



## Mixing Morality with Medicine

*I never thought it would happen to me . . .*

A 20-year-old undergraduate receives a phone call from her ex-boyfriend. He nervously informs her that he has just been diagnosed with genital warts and is in the process of having them “frozen off” with liquid nitrogen. He explains that he called her because there was a chance that he might have had *this* when they had last *been together*. He adds that he is not sure she is at risk because he had not noticed symptoms until recently. She quickly thanks him for calling, hangs up the phone, and sits in stunned silence.

She thinks to herself: *How could this have happened to me? I'm not a slut: I've only had sex with three guys and always used condoms. I talked with both my ex-boyfriends and current boyfriend before we ever had sex—they told me about their sexual histories and sexual health. These guys had all tested negative for HIV, so they were “safe”—healthy and trustworthy—right? My high school sex education focused on HIV/AIDS, so I've only been worried about fluids being transmitted. Is it possible to get a disease even when you're using condoms?*

A series of scary questions runs through her mind. *Do I have warts, too? How could I? My last annual gynecological exam was less than six months ago, and my Pap smear results were normal. Wouldn't my doctor have noticed if I had warts? Could I have warts that are so*

*tiny I've never noticed them?<sup>9</sup> Have I already infected my current boyfriend?<sup>9</sup>*

With no answers to any of these questions, one horrific image appears in her mind with unsettling clarity: inspired by the one film about sexually transmitted diseases (STDs<sup>1</sup>) that was shown in her high school health class, she envisions her vulva sprouting cauliflower-like growths, more and more fleshy warts, ultimately covering her genitals inside and out. This image brings her to tears. As she begins to cry, she wonders: *Will any guy ever want me? Will I ever get married or be able to have a healthy baby?*<sup>22</sup>

## More than Just an Infection: Gendered Morality and Sexual Diseases

The preceding snapshot gives one example of how it feels to find out that you have a STD. Many infected individuals feel “dirty,” disgusted by the bumps and sores that require medical attention and mar body parts, which are supposed to be the most private, sensual, and erotic. These negative feelings are compounded by the social acceptability of blaming infected individuals for their illnesses. Often the blame comes with judgments, such as *irresponsible*, *naïve*, or *stupid*. Others will likely view this illness as a sign of immorality and label the infected person a promiscuous *slut*, having low character and bad values. This kind of disease will likely be experienced not only as a health crisis but also as an identity crisis. It is easy to understand why many Americans with STDs are left wondering if they are, in fact, *damaged goods*—their bodies and reputations so spoiled that they may never again feel healthy, whole, and valuable.

Every year, versions of this scenario become reality for many of the over 15 million Americans who contract a STD. Chronic STDs are a significant part of this epidemic in the sexually-active population: U.S. rates of genital human papillomavirus<sup>3</sup> infections (HPV—the virus that causes anogenital warts and cervical lesions) are as high as 75 percent (ASHA 2006a), and genital herpes infections (HSV) are estimated at more than 20 percent (ASHA 2006b). Since 2000, HPV infection has ranked as the most common STD infecting American youth (Weinstock et al. 2004). Medical experts believe that these

rates will continue to rise, in part because genital HSV and HPV infections are often asymptomatic and frequently transmitted by individuals who do not know that they are infected. If present, symptoms may be mild, mistaken for other conditions, or seem to be “cured” during long periods of latency.<sup>4</sup> The failure to recognize symptoms of these infections translates into a serious public health problem because both of these viruses are contagious, even in the absence of noticeable symptoms.

A recent study pointed out that, “[w]hile these diseases are of epidemic proportion, we actually see surprising little about them in the media, and we talk about them even less” (Cline 2006:353). In an era of public health campaigns and mandated education targeting HIV/AIDS, the use of latex condoms is more and more the behavioral norm for “safer” sex. However, both HPV and HSV are transmitted by skin-to-skin contact.<sup>5</sup> So, even when a latex condom is used consistently and correctly, it will provide a barrier for only a portion of the genital skin that will likely come in contact with a partner’s skin during sexual intercourse. In addition to the promotion of using latex condoms as the standard for ‘safer sex,’ HIV-testing has also been successfully promoted as a sexual responsibility norm. Currently, more than 50 percent of adults have only been tested for HIV and not for any other STDs (ASHA 2006c). Given our medical norm of annual gynecological exams for women, but no comparable exam for men, a significant portion of the sexually-active population is not regularly screened for any STDs.

When individuals do seek sexual health exams, less than one-third of US physicians consistently screen these patients for the full range of sexually transmitted diseases, leaving many patients unaware of their infection status with regard to either HPV or HSV (ASHA 2006c).<sup>6</sup> Some sexual health educators believe that, because these two diseases are understood as nonfatal, there has been less funding for research, education, and prevention efforts. However, genital herpes and HPV infections can have devastating effects if transferred from mother to fetus, and medical researchers have linked certain strains of HPV to cervical and anal cancers.<sup>7</sup>

Odds are, you have not heard of the “HPV vaccine.” On the other hand, if you live in the U.S., then you have probably seen or heard one of many ads promoting a “cervical cancer” vaccine sold by Merck as

GARDASIL. Originally, this vaccine was called what it actually is: a vaccine to protect against several strains of sexually transmitted human papillomavirus (HPV). When the press began to cover the trials of this HPV vaccine, several conservative organizations protested. The Family Research Council (FRC), for example, was initially concerned that the HPV vaccine equated to a “license” for young people to have premarital sex. Strong objections from such socially-conservative organizations, in addition to focus groups conducted by the CDC, may have informed Merck’s marketing campaign of GARDASIL, in which all advertisements, marketing, and health education materials aim to sell this to the American public as a vaccine that protects against cervical cancer. Parry (2007) notes that this is not an easy plan or necessarily a solution to the problem of longstanding negative stigma against STDs: “Promoting an anti-cancer vaccine and, at the same time, making it clear that HPV is a sexually transmitted infection will require deft handling in the wording of policy, education and publicity materials” (90). Many health organizations, including the American Cancer Society, expressed concerns that acceptance of the drug would be influenced by whether the American public perceives the vaccine to be one aimed at reducing the risk of cervical cancer, or as a vaccine designed to prevent a sexually transmitted virus.

So, is there really a “cervical cancer” vaccine? In short, the answer is “No.” Merck’s vaccine, trademarked as GARDASIL, protects against four HPV types, which together are associated with 70 percent of cervical cancers, but these cancers are relatively rare. The American Cancer Society estimated that, in 2006, approximately 9,710 women were diagnosed with invasive cervical cancer and another 3,700 died from it (2007). In June 2006, the Food and Drug Administration (FDA) licensed GARDASIL, a prophylactic vaccine<sup>8</sup>, that prevents over 95 percent of HPV infections, caused by four types of virus: Together, these are estimated to be responsible for about 70 percent of cervical cancers (HPV types 16 and 18) and 90 percent of genital warts (HPV types 6 and 11) (Temte 2007). This vaccine is not an effective treatment for existing HPV infections (genital warts, cervical cancers or precancerous lesions). It has been tested and approved for use on girls and women from 9 to 26 years of age. Given the expense, limitations, and controversies surrounding this new approach to the prevention of HPV, the ultimate impact of this vaccine

remains to be seen. As this new vaccine protects against only four strains of HPV, girls and women who receive the vaccine will need to continue routine gynecological exams and practice safer sexual behaviors<sup>9</sup>, as these individuals will be vulnerable to infection with the dozen or so other strains of this virus. As for the ongoing work on developing an HSV (herpes) vaccine, medical researchers are not sure whether a safe and effective one will be developed. Those who study pediatric infectious diseases have noted that, “Once an efficacious herpes vaccine is available, its effectiveness will depend ultimately on vaccine acceptance by professional organizations, healthcare professionals, and parents” (Rupp et al. 2005, 31).

The development and widespread use of any STD vaccines will not necessarily result in a world that is kinder and gentler to those who become infected. In fact, there is reason to believe that STD-related stigma may negatively affect the public’s response to the new vaccine that is being marketed as a “cervical cancer” vaccine. A recent behavioral health article on HPV and cervical cancer emphasized the need for research that explores how the nature of this virus being sexually-transmitted affects the experiences of those who test positive. These findings could help us to better understand how individuals will make decisions about cervical cancer screening (Waller et al. 2004) (See Chapter 8 for more discussion of STD vaccines.).

The cost of diagnosing and treating all sexually transmitted diseases in the U.S. is about \$8 billion per year. HPV and HSV account for a sizeable portion of these costs (ASHA 2006c): HPV infections alone add up to health care expenses of over \$2 billion per year (CDC 2006). It is difficult, however, to put a price tag on the variety of personal costs to infected individuals. Individuals experience social and psychological costs of these infections differently, depending upon their sex, socioeconomic status, ethnicity, age, religious upbringing, and other factors. Sex differences are the most obvious: HPV and HSV present more negative consequences for women, in terms of both reproductive health and self-concept. For instance, a woman’s reproductive health can be greatly compromised by a cervical HPV infection that necessitates the removal of significant amounts of her cervix, the bottom portion of the uterus, which must be thick enough and strong enough to bear the weight of a growing fetus. Should she be able to carry the baby to term, there is the additional risk that, genital infections of

both HPV and HSV can pass from mothers to babies during vaginal deliveries.

Although the CDC reports that few women suffer serious reproductive consequences of HPV and HSV infections, the typical infected American woman is likely to experience one of these incurable STDs as a severe stress on her sense of wellbeing. This negative shift can occur even at the receipt of a diagnostic result, which merely indicates the possibility of HPV infection: Zimet (2006, 23) documented “the emotional suffering associated with abnormal Papanicolaou (Pap) test results.” In a U.S. society, which supports a double-standard of sexual behavior and, consequently, a sexist magnification of the negative impact of STDs for women, a clinically minor problem (like an abnormal Pap result) can quickly become a cause for major concern.

Most Americans subscribe to a gender ideology in which girls and women are morally and socially demeaned by non-marital sexual encounters, whereas these same behaviors serve to elevate the social statuses of boys and men (Eyre, Davis, and Peacock 2001). Sexual health researchers find that the traits which U.S. society associates with contracting STDs—“indiscriminate promiscuity, pollution, and uncleanness” (Lawless, Kippax, and Crawford 1996, 1371)—are incongruous with cultural definitions of feminine ‘goodness.’ In this climate, a woman with a lifelong STD tends to become fearful about how others will view her.

## Chronic STDs as Turning Points in Women’s Lives

To understand how women view themselves with chronic STDs, I use the theoretical lens of *symbolic interactionism* in which, “Identities are meanings attributed to self, by others and by self. They are developed in interaction as others respond to particular presentations of self” (Kelly 1992, 395). An *interactionist* would say that how we see ourselves and how others see us are interdependent concepts because we construct personal identities through social interactions. Contracting an incurable sexually transmitted disease creates a “turning-point moment” (Strauss 1959) for most American women, in that the illness initiates an “identity dilemma.” As Charmaz (1994) found, “Identity

dilemmas result from losing valued attributes, physical functions, social roles, and personal pursuits through illness and their corresponding valued identities" (269). In many social contexts and social roles, a person's sexual health status may have little, if any, impact on how they view themselves or how others view them, but STDs present a particular threat to an individual's *sexual self*.

*Damaged Goods* draws on women's firsthand experiences to explore how social constructions of female sexual morality merge with stereotypes about STDs to threaten women's *sexual selves*: Individuals' views of themselves as sexual beings that exist in relation to their general views of themselves. My conceptualization of a *sexual self* draws on components of Dowd's (1996) theory of a *secret self*: "Privacy allows individuals to have a secret self, which may be a sphere of behavior that is engaged in behind closed doors, out-of-view, and which the actor would prefer to keep separate from the public sphere" (249). In this sense, the term "sexual self" signifies a typically private self, shaped by emotions, cognitions, and memories of sexual experiences.

I conceive of the sexual self as encompassing individuals' self-evaluations of their own sexual desirability and how they think of their own imagined and experienced erotic sensuality. Other researchers have posited similar operational definitions of the term *sexual self* (Breakwell and Millward 1997; Cranson and Caron 1998; Sandstrom 1996) to refer to something fundamentally different from a gender identity or a sexual identity. I agree with Breakwell and Millward that, "the structure of the sexual self-concept is significantly influenced by dominant social representations of gender differences and relationships" (1997, 29).

While a few other researchers and theorists have referred to the sexual self-concept, this term's definition has not been agreed on. I posit the components of a sexual self to include the level of sexual experimentation, emotional memories of sexual pleasure (or lack thereof), perception of one's body as desirable or undesirable, and perception of one's sexual body parts as healthy or unhealthy. Research has yet to explore why the sexual self is uniquely susceptible to damage. Applying Goffman's (1963) concept of a "spoiled identity," I propose that STDs, in addition to other traumatic experiences, may create, add to, or maintain a *spoiled sexual self*, resulting in both intrapersonal and interpersonal costs: these traumas include molestation, rape, homophobia,

self-loathing brought on by social constructions of attractiveness, and other sexually-related medical conditions (e.g., infertility, breast cancer, and impotency). Social interactions that communicate that some physical bodies are less attractive, particular sexual preferences are unacceptable, or certain levels of sexual experience are immoral, can also transmit messages that damage sexual selves. *Damaged Goods* expands on the work of medical sociologists (Charmaz 1994; Sandstrom 1996; Swanson and Chenitz 1993) by examining how these women are transformed during each stage in their illness experiences. At each of the six stages, particular factors create, maintain, challenge, and reshape how they see themselves as sexual beings.

## The Roots of STD Stigma

Ancient Greeks used the descriptive term “stigmata” to refer to visible marks which signified the bearer as one who was tainted and deserved to be ostracized. Manzo (2004) clarified Goffman’s (1963) conceptualization of stigma by looking for the qualities that made social scientists likely to label a condition as “stigmatizing.” He determined that STDs fit the criteria of being stigmatizing because of contagiousness and culpability. Manzo highlights a key point of Goffman’s earlier work, “that stigma attaches not only to persons but to specific social contexts” (Manzo 2004, 414). Stigma is not simply a discrediting attribute; rather, each stigma is the product of a process of social interactions within a cultural context.

Centuries before the first case of HIV/AIDS, the social stigma and health ramifications of other sexually transmitted diseases scarred the lives of many around the world. The experiences of U.S. women and men today must be seen in historical context. Sexual health services in the U.S. became strongly influenced by moral objectives when, in the late 1800s, male physicians “professionalized” midwifery. The growing preference and respect for scientifically educated male professionals in the field of women’s health allowed for sexist moral agendas to shape American medical philosophy and public health services related to STDs. Public opinion and public health campaigns have often targeted sexually active, working-class and minority women as the “vectors and vessels” of sexual disease (Davidson 1994; Luker 1998; Mahood 1990). Scholars have elaborated on the class dynamics of



these campaigns. For example, Ehrenreich and English (1973) found that Victorian-era upper-class women received an abundance of medical care, whereas lower-class women received almost no general health care services. However, the lower-classes, and lower-class *women* in particular, have been viewed as the transmitters of disease to the wealthier classes.

During the social hygiene movement of the Progressive Era (1890–1913), physicians and women moral reformers combined forces to explicitly shape the moral boundaries of sexual behavior, under the justification of public good/health. However active the women reformers may have been, these boundaries were decidedly sexist. The doctrine of “physical necessity” was deemed to justify, and often excuse, men’s forays into promiscuity. As early as 1910, Dock pointed out the bias in how the (then popular) *theory of innate depravity* was applied to “fallen women” and not to their male counterparts, whose sexual escapades were equally, if not more, shameful than those of the women.

Historical documents reveal that, during this period of the early 20th century, physicians had constructed a spectrum of culpability, positing “innocent patients” at one end—those children and married women who had been infected via an adulterous husband—and infected married men and “problem girls” at the other end (Davidson 1994). Not only had these “problem girls” contracted diseases willfully, but they were also the “major vectors of disease” by virtue of their promiscuity and low morals.

This view of women regained momentum in the 1980s when early AIDS research studies viewed women “not as victims of the disease but as risk factors to others,” and the public regarded HIV infections in women as “simply the natural consequence of the way they choose to live, the ‘wages of sin’” (Nechas and Foley 1994, 98; 101). A recent overview of findings from qualitative studies of HIV-positive women asserts that women’s experiences of HIV-related stigma were intensified because they were female: They had been socialized to believe in gender norms and values that meant that their social relations and moral identity were threatened by others’ awareness of their infection status (Sandelowski, Lambe and Barroso 2005). Beyond HIV, studies have examined the gendered nature of American attitudes toward other STDs, looking at the interplay between negative social constructions of

STDs and culturally defined gender roles in differentially shaping patients' experiences of diagnoses, symptoms, and treatment (e.g. Meyer-Weitz et al.1998). Eng and Butler (1997) have argued that sexual mores *explicitly* shaped public health policy and are reflected in past and present societal attitudes toward sexual health. Society's focus on assigning moral culpability to illness encouraged policy makers to ignore the social and environmental factors that contributed to disease and reinforced the tendency to reject, ridicule or simply ignore those who suffer from an illness.

A few researchers have charted social histories of the moralization of STDs (Brandt 1987; Davidson 1994; Luker 1998) and illuminated issues of social power and subordination. Others have examined the ways in which public perceptions of health policy and practice have reflected social acceptance of the sexual subordination of women (Lock and Kaufert 1998; Lorber 1993). The social history of sexually transmitted diseases in the United States reflects a tradition of not only assigning moral responsibility to those infected with STDs, but also of differentially assigning moral stigma on the basis of gender, race, and class (Brandt 1987; Luker 1998).

Social stereotypes of sexual immorality and disease are specific to sex, gender, ethnicity, and socioeconomic status. Researchers have found that biased norms of sexual morality have influenced a wide range of sexual health programs: "Current campaigns against STDs which are aimed at women are infused with the same moral judgments found in earlier campaigns" (Leonardo and Chrisler 1992, 1). In addition to inaccurately targeting populations for outreach, biased health research has increased the likelihood that the more complex issues faced by individuals with STDs will not be addressed. For example, Lock (2000) explained how the targeting of certain populations on the basis of ascribed traits, such as sex and ethnicity, sets the stage for medically ineffective and socially destructive health policies and programs. She cautioned that it becomes easy to overlook true inequalities, like poverty, when we are comfortable blaming individuals' biological traits, such as ethnicity and sex, for their designation as 'high-risk' groups for particular diseases.

Thus we need to examine women's experiences of STD diagnostic and treatment interactions within a larger social context (including race/ethnicity, socioeconomic status, religious identity, age, etc.) of

how female sexuality and sexual morality have been constructed in the United States. In line with Mechanic's (1989) conceptualization of illness experiences as "shaped by socio-cultural and social-psychological factors," my research explores women's experiences of chronic STDs within medico-moral interactions that are shaped by race, class, and gender norms of sexual health and behavior.

## Sex, Gender and STD Stigma

Feminist scholars have highlighted the resilience and salience of gender: "despite the impact of feminism and deconstruction, gender has not been abolished, but continues to be reinscribed in our identities, desires, and thought" (Thomson and Holland 1997:2). While it is true that gender norms may be influenced by norms of race/ethnicity, sexuality, age, etc., a woman negotiates her sense of self and identity by referring to and measuring herself against the gender norms that have been constructed as most important in her life experiences. Hughes (1945) conceptualized a "master status" as a social identity that is dominant and influences the way in which individuals are viewed. As long as being a woman is one's master status in common contexts (e.g., intimate relationships, the gynecologist's office, and motherhood), then one is expected to meet stereotypical expectations of femininity, including sexual behavior norms and sexual morality norms.

Looking back at the late 19th and early 20th centuries, the meaning of 'femininity' created categories for women on either side of the sexual morality dichotomy: "God's police" posed in opposition to "damned whores" (Summers 1975). Historically, these labels gave one group of women a sense of duty to keep a critical eye on their *sinful* sisters and to dole out stigmatizing labels when necessary. Current debates about surveillance and sexual health question the value of public health professionals labeling certain groups as 'at-risk' (O'Byrne and Holmes 2005). This type of labeling has been linked to promoting sexism, racism, and homophobia, both inside and outside the U.S.

Researchers on AIDS in Africa found significant gender differences with regard to stigma: "Popular ideas about STDs suggest little stigma is attached to male infection. Having an STD is almost regarded as a rite of passage into manhood, proof of sexual activity: 'A

bull is not a bull without his scars’” (Bassett and Mhloyi 1991, 143). These researchers found that African women experienced greater degrees of stigmatization and ostracism as a result of a HIV infection. Other researchers, looking at the gendered implications of non-HIV sexual transmitted diseases, confirmed that, “women feel particularly shamed and isolated as a result of the infection” (Pitts et al. 1995, 1303). A recent study of adolescents’ views of sex found one ideology to dominant among young women and young men: “the gender ideology linked with the ‘double standard’ in which males are morally elevated by multiple sexual encounters, while females are morally demeaned” (Eyre, Davis and Peacock 2001, 13).

Across cultures, sexually transmitted diseases have been connected to promiscuity. The traits our society has traditionally associated with contracting an STD—promiscuity, irresponsibility, uncleanness, immorality, and even naïveté—were incongruous with cultural definitions of being a “good” girl/woman. In this way, the context of gender is especially important for understanding both the social construction of sexual disease in the United States and why contracting a STD, especially an incurable one, can be a severely stigmatizing illness experience for women.

Goffman (1963) discussed stigma as contextual phenomena: “Not all undesirable traits are at issue, but only those which are incongruous with our stereotype of what a given type of individual should be” (3). From a symbolic interactionist perspective, individuals intersubjectively create meanings about STD infection during interactions. For example, interactions between medical practitioners and lay people have been found to be the conduits through which STD stigma are reinforced (Brandt 1987). Social constructionist, labeling and conflict theories enhance our understanding of how people come to understand different illnesses: individuals and social control agents (e.g., medical practitioners), “construct particular acts as deviance and individuals as deviants” via processes that entail the creation of and sharing of meanings (Best 2006). *Damaged Goods* illuminates important facets of stigma in the “moral careers” (Goffman 1959) of female STD patients.

Social prejudices have been found to intensify against individuals, such as those infected with STDs, who were believed to have caused their own stigmatization (Goffman 1963). Tewksbury and McGaughey

(1997) applied this concept to the development of HIV-related stigma. They contended that the physiological and social qualities of this disease make it likely for persons living with HIV to experience the three faces of stigma as put forth by Goffman (1963, 4): “Abominations of the body . . . blemishes of individual character . . . tribal stigma.” Given the global devastation resulting from HIV/AIDS, the majority of contemporary scholarship on chronic illness, moral identity, and the self has focused on this disease. However, *Damaged Goods* is the first book to focus exclusively on the social-psychological impact of two other incurable STDs. While the physiological impacts of these viral infections differ greatly from HIV, I argue that genital herpes and HPV infections similarly challenge women’s perceptions of themselves with regard to health, morality, and social status.

## Medical Sociological Studies of Sexual Health

American sexual health policies and attitudes have always been shaped, in part, by prevailing medical beliefs and practices. In the 1970s, American cultural views of health shifted from a focus on germ theory—that certain microorganisms cause disease—to an emphasis on individual responsibility for behaviors that might cause disease. Epidemiological studies from that period show that behavioral choices, such as smoking and exercise, influence ill health. “No longer would disease be viewed as a random event; it would now be viewed as a failure of individual control, a lack of self-discipline, an intrinsic moral failing” (Brandt 1997, 64). The ways in which both medical and lay people speak about particular diagnoses have often denoted blame and individual responsibility to the sick. When we feel comfortable blaming the sick for their own illnesses—if their own ‘bad’ choices caused their health problems—then the rest of us who are making ‘good’ choices can all feel less at-risk.

Along with scholars who have documented the popularity of blaming individuals for their own poor health, researchers have also examined the role of medical practitioners in the social construction of health and illness. Medical practitioners, for example, in addition to controlling health information and services, also have the capacity

to serve as social control agents, in that they have implicit authority to assign moral statuses to different illnesses. Early work on hospital staff documented the prevalence of “moral evaluations” of patients (Roth 1972). Foucault (1978) argued that social control in the field of medicine had become more professionalized and oriented to the surveillance of deviant behavior. Social responses to STDs illustrate how medico-moral discourses have served to construct and regulate sexuality (Foucault 1978, Mort 1987, Davenport-Hines 1991, Davidson 1994).

Pryce (1998) pointed to a critical gap—the “missing” sociology of sexual disease—and asserted that this application of sociology should focus on the social construction of the body as central in the medical and social understandings of STDs. Sociological research on sexual morality and health has primarily addressed HIV/AIDS (Fernando 1993; Matthews 1988; Nechas and Foley 1994; Plumridge and Chetwynd 1998; Ray 1989). The overwhelming focus of social scientific studies of STDs, other than HIV, has been on evaluating the effectiveness of education/prevention strategies, environmental determinants, and understanding risk assessment and risk-taking behaviors (e.g., Beadnell et al. 2006; Rogers 1999; Shrier et al. 1999; Thomas et al. 1999).

Most research on morality in the socio-medical politics of STDs has addressed the issue from a national level. Few studies examine micro-level interactions in sexual health services, especially from patients’ perspectives. Such studies can illuminate issues that occur at the interface between medical practitioners and patients. As such, qualitative studies have not fully examined affected individuals’ “illness behaviors,” which Mechanic (1982) defines as “the manner[s] in which persons monitor their bodies, define and interpret their symptoms, take remedial actions, and utilize the health-care system” (1). A more recent study focused on how the stigma of sexually transmitted diseases may affect one particular illness behavior—that of seeking treatment for STD infections. Lichtenstein (2003) found that African-Americans’ willingness to access sexual health treatment at public health facilities was directly and indirectly impacted by STD-related stigma: specifically, religious ideation, privacy fears, racial attitudes, and the fear of being “scarlet lettered” proved to impact individuals’ willingness to seek medical treatment.

The practitioner-patient interactions that comprise STD diagnoses differ from other chronic illness in that there are explicit and im-

plicit threats of negative health *and* negative moral consequences. A study on media coverage of herpes in the early 1980s found that the stories stressed “a psychological and social deadliness”—evidence that the detrimental effects of herpes diagnoses extended beyond the physical (Signorielli 1993, 60). Medical research determined “the most common and usually the most devastating problem of having genital herpes is its psychological impact” (Bettoli 1982, 925). However, most studies of individuals infected with herpes have neglected to address the identity impacts of the physical, moral, and social consequences of receiving a diagnosis (Reiser 1986; Rosenthal et al. 1995; Swanson and Chenitz 1993). Two recent articles (Melville et al. 2003; Breitkopf 2004) confirmed the presence and ramifications of stigma experienced by individuals living with genital herpes. The later concluded that the stigma experienced by those living with herpes will lessen as we see more media portrayals of these individuals as normal and the infection as treatable. For example, recent commercials for *Valtrex*, a popular antiviral medication, have portrayed infected individuals as active (e.g., riding mountain bikes) and happily involved in intimate relationships (e.g., embracing a significant other while professing their understanding that even correct and consistent use of this medication does not guarantee protection for an uninfected partner).

With regard to HPV, most studies of affected individuals focus on risk evaluation/risk-taking behavior (e.g., Ford and Moscicki 1995). One clinical study (Keller et al. 1995) advised practitioners to be aware of the psychosocial aspects of HPV diagnoses, but did not examine why these negative implications exist or how they might affect patients in different ways. While this study noted the “potentially traumatic nature of HPV infection” (Keller et al. 1995, 356), my study is the first to fully analyze the social-psychological impacts of having HPV. A more recent study noted that HPV-related stigma may create feelings of embarrassment and fear of rejection, which could lead to infected individuals choosing not to disclose their HPV-positive status to sexual partners (Keller et al. 2000). This dangerous public health consequence of STD stigma emphasizes the urgency for a more complete understanding of how being diagnosed with a chronic sexually transmitted disease may affect the self-concepts and decision-making processes of infected individuals.

For the past two decades, interactionist medical sociologists have studied first-hand accounts of illness experiences. Analyses of chronic illness, in particular, have led to the creations of theories about the social and psychological consequences for those affected. Several scholars have examined the challenges posed by chronic illness to self and identity (e.g. Charmaz 1994; Frank 1991; Sandstrom 1996). Medical sociologists have specifically explored the impact of stigma by focusing on how chronically ill individuals manage both identity dilemmas and interpersonal relationships (Conrad and Schneider 1980; Tewksbury and McGaughey 1997; Weitz 1991).

Interactionist studies of chronic illness have begun to explore sexual-self concepts. For example, Sandstrom (1996) sought to fill an important gap in the literature on the self in chronic illness by exploring how HIV/AIDS, “affects the sexuality and sexual identity work of diagnosed individuals” by examining men’s “sexual self-images” (242). Other research on HIV/AIDS has looked at how the diagnosis serves to redefine not only affected individuals’ health statuses, but also their sexual statuses (Sandstrom 1990; Weitz 1991). These scholars have documented redefinitions of self and status; however, none of these researchers have addressed infections, like genital herpes and genital HPV, which are lifelong but manageable. *Damaged Goods* details the different ways in which these sexually contagious and highly stigmatizing infections transform women’s sexual selves.

Genital HPV and herpes infections, as sexually stigmatizing chronic illnesses, pose specific challenges to infected women’s selves and identities. Pioneers in researching the connection between self-conception and sexual health, Swanson and Chenitz (1993) used qualitative methods to examine the relationship between herpes infections and a “valued” self, which began analysis at the point of diagnosis. While these researchers theorized a three-stage model of regaining a valued sense of self after herpes diagnoses, their findings indicate a more complex process that begins well before the point of contracting an STD and is shaped by social dynamics of gender, race, class, sexuality, etc. In *Damaged Goods*, I aim to detail six stages of how chronic STDs transform women’s sexual selves and include stages prior to diagnosis.



## On Methodology: Researching an Invisible Population

Motivated by personal experience, I entered this research setting as a “complete member” (Adler and Adler 1987). At age 20, I was diagnosed with a cervical HPV infection. In fact, the prose “snapshot” that began this chapter is actually the beginning of my own story.<sup>10</sup> Self-education helped me to manage the initial stress of diagnosis and treatment. Then, volunteer involvement with sexual health education and outreach became the foundation for my research and provided me with insights and legitimacy to connect with others facing STD diagnoses. Ultimately, I worked as a professional sexual health educator, and I drew on these experiences for the clinical knowledge necessary to understand and interpret the women’s illness narratives. (See Appendix A for a complete discussion of my auto-ethnography.)

As a professional sexual health educator in the late 1990s, I began to question how individuals infected with chronic STDs managed the intrapersonal and interpersonal challenges. To more fully understand the social and psychological impact of chronic STDs on women, I aimed to uncover how these women created, maintained, and transformed the meanings of their STD illness experiences. My goal was to collect data that could provide an empirical foundation from which to test the prevailing medical, sociological, and lay assumptions about women living with chronic STDs.

Women with STDs are a hidden population, their identities protected by medical confidentiality. Aware of the negative social attitudes toward infected women, most keep their sexual health statuses a secret. In this sense, their stigmatized condition is *discreditable* (Goffman 1963), and the women can *pass* as sexually healthy in most social contexts. With this norm of secrecy, women with non-HIV STDs are also a fragmented population, unlikely to engage in support groups or identity politics for fear of outing themselves.

Having conducted a survey study that found women strongly preferred maintaining the confidentiality of their sexual health statuses, I determined that one-on-one interviews were the best method of data collection. As this topic is sensitive and laden with sociocultural “baggage,” talking with these women individually created an intimate

research space in which I had the best chance for high construct validity. In this manner, I was able to develop what Blumer (1973, 798) described as, “a close, flexible and reflective examination” of contemporary social facts about women with STDs. The data I collected can be conceptualized both as *sexual stories* (Plummer 1995) and as *illness narratives* (Frank 1993), in that each woman spoke about intimate, sexual, and sensual aspects of her life; while she also described her encounters with the medical profession as a patient being treated for one or more STDs.

As with many studies of individuals living with HIV/AIDS (e.g., Cranson and Caron 1998; Grove, Kelly, and Liu 1997; Sandstrom 1996), I employed a mixture of convenience and snowball sampling (Birnacki and Waldork 1981) because of the research topic’s sensitive nature. In keeping with the principles of grounded theory, I sampled for theory construction, rather than for representativeness (Charmaz 1995). In all, I interviewed forty-three women who had been diagnosed with genital herpes and/or HPV infections for this study. My final sample size resulted from ethical restrictions on subject recruitment: I was not allowed to actively recruit subject; rather I could only post flyers, print ads, and announce my study when giving public presentations on sexual health. Given doctor-patient confidentiality, there was no way for me to obtain a list of the women who met the sampling criteria and then engage in any form of random or purposive sampling. In sum, due to the sensitive topic, medical policies, and research ethics, I was limited in my ability to create a more diverse sample.

The women who participated in my study ranged in age from 19 to 56 years old at the time of their interviews. Though these participants comprised a convenience sample, my goal was to interview women who varied in how they identified with regard to ethnicity, socioeconomic status, religion, and sexuality. I viewed these categories of characteristics as being highly relevant to the exploration of meanings for feminine sexual morality and sexual disease, in addition to potentially impacting the women’s experiences of and options for sexual health care. In terms of ethnicity, thirty-eight identified as European American (including Jewish, Greek, and Persian ethnicities), three as Latinas, one as African-American, and one as Native-American. Socioeconomically, they ranged from upper-class (1) to working class (9), with the majority identifying as lower-middle (5), middle (18), or upper-middle (10) class.

The participants represented a variety of religious upbringings and current practices: Buddhists, Jews, Muslims, Pagans, and Christians (Catholics, Protestants, and Southern Baptists). Catholics (12) were the largest group, but fourteen women had been raised with no religion, and nineteen reported being currently nonreligious. With regard to sexual identity, the majority (37) identified as heterosexual, five identified as bisexual, and one identified as a lesbian. (See Appendix C for more detailed information about the participants and research methodology.)

In-depth, semi-structured interviews allowed me the flexibility in the data gathering process to uncover what having a chronic STD meant to this sample of women. Constant comparative analysis (Glaser and Strauss 1967; Glaser 1978) provided the guidelines by which I was able to ferret out the shared meanings of STD stereotypes, symptoms, diagnoses, and treatments from the subjective point of view of those living with these infections and accompanying social stigma. Utilizing a symbolic interactionist approach to guide my data collection and analysis, I tested emerging hypotheses about the empirical realities of women with STDs, via a thorough and continuous examination of their world (Blumer 1969).

While their identities are protected by pseudonyms in this work, the details of their stories are exactly as they told them to me. No story is identical to another, but many shared similar motivations for participation in this research: (1) To help others by giving voice to the real struggles of millions of women who live with these infections, and (2) To personally benefit from managing their STD stigma, via cathartic disclosure, relief from the burden of secrecy (Adler and Adler 2006). My goal, in sharing their stories, via sociological analysis, is to frame their individual struggles within a larger, social context and highlight opportunities for improvement in sexual health education and medical services for women and their sexual partners. (See Appendix B for a detailed methodology discussion.)

## Organization of the Chapters: Six Stages of Sexual Self-Transformation

*Damaged Goods* draws on in-depth interviews with women who have been diagnosed with genital HSV and/or HPV infections. Highlighting

the voices of these women, I write about the transformations of their *sexual selves*—how they see themselves as sexual beings—and how they understood and made choices about sexual health issues. I document the physical, moral, and social consequences of living with these diseases, by analyzing their experiences within a six-stage framework. I use symbolic interactionist, social psychological, and feminist theories to explore the ways in which these women's sexual-selves are transformed throughout their STD illness experiences.

In Chapters 2 through 7, I draw on the women's stories to illustrate the six stages of sexual self transformation. Each of these chapters explains a different stage in how the women constructed STDs as meaningful in shaping their sexual selves and interpersonal relationships. The women I interviewed came from a variety of backgrounds, but common threads emerged, as illustrated by their quotes and anecdotes, that conveyed the interplay between socio-demographic factors, cultural constructions of health, gender, and sexual morality, and structural norms of the American medical system.

I created a model that illuminates stages in the “moral careers” (Goffman 1959) of STD patients and documents the event series that ultimately shape changes in patients' sexual selves and social relationships. This theoretical model represents “ideal types” in the sense that not all women went through each stage in the same manner, and the following chapters detail and analyze variation between individuals' experiences. In stage one, *Sexual Invincibility*, early portions of women's socio-sexual histories create and maintain beliefs in a myth of STD immunity. In stage two, *STD Anxiety*, women's experiences of initial symptoms or practitioners' suggestions of possible infection replace feelings of invincibility with anxiety. In stage three, *Immoral Patient*, they experience practitioners' deliveries of STD diagnoses as imparting health, moral, and social stigma. In stage four, *Damaged Goods*, women employ individual stigma management strategies within interpersonal relationships. In stage five, *Sexual Healing*, they face the interpersonal, physical, emotional, and financial challenges of treatments. Finally in stage six, *Reintegration*, many women reconcile the meanings of their illness experiences by integrating risk awareness and desire for intimacy within revised sexual selves.

*Damaged Goods* expands discussions of moral identity and sexuality in chronic illness by examining genital herpes and HPV from social-

psychological and interactionist perspectives. Highlighting the role of social power, it focuses on how their illness experiences serve to create “turning-point moments” (Strauss 1959) in the women’s narratives of their sexual selves. By interweaving their stories, via sociological analysis, *Damaged Goods* creates a virtual community for women who have felt alone in their struggles for health, self-acceptance, and sexual intimacy. Ultimately, I hope that this work contributes to a widespread de-stigmatization of these illnesses.