CONCLUSION

In efforts to contextualize what Goffman refers to as spoiled identity, and to develop as individuals, aged deaf people have lived their lives on two levels: (1) the superficial interactions with hearing "strangers," and (2) the intimate interactions with deaf peers. As time passes, intimate interactions become increasingly important to the self-concept. The awkward, tension laden interaction with strangers, although they are re minds of one's deafness, become easier to avoid as people age. By limiting the intensity and frequency of their contacts with the hearing world, elderly deaf people reduce the level of frustration with which they must live. The combination of deaf identity and a strong system of social support sustain elderly deaf people against isolation and loss of self-worth. Thus, they have created a climate that enables them to adapt to their disability.

REFERENCES

1. A pseudonym is used to protect confidentiality.
15. I am indebted to George Atwell of the California Deaf Center for calling the history of this sign to my attention.

Genital Herpes: An Ethnographic Inquiry into Being Discreditable in American Society

Marcia C. Inhorn

For many students, this selection will hit close to home. Sexually transmitted diseases (STDs) are a risk, a worry, and a problem to many sexually active college-age people. The stigma of the origin of the sign has been forgotten, and it has become a powerful symbol of unity and af- fection that is now used by deaf people all over the United States.

HIV/AIDS, and it is causing massive mortality and untold suffering. On a global level, roughly one-half of the victims of HIV/AIDS are women—and most have "done" nothing more than have sex with their husbands. Nonetheless, they are often blamed for their condition (Farmer, Connor, and Simmons 1996).
Throughout the world, STDs are frequently stigmatized conditions that reflect on the morality of the patient (Gregg 1983). Often there is also a double standard in terms of stigma. In this selection, Marcia Inhorn analyzes the problem of information management—that is, the decision of whom to tell about one’s condition. The problem of living with herpes is less a medical problem than a social and psychological problem. The fact of having a secret, and the shame associated with hiding the truth come out, is part of the illness experience of people with genital herpar.

This selection may seem dated, in large part because the HIV/AIDS epidemic changed the situation enormously. At the time it was written, the emerging genital herpes epidemic seemed terrible and noteworthy. Many people had recognized that a marked increase in STD prevalence accompanied the sexual revolution in the late 1960s and 1970s (the era before AIDS). Some people did not consider these infections to be serious or to merit the same epidemiologic and other "new," untreatable, and potentially lethal STDs like AIDS. This attitude, however, ignored the fact that STDs, particularly in women, could result in long-term infertility. The big change in attitude came with AIDS; public health workers believe that the risk of AIDS has made the general population more careful about STDs.

**INTRODUCTION**

In her widely acclaimed book Illness As Metaphor, Susan Sontag (1979) narrates 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 around a . . . disproportionate sense of honor. In the Middle Ages, the leper was a social text in which corruption was made visible; an emblem, 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 in effectual, tends to be shunned 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 1990s, two “diseases of individuals” would have to be added to the list of metaphorical maladies 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, nonlife-threatening physical condition itself. The reason for the psychosocial ramifications, according to genital herpes patients, 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 has herpes is thought of as—after all, newly acquired, or reawakened, or weak. The changing nature of epidemiological information and the suffering caused by stigma, the role of the media can be a two-edged sword. There is value in informing the public, but there is also the danger associated with irrational social reaction to epidemics. As you read this selection, consider these questions:

- Does the stigmatization of genital herpes mean that the normal rules of the sick role are not applicable?
- Why is information management a problem associated with this illness?
- What does the author mean by “discriminatory”? Why would an infection make someone less creditable?
- What are the functions of self-help groups, like the voluntary association called HELP?
- Can the stigmatization of an illness change over time? Why?

**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 field work 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 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—“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 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. 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 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 “discriminatory” stigma, such as genital herpes. He states:

when his differentiation is not immediately apparent, and is not known beforehand (or at least known to be to known to the others), when in fact his is a discriminatory, not a discriminated, 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 “discriminatory” person are quite germane to the discussion of genital herpes. Genital herpes is truly a discriminatory 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, the 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 infected individual, or a sexual partner of a known infected individual. Stigma is 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 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 it is 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, ‘You know, I 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 lithuanian 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 talk; (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. However, according to most informants, this suggested approach is easier said than done, and actual disclosure experiences ranged from "histories" on the part of several informants to avoidance of sexual- ity altogether in the case of others.

According to informants, the reason disclosure to intimates is so difficult is because of an underlying 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 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 sexual lives had changed significantly as a result of genital herpes and that they were now much more circumspect about entering new relationships 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 whom they knew they had herpes—and said that they would do it again if the situation ever arose. The third individual, further- more, confided that genital herpes would be a "superfluous" factor in deciding whether or not to have a relationship. All three individuals added, how- ever, that their attitudes toward genital herpes had changed drastically—toward a more positive, enlight- ened view—over time.

Friends

Likewise, many of the individuals with genital herpes were extremely reluctant to tell their friends—or will- ing to reveal their genital herpes histories, even to those who lived near them. When confronted with their friends’ opposition to their disclosure, many of the individuals found it necessary to use over-the-counter "pre-stigma" acquainances (Goffman 1963:35)—about their newly acquired problem. Although some individ- uals attending the HELP meetings said they had told most of their friends, acquaintances about their condition, two of those interviewed, both male, had not divulged this information to any pre-stigma acquainances, 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 fear of widening 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 individ- uals, 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 "normal 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 possibil- ity 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, then10 people already know. If I have even one or two people double in my mind, I don’t tell.

Families

The fear of telling "Mom and Dad" was 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 na- ture. Thus, unlike other "stigmatized conditions, in which family members are immediately 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 tell only one member of the family, usually the "closest" sibling. In most cases, too, the disclosure was accom- panied 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 her- pes, 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.
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 a secure place among those 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 stand out as a top billing—out ranking 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 nature of stigma in general 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 contacted 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 "incubable," "recurrent" nature of the disease. This started 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 lynching 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, resurgence of interest has 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 "big deal" 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 effort by social scientists has yet to other place to take.

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 condensed the media's attention. One informant explained his frustration in this way: "Before the Scarlet letter cover, you could scroun 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 herp- ses 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 souring 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 offensive. 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 setup.

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 laugh at these offensive remarks was curbed by their fear of exposure. As one informant put it, "I guess most new- formants simply 'kept their mouths shut' to prevent being 'treated like a leper' in social settings. Indeed, the term 'leper' or 'leprosy' were used at least once by live 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—and that it has a certain stigma even at all costs. This attitude, although understandable, is undeniably 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 herp- ses is, in some senses, its most perplexing attribute—creating emo- tional, practical, and ethical dilemmas in the private, "disease-free" environments 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: women who had been diagnosed with herpes, 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, to tell, tell or not to tell, to let or not to let on—these are the choices 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., par- ents), too rejecting, or too garrulous to be noted with the secret; (2) by limiting sexual partners, in order to avoid transmission of the virus, and more important, to avoid the emotional 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 herp- ses from an unknown, relatively benign, stigmatized condition into an "incubable, 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 gen- ital herpes is non-life-threatening, nonaparent, and easy preventable when proper precautions are taken. But because of the public's ignorance and fear, genital herpes has now been lumped with such stigmatized conditions as leprosy, AIDS, tuberculosis, cancer, and life has become difficult for those with the disease, who fear social ostracizing, cruel humor, and the stigmatization of genital herpes.

Whether genital herp- ses will continue to be stigmatized in American society remains to be seen. In all likelihood, the degree of stigma will diminish sub- stantially 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 hand. Once we understand how discreditable stigmata—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 mem- bers—the world over.

NOTES

1. I prefer to use the term "patient" rather than "victim" or "sufferer."

2. Information on clinical concerns of genital herpes pa- tients may be obtained from the author.

3. Likewise, in an article on "Talking About Herpes" in The Helper (Summer 1984), some additional advice was pre- ferred, including "tell a lie about herpes;" (2) do not 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) do not worry in advance about telling (because it doesn't help); (5) don't feel as though you have to be a walking encyclo- pedia about every herpes-related topic; (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.

4. In 1982, the ASHA (changed the name of its genital herpes self-help organization from the previous Self-Helping Productively [HELP] to the Herpes Resource Center [HRC]), because the term "herpetica" was viewed negatively by the mass media. 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.

5. HELP also serves a number of other less widely discussed but important functions: (a) provides education and drives; (b) lobbying; (c) provision of a telephone "hotline;" (d) symposia coordination; (e) epidemiological, demographic, and psychosocial surveys of the membership; (f) formulation of medical advisory boards; (g) publicity re- lations and media interviews; (h) legal advice; (i) an- nouncement of clinical and research opportunities; (j) review and evaluation of the medical and popular literature on genital herpes. To see how HELP compares with other national self-help organi- zations, refer to Borman et al. (1982); Borman and Lieber- man 1976; Killins 1976; and Silverman 1978.

REFERENCES
Robert F. Murphy

As Gregor Samsa awoke one morning from uneasy dreams he found himself transformed in his bed into a gigantic insect. He was lying on his back, as if it were armor-plated, and when he lifted his head a little he could see his disbelieving brown belly divided into stiff arched segments. . . . What has happened to me? he thought. It was no dream.

—FRANZ KAFKA, The Metamorphosis

This selection is autobiographical, written by an anthropologist who attended Columbia University. Robert Murphy has done anthropological fieldwork in the Amazon and other parts of the world. Murphy and Murphy (1983, 1984) have researched the world of the disabled and wheelchair-bound began under a slow-growing cancer began pinching his spinal cord, ultimately leaving his legs paralyzed. This selection is a chapter from the book, The Body Silent (1987) that tells both a poignant personal story and provides keen anthropological observations on the illness experiences of disabled people.

The focus of this selection is on the self: the cultural construction of the individual as a social, corporeal, and psychological entity. Murphy uses Freudian theory to explore the notion of self and how the illness experience changes that notion. The relationship between the self and the body is particularly important. In recent years, the anthropology of the body—the study of the symbolic meanings of the body and the embodiment of meaning through lived experience—has become an increasingly important theme. Murphy's experience with a disabled body and an incurable disease resulted in many powerful insights about the world. (A similarly powerful book from this perspective is Reynolds Price's A Whole New Life (1994).) Some insights come from the daily struggle to do simple things and the loss of taken-for-granted abilities. Murphy talks about the sex life of paraplegics in this vein. Further insights come from interactions with others who are affected not only by the physical reality of the wheelchair but also by cultural notions of stigma and the social creation of the "other." The necessity of adapting to new life circumstances—and the emotional impact of those adaptations—is a theme we saw in the selection by Gaylene Becker on the lives of deaf people. The disabled must adapt to limitations in mobility and to living daily with pain, but the nonphysical aspects of the illness experience remain very important. In this selection, Robert Murphy frankly discusses the suffering caused by depression and decreased self-esteem as well as criticizing biomedicine for its inability to deal with the entire self.

As you read this selection, consider these questions:

Why are children often afraid when they see a disabled person? How are definitions of "normal" learned?

Murphy's paralysis developed relatively slowly, whereas most spinal-cord injuries occur suddenly as a result of car crashes and other accidents. Would the cause of the injury have any relation to the illness experience? To the ways that other treat the disabled?

What does Murphy mean by "unmarked categories" and the creation of the "other"? Is his analogy to the importance of race and the experience of racism relevant here?

Think for a moment about what your life would be like if you were suddenly confined to a wheelchair. How would your life be different? How would your relationship with your body be different? How would people treat you differently?

From the time my tumor was first diagnosed through my entry into the world of illness, I had an increasing appre- chension that I had lost much more than the full use of my legs. I had also lost a part of my self. It was not just that people acted differently toward me, which they did, but rather that I felt differently toward my- self. I had changed in my own mind, in my self-image, and in the basic conditions of my existence. It left me feeling alone and isolated, despite strong support from family and friends; moreover, it was a change for the worse, a diminution of everything I used to be. This was particularly frightening for somebody who had clowned his way up from poverty to a position of respect. I had become a person of substance, and that substance was oozing away. It threatened everything that Yolanda and I had put together over the years. In middle age, I was now what he had conveyed.

And I had no idea why and how this had happened.

I cannot remember ever before thinking about physical disability, except as something that happened to other, less fortunate people. I certainly had no relevance to me. A disabled person could enter my field of vision, but my mind would fail to register him—a kind of selective blindness quite common among people of our culture. During a year that I spent in the Sahel and Sudan zones of Nigeria and Niger, a region of endemic leprosy and missing hands, feet, and noses, the plight of those people was as alien to me as were the language, culture, and circumstances. Because of this gulf, I had no empathy for them and just enough sympathy to drop coins into cups extended from the ends of stumps. A few pence were all that it took to buy the dubious grace of almsgiving. It was a bargain, a gesture that did not assert my one- ness with them, but rather my separation from them.

With the loss of my own impairment, I became almost morbidly sensitive to the social position and treatment of the disabled, and I began to notice nuances of behavior that would have gone over my head in times past. One of my earliest observations was that social relations between the disabled and the able- bodied are tense, awkward, and problematic. This is something that every handicapped person knows, but it surprised me at the time. For example, when I was in the hospital, a young woman visitor entered my room with a look of total consternation on her face.

She exclaimed that she had just seen an awful sight, a girl who was missing half of her skull. I knew the girl as a very sweet, but quite retarded, teenage patient who used to drop in on me a few times a day; we always had the same reaction conversation. I asked my guest why the sight bothered her so much, but she couldn't tell me. She in turn asked why it didn't trouble me. After a moment's thought, I replied that I was one of them, a notion that she rejected vehemently. But why did my visitor, a poised and intelligent person, react in this way? It aroused my curiosity.

There is something quite significant in this small encounter, for it had elements of what Erving Goffman called "one of the primal scenes of sociology." Borrowing the Freudian metaphor of the primal scene (the child's traumatic witnessing of the mother and father in sexual intercourse), Goffman used the phrase to mean any social confrontation of people in which there is some great flaw, such as when one of the parties has no nose. This helps us understand cultural guidelines, traumatizing it and leaving the person involved wholly uncertain about what to expect from each other. It has the potential for social calamities.

The intensely problematic character of relations between those with damaged bodies and the more-or-less unmarked cannot be shrugged off simply as a re- sult of the latter's ineptitude, bias, stupidity, and so forth, although they do play a part. Even the best-intentioned able-bodied people have difficulty anticipating the reactions of the disabled, and interpretations are warped by the impairment. To complicate matters, the disabled also enter the social arena with a skewed perspective. Not only are the bodies altered, but their ways of thinking about themselves and about the world and objects of the external world have become profoundly transformed. They have experienced a revolution of consciousness. They have undergone a metamorphosis.

Nobody has ever asked me what it is like to be a para- plegic—and now a quadriplegic. This would violate all the rules of middle-class etiquette. A few have asked me what caused my condition, and, after hearing the answer, have looked as though they wished they hadn't. After all, tumors can happen to