of sexual partners (i.e., so-called "promiscuity"), but, rather, to the insidious nature of the disease; namely, it may have appeared for the first time during periods of sexual inactivity or during periods of monogamy with a supposedly uninfected sexual partner.

For others, the disease was clearly contracted from a known sexual partner, who either did not tell of his or her problem or, in some cases, miscalculated the length of an outbreak and, hence, the period of contagion. For those who were "lied to" by their partners, a degree of anger or outright rage was felt by all.

Indeed, the issue of "honesty" was raised by all individuals interviewed and appears to be *the* major information management dilemma faced by genital herpes patients—or, as Goffman would put it, "to tell or not to tell; to let on or not to let on; to lie or not to lie" (1963:42). Although the decision to disclose information about one's genital herpes is optional in most cases, it seems that, for most individuals, this matter of choice disappears—either morally or practically—when it comes to telling a potential sexual partner. Yet, the individual with genital herpes is caught in a "double bind" when it comes to forming intimate, "post-stigma" relationships, for, if this "failing" is revealed too soon, the other party may flee, while, if disclosed too late, guilt, accusations or dishonesty, and actual transmission of the stigmatized viral condition may ensue.

For example, one married man said he considers himself fortunate to be in a permanent relationship because of the disclosure implications faced by single men and women. He explained:

If I weren't in a relationship, I know I'd have a lot more to deal with. Having to tell someone after two or three dates, "I have herpes. Will you go to bed with me?" is not a pleasant thought.

I would say "No" myself if I didn't have it! So I see all these single people in the group [HELP] having to come up with little schemes to delay sex and build up other aspects of the relationship first.

Such "sex-delaying" schemes and ways to "break the news" are the topics of much conversation, both at the HELP meetings and in *The Helper*. At one meeting, the group leader suggested some "do's and don'ts" for telling a partner, including: (1) don't make it into a dramatic production; (2) don't use words like "incurable," "highly contagious," and "venereal"; (3) don't give more information than the person can handle (e.g., an hour on the statistics alone); (4) do present it in a matter-of-fact tone of voice; (5) do pick a quiet, relaxed moment to tell; (6) don't wait until you're in bed with your clothes off; and (7) don't wait until you've had sex with the person 16 times.<sup>3</sup> However, according to most informants, this suggested approach is easier said than done, and actual disclosure experiences ranged from "histrionics" on the part of several informants to avoidance of sexuality altogether in the case of others.

According to informants, the reason disclosure to intimates is so difficult is because of an overwhelming fear of rejection—a fear that appears to loom large in the minds of those with genital herpes. Several informants admitted that they now avoid, to a great degree, intimate relationships because of their fear of potential rejection. Others, primarily women, said that they had stayed in problematical relationships much longer than they would have had they not had genital herpes, because of their timidity in striking up new sexual partnerships. Virtually all informants stated that their sex lives had changed significantly as a result of genital herpes and that they were now much more circumspect about entering into new situations of intimacy.

Nevertheless, despite this overriding pessimism, actual experiences with new sexual partners suggest that the worst fears of rejection are rarely realized. Of the six individuals with genital herpes who had attempted to have post-herpes sexual relationships, only two could cite definite cases of rejection because of the disease; most informants had at least two, and often many more, instances of acceptance. Furthermore, of the three individuals interviewed who did not have genital herpes, two of them had already engaged in sexual relationships with partners whom they knew had herpes—and said that they would do it again if the situation ever arose. The third individual, furthermore, concurred that genital herpes would be a "superfluous" factor in deciding whether or not to have a relationship. All three individuals added, however, that their attitudes toward genital herpes had changed drastically—toward a more positive, enlightened view—over time.

*Friends* Likewise, many of the individuals with genital herpes were extremely reluctant to tell their friends—or their "pre-stigma" acquaintances (Goffman 1963:35)—about their newly acquired problem. Although some individuals attending the HELP meetings said they had told most of their friends and acquaintances about their condition, two of those interviewed, both male, had not divulged this information to any pre-stigma acquaintances, and the other six said they had told only a few of their closest friends, most of whom had reacted supportively.

At least part of the reason why most individuals chose not

to tell more than a few close friends was their paranoia over widespread exposure of their "failing" and a desire to uphold their pre-stigma reputation. This, in turn, was related to the aforementioned fear of rejection: of being made a pariah by one's larger circle of friends and acquaintances. This paranoia over exposure was understandable when one considers that most of the individuals attending the meetings—and certainly those interviewed—appeared to be bright, attractive, articulate, highly successful individuals, with positions of responsibility in the community. Widespread knowledge of the stigmatized condition would not only spoil the well-developed image, but might cast doubt on the so-called "moral character" of the individuals involved—especially considering the route of transmission of the disease. Thus, most of the individuals interviewed were extremely protective of their "secret," and the fear of exposure was a possibility that haunted many of their lives. As one woman stated:

Some of my very closest friends don't even know. You have to *really* know who you trust, because if you tell one wrong person, and that person tells one person, then 101 people already know. If I have even a one-percent doubt in my mind, I don't tell.

*Families* The fear of telling "Mom and Dad" was often even more pronounced in interviews with genital herpes patients. By telling parents or brothers and sisters about the condition, the genital herpes patient not only admits to his or her own sexuality, but that the sexual activity may have been of a questionable nature. Thus, unlike many other stigmatized conditions, in which family members are intimately involved in the individual's welfare (see, for example, Ablon 1984 or Ablon, Ames, and Cunningham 1984), genital herpes seems to be a condition with little involvement of the family group itself, since families, particularly parents, are rarely informed directly about their now "discreditable" member. Instead, informants, if they divulged this information at all, tended to choose only one member of the family, usually the "closest" sibling. In most cases, too, the disclosure was accompanied by promises of secrecy, especially regarding exposure to parents.

One informant, who told her brother about her condition, added:

As for my parents, I *can't* tell them. The sad part is that if you had the flu or pneumonia, your family would stand by you. But you're a pariah if it's something like this.

Another informant, who also told a brother about herpes, explained:

It's helped psychologically to have someone to talk to about it. Herpes is not one of your major two or three diseases, but it can get depressing. Most people are not in stable relationships when they get it, and they're lonely. Loneliness is the main aspect of the disease.

### HELP: Educational and Social Functions

This last statement—that "loneliness is the main aspect of the disease"—explains why many individuals with genital herpes seek out HELP, if only temporarily. HELP, a program of the ASHA's Herpes Resource Center,<sup>4</sup> is the country's only self-help organization for individuals with genital herpes. Of the more than 80 local chapters nationwide, most are located in major metropolitan areas.

For many individuals, this volunteer-run, self-help organization is a source of clinical information, but its major function is as a support system of "sympathetic others," who can serve as role models, confidantes, and advisors during both clinical and emotional crises. Many individuals use the group intensively during the primary stages of their illness and then later settle into less frequent attendance patterns or, in some cases, stop going. Others use the group less as a resource and more as a social club. As one informant stated: "The honest truth is that I go to HELP to meet a woman. Sometimes I just think it would be easier having a relationship with someone who already understands."

Meeting others with similar "moral careers" (Goffman 1963) for the purpose of trouble-free dating and sex may be a covert function of the group; in fact, several individuals at the meetings mentioned their desires to date someone who also had genital herpes, for this, they believed, would solve some of their anxieties over information disclosure and transmission. Herpes "dating services" were also discussed at meetings; however, several members shared their negative experiences with these services, which are expensive and seemingly ineffectual, according to informants.

However, when the issue of "endogamous" dating was raised at meetings, the group leader provided convincing clinical evidence to discourage this practice: namely, the possibility of contracting two different strains of herpes virus, thereby exacerbating the recurrence problem. As a result of these clinical discussions, most of the individuals interviewed said they preferred to have sexual relations with individuals who did not have genital herpes, despite the difficulties encumbered in having to divulge their "secret stigma."

### The Media and the Process of Stigmatization

Without question, if genital herpes were to be ranked today by degree of social stigma in the long list of STDs, it would take second place, with AIDs assuming the top position. If, however, one were to rank genital herpes by degree of social stigma in a list of STDs normally found among heterosexuals alone (thereby eliminating AIDs), it would surely attain top billing—outranking the now curable syphilis and gonorrhea. Indeed, if one were to rank genital herpes in terms of stigma among all the diseases known to American society, it would certainly fall among the top dozen diseases, and possibly even among the top four or five. The reason for this notoriety is believed to be due to the media—and a process of stigmatization that took place almost overnight. As one informant stated, "We are victims of the media."

According to everyone interviewed, including those without genital herpes, the media have caused most of the problems for individuals with genital herpes. Those who could remember—particularly those who had already contracted the disease by the end of the 1970s—say that the media seemed to pick up on genital herpes in the very early 1980s, with a strong emphasis on the "incurable," "recurrent" nature of the disease. This culminated in August 1982, when *Time* magazine printed a cover story in which genital herpes was called "the new scarlet letter" (Leo 1982). At HELP meetings and in interviews, several persons pointed directly to this article as the lynchpin in the subsequent "epidemic"

of paranoia and fear of herpes in the United States.

Although the media's sensationalist enthusiasm for genital herpes diminished substantially with the onset of AIDS, resurgences of interest have continued to occur, as seen most recently in the "little Johnny Bigley" case, in which a three-year-old child, affected at birth by neonatal Herpes simplex Type 1, caused fearful parents to remove their children from his classroom, thereby creating nationwide panic. The fact that such a "herpes scare" could take place in 1985 indicates that fear of genital herpes is still very strong in the United States, that misinformation and misconceptions about the disease abound, and that a corrective educational effort by the media has yet to take place.

As a result, a great deal of anger is directed at the press; this was evident at HELP meetings, in interviews with informants, and even in *The Helper* publication, which had initially condoned the media's attention. One informant explained his frustration in this way: "Before the scarlet letter cover, you could screw around as much as you wanted—as long as you didn't have a conscience. But now, everything's changed." Or, as another informant concluded, "The best thing that ever happened to herpes was AIDS."

Even those individuals without genital herpes who were interviewed said they thought the media were responsible for the public's fear of the condition. One person noted that the media have done a further disservice ("adding insult to injury") by lumping herpes with AIDS in terms of health risk, even though they are "orders of magnitude different in their severity."

But how does this media-generated social stigma translate into everyday life for those with genital herpes? According to all informants, the innocent jokes and cruel remarks made about herpes hurt the most—turning otherwise average days into bad ones and even scouring friendships. As one woman explained:

It's still an "hysterical" issue for people—in both senses of the word. For instance, I'll be talking with a group of friends about our love lives, and someone will say, "Boy, you're lucky you didn't catch herpes from him!" Then everyone laughs. They would never in a million years imagine that I have it, and, if they knew, some of them probably wouldn't sit in the same room with me for fear of catching it. I never say anything, but I really think those kinds of remarks are insensitive. Nowadays, you never know who might have it—maybe even your best friend. So it's better to just keep your mouth shut.

Another said that herpes has become "funny" because (1) it is sexually transmitted, and (2) it is incurable. Underlying this humor, however, is a great deal of fear. He asserted:

People always joke about that which they're most afraid of. There is a lot of ignorance out there, and where there's ignorance, there's fear, and where there's fear, there's humor. That's the syllogism.

Thus, although most informants could accept the jokes on an intellectual level, humor about herpes also presented something of a Catch 22; namely, most informants said their natural desire to lash out at these offensive remarks was curbed by their fear of exposure and subsequent rejection. Hence, most informants simply "kept their mouths shut" to prevent being "treated like a leper" in social settings. Indeed, the terms "leper" or "leprosy" were used at least once

by five informants and by two of the individuals without herpes also interviewed. Although most informants said they did not regard themselves as "lepers," they acknowledged that the public may regard herpes as being like leprosy—contagious and to be avoided at all costs. This attitude, although understandable, is unfair considering the relatively benign nature of the disease, and has made living with herpes much more difficult, according to all those questioned.

## Conclusion

The "invisible" nature of genital herpes is, in some senses, its most perplexing attribute—creating emotional, practical, and ethical dilemmas in the private, "discreditable" domain of information management (Goffman 1963). This article has attempted to explicate that domain, through an ethnographic inquiry into the lives of some marginalized members of our own society. Interviews with eight young adults, all affected by genital herpes, reveal how fear of disclosure—and subsequent rejection—plays a powerful role in the daily lives of these individuals. Deciding whether or not and how to tell friends, families, acquaintances, strangers, and worst of all, potential lovers about one's "secret stigma" proves to be a continuous conundrum for most. To tell or not to tell, to lie or not to lie, to let or not to let on—these are the questions that individuals with genital herpes must face with each relationship, new or old, and the answers are not easily forthcoming.

Most individuals opt to solve these problems in the following ways: (1) by dividing the world into two groups, a select group of trusted "insiders," and the "outsiders," who would be too distraught (e.g., parents), too rejecting, or too glib to be trusted with the secret; (2) by limiting sexual partners, so as to avoid transmission of the virus and, more important, to avoid the issue of disclosure to intimates; and (3) by joining HELP, a self-help group for genital herpes patients, which offers both emotional and clinical support.

These steps are necessary, informants insist, because of the recent stigmatization of the disease. Namely, in the early 1980s, the media transformed genital herpes from an unknown, relatively benign, nonstigmatized condition into an "incurable, highly contagious, recurrent venereal disease, threatening the life, liberty, and happiness of every American who uses public toilets." This loathsome and leprous image, informants say, is entirely undeserved, for genital herpes is non-life-threatening, nonapparent, and easily preventable when proper precautions are taken. But because genital herpes has now been lumped with such stigmatized conditions as leprosy, AIDS, tuberculosis, and cancer, life has become difficult for those with the disease, who fear social outcasting, cruel humor, and other forms of outright stigmatization.

Whether genital herpes will continue to be stigmatized in American society remains to be seen. In all probability, the degree of stigma will diminish substantially if a vaccine to prevent transmission or, better yet, a true antiviral agent becomes available. But until that time, we, as medical anthropologists, have a rare opportunity to study the processes of stigmatization and marginalization at home. Once we understand how discreditable stigmas—the "new scarlet letters"—of our own complex society are created, maintained,

and managed by individual members, we may be able to shed light on the phenomenon of acquired deviancy—on becoming society's discreditable members—the world over.

#### NOTES

<sup>1</sup>*Acknowledgment.* The author wishes to thank Drs. Joan A. Aron and Nelson Graburn for their support and for their valuable comments on earlier drafts of this paper.

<sup>2</sup>I prefer to use the term "patient" rather than "victim" or "sufferer."

<sup>3</sup>Information on clinical concerns of genital herpes patients may be obtained from the author.

<sup>4</sup>Likewise, in an article on "Talking About Herpes" in *The Helper* (Summer 1984), some additional advice was proffered, including: (1) don't feel guilty about herpes; (2) do assume that the person you are about to tell has little, if any, accurate information about herpes; (3) do be prepared to dispel fears and misconceptions; (4) don't worry in advance about telling, because it doesn't help; (5) don't feel as though you have to be a walking encyclopedia about every herpes-related nuance; (6) do use appropriate analogies wherever possible; (7) don't forget to emphasize how preventable herpes is; and (8) don't be surprised to learn that the person you are anxious to tell has wanted to tell you, too.

<sup>5</sup>In 1982, the ASHA changed the name of its genital herpes self-help organization from Herpetics Engaged in Living Productively (HELP) to the Herpes Resource Center (HRC), because the term "herpetics" was viewed negatively by its membership. However, the acronym HELP is still used by the 80-odd local chapters, and the ASHA's publication is still called *The Helper*. Thus, the acronym HELP has been used throughout this paper to conform to current usage.

<sup>6</sup>HELP also serves a number of other less widely discussed but important functions. These include: (1) research fund drives; (2) lobbying; (3) provision of a telephone "hot-line"; (4) symposia coordination; (5) epidemiological, demographic, and psychosocial surveys of the membership; (6) formulation of medical advisory boards; (7) public relations and media interviews; (8) legal advice; (9) announcements of clinical trials; (10) announcement of new clinics and chapters; and (11) review and evaluation of the medical and popular literature on genital herpes. To see how HELP compares with

other national self-help organizations, refer to Borman et al. 1982, Berman and Lieberman 1976, Killilea 1976, and Silverman 1978.

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#### Original Article

## THE REPLICATION OF THE MEDICAL DIVISION OF LABOR IN MEDICAL ANTHROPOLOGY: IMPLICATIONS FOR THE FIELD

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In anthropology, as in any other discipline, specialization is inevitable as the knowledge base expands. Nevertheless, anthropologists, more so than other scholars concerned with the human scene, subscribe to the principle of holism. In practical terms, this means that whatever our specific research interests may be, we rely upon a broader corpus of theoretical literature that attempts to tie the specific to the general. Medical anthropologists often assert that holism is an important contribution that they can make to the understanding of health-related issues. Conversely, we view biomedicine as reductionist in its view of illness and fragmented in its treatment of the patient—patterns that are accentuated with increasing specialization in medicine. A closer look, however, suggests that medical anthropology may be replicating the complex division of labor characteristic of biomedicine, and consequently becoming more reductionist.

This essay will explore possible reasons for this development and its implications for the future of medical anthropology.

### The Pattern of Growing Specialization in Medical Anthropology

My graduate education was primarily in sociocultural anthropology. I still view myself as a sociocultural anthropologist with interests in several areas, including medical anthropology. Yet when I became a postdoctoral fellow in a medical anthropology program, I discovered that a distinction was being made in the department between sociocultural anthropology and medical anthropology. Many students, apparently following the lead of their mentors, identified themselves as either "sociocultural" or "medical" anthropologists. Rather than viewing medical anthropology as a link between physical anthropology and sociocultural anthropology, as Alexander Alland (1970) does, it was treated as a fifth subdiscipline of anthropology. The pattern that I observed does not appear to be unique. A friend in another medical anthropology program told me that many of her fellow graduate students are not exposed to the broader theoretical paradigms and issues in anthropology, but rather are encouraged to focus on narrow solutions to specific health problems. Furthermore, many students in medical anthropology programs devote considerable time to mastering courses in the health sciences, such as physiology, anatomy, genetics, and nutrition.

Medical anthropology is becoming more and more fragmented into an increasing array of subspecialties, such as clinical, therapeutic, psychiatric, and nutritional anthropology. The Society for Medical Anthropology is devolving into a conglomeration of special interest groups. These include the Council on Nursing and Anthropology, the Council on Anthropology and Reproduction, and the Alcohol and Drug

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