Discrimination and stigma have been identified as barriers to health care, suggesting that HIV-infected, pregnant women may be disinclined to seek prenatal care if health-care workers exhibit negative attitudes. In a qualitative study of the attitudes of health-care workers toward pregnant, positive women, several theoretical perspectives emerged as a way to evaluate the gender, race and class issues inherent in pregnancy decision-making for HIV-positive women. Because HIV-infected people have been stigmatized since the epidemic began, Goffman’s stigma theory provides a reasonable starting point for analyzing why HIV-positive women who become pregnant experience discrimination and stigmatization. Foucault’s discussion of the power/knowledge matrix affords a historical context for the suppression of people with HIV and offers suggestions for breaking the pattern. Finally, Bandura’s Social Cognitive Theory offers a framework for understanding HIV-infected women’s health behaviors. These theories can broaden our understanding of the impact of prevailing negative attitudes toward pregnant, HIV-positive women.

Over a period of 20 years, the management of HIV disease has gone through a major evolution and, to a lesser extent, so have societal attitudes. With the advent of combination antiretroviral therapy that has radically improved patients’ survival (Hammer et al., 1997; Jaffe, 2004), HIV infection has become, in the public consciousness, just another serious illness. The amount of news coverage that HIV/AIDS receives has plunged significantly over the last two decades (Jaffe, 2004), to the point where a promising new treatment merits only a few seconds on the evening news. As the profile of persons with AIDS in the U.S. has shifted from white, middle-class, gay men to poor African Americans and Hispanics from the inner cities and particularly to women, the public appears to find the epidemic less alarming. In national surveys, the proportion of Americans who consider HIV to be the most urgent health problem more than halved from 38% in 1997 to 17% in 2002 (Jaffe, 2004).

While on the surface, there is an apparent complacency about AIDS, the wariness persists. Just ask a small town parent if she would want her child to be taught by an HIV-positive teacher. But this should not come as a surprise. Weiss and colleagues (2006) believe that the capacity to stigmatize appears to be rooted deep within human nature, as exemplified by the long history of stigmatization against people with a wide variety of illnesses and diseases. HIV and AIDS continue to carry enormous social stigma as they have since the beginning of the epidemic, although it has become more subtle as the face of AIDS has changed. To wit, the population most affected today by AIDS-related stigma tends to be low-

1 All inquiries should be directed to Donna Rochon, Baylor College of Medicine, 3701 Kirby, Suite 600, Houston, TX. 77098, (e-mail: drochon@bcm.edu)
income minorities and especially HIV-positive women who become pregnant.

It is not unexpected then that the subject of pregnancy in HIV-infected women continues to garner debate. Feedback from health-care and service providers in the HIV community indicates that fellow colleagues have been expressing disapproval of HIV-infected women who chose to become pregnant or who proceed with a pregnancy after testing positive for HIV, despite the fact that the risk of perinatal transmission is now less than 1% if the mother is on an antiretroviral regimen (Cooper et al., 2002). One would expect such contentious outlooks to have an impact on the care and delivery of services to HIV-positive women and the growing body of literature on women’s relationships with their health-care providers and use of health-care services (Healton et al., 1999; Solomon & Cohn, 1996; Sowell et al., 1999) confirms this.

Discrimination and stigmatization have been identified as barriers to health care (Oliva, Rienks, & McDermid, 1999). Bunting and Seaton (1999) found that African American women felt that the treatment they received was inferior to that received by white women. Because of their suspicions and mistrust of medical treatment, many HIV-positive women avoided health care. Milligan et al. (2002) ascertained that the attitudes of health-care workers presented a barrier to prenatal care for vulnerable, disenfranchised women: When the staff were friendly, it motivated the women to seek care, but when staff were threatening or judgmental, the women were reluctant to seek care. Lancioni et al. (1999) found that HIV-positive women had specific concerns about prenatal care that included fear of disclosure and anger from health-care providers. Lindau et al. (2006) reached similar conclusions, but with the disturbing realization that a poor care environment actually led to higher rates of perinatal transmission. In their article on the psychological concept of the double bind, Ingram and Hutchinson (2000) discovered that health-care workers react negatively toward pregnant, HIV-positive women. The “women believed that health-care providers saw reproduction as bad because of their HIV infection” (p. 122). In addition, health-care providers showed little understanding of the reproductive choices that positive women made because they thought that infected women “should not reproduce under any circumstances” (p. 122).

The literature is clear that patient participation in ongoing care, including prenatal care, is important in reducing HIV-related morbidity and mortality for women and children (Baldwin et al., 1998; Buescher et al., 1991; Scheideberg, 1997). Unfortunately, women at greatest risk for HIV infection are the most disempowered (Anderson, 1996; Lindau et al., 2006). Without the much-needed contact between the health-care system and patients, women will make decisions regarding their health care and childbearing without the benefit of consultation with medical experts (Solomon & Cohn, 1996).

The stigmatizing process and its harmful outcomes did not begin
with the AIDS epidemic. Therefore, we need to investigate how HIV-positive, pregnant women have come to be marginalized and regarded as undeserving of equitable health care. With this in mind, a brief overview of the literature on stigmatizing health conditions will help place the current discussion of stigma toward HIV-related and pregnancy in context.

**STIGMATIZING HEALTH CONDITIONS**

The fear of leprosy was based on the fear of contagion (Cross, 2006). Therefore, disseminating information about the mildly contagious, curable nature of the disease should have succeeded in reducing stigma about leprosy. But, it is the disfigurement and disability caused by the disease that perpetuates the stigma (Berreman, 1984; Rao, 1992; Valencia, 1989). One way to deal with these outward signs of leprosy was to force its sufferers into isolation in sanatoria, or leprosaria and even though the forced quarantine or segregation of patients has long been understood to be unnecessary, a few leper colonies remain around the world (Wikipedia, 2008).

The recognition in the 1880s that tuberculosis (TB, commonly known as consumption) was contagious caused widespread public concern. Based on the unfounded beliefs about transmission (Macq, Solis & Martinez, 2006), officials mounted campaigns to stop spitting in public places. Additionally, the infected poor, among whom the disease had become endemic, were ‘encouraged’ to enter sanatoria that resembled prisons (McCarthy, 2001). In contrast, the middle and upper classes who became infected with TB spent time in sanatoria that offered excellent care and constant medical attention. Unfortunately, the stigma surrounding TB persists because of its association with other sources of discrimination, such as poverty (Cambanis et al., 2005; Johansson et al., 2000) and gender (Cambanis et al., 2005; Hoa et al., 2004; Johansson et al., 2000).

Venereal disease (VD) had been a health problem for centuries before any of the etiological causes were discovered. All that was known was that these diseases were usually incurable and that treatment only alleviated the symptoms. The social hygiene movement of the early 20th century had succeeded in casting VD as an affliction of those who violated the moral code (Goldin, 1994), the ‘carnal scourge’ became a ‘family poison’ that men brought home as the result of sexual indiscretions while fighting overseas. With the discovery of antibiotics, a large number of sexually transmitted diseases (STDs), as VD is now known, became easily curable, but like leprosy, the outward signs of STDs have come to indicate pollution and contamination (Goldin, 1994), so the social stigma remains part of the public consciousness.

Although tangential to the stigma connected with contagious disease, there is a similar history of social stigma related to cancer and mental illness. Even today, cancer remains a mysterious, silent killer with unknown origins that challenges our ability to conquer invasive disease
Reactions to cancer summon old-fashioned notions of dread similar to those of TB and leprosy and prompt the belief that it is “morally, if not literally, contagious” (Sontag, 1978, p. 6). The stigma of cancer was once so pervasive that it was discussed in hushed terms and family members rarely shared information with others. Further, the diagnosis was often withheld from the patient. Obituaries indicated that the deceased had “passed away after a long illness.” Sontag (1988, p.5) used Aristotle’s definition of metaphor, “giving the thing a name that belongs to something else,” to describe this phenomenon.

Mental illness generates the kinds of stereotypes and rejection that are reminiscent of leprosy. Individuals with bipolar disorder, schizophrenia, or major depression have reported being shunned or avoided and being treated as less competent. Unfortunately, the stigma directed at the mentally ill goes further than many of the other stigmatized health conditions discussed here: Mental illness is equated with violence. Particularly in the media (Wahl, 1999), people with mental disorders are depicted as committing violent crimes and as being dangerous (Bilic & Georgaca, 2007; Hinshaw, 2007). Stemming from conditions in the 17th century, when the mad were defined as a subcategory of the poor and unemployed, the punishment was confinement (Foucault, 1965). Like TB, the institutionalization in state facilities differed greatly from the luxurious rest homes available to people with greater resources.

Leprosy, TB, VD, cancer, madness. These conditions now sound like problems from a distant past, surrounded by folk beliefs, superstition and home remedies built on old wives tales. Yet as distinct as these health conditions seem, they have many things in common. They are generally life threatening, believed contagious, identified by debilitating symptoms, or associated with abnormal behavior. They are also more likely to provoke negative judgments that include fear, blame, isolation and discrimination. These stigmatizing circumstances undoubtedly impact the emotional, physical, psychological and social well-being of the affected individuals, leading to feelings of guilt, shame and resignation (Brieger, Oshiname & Ososanya, 1998), fear of reprisal (Lichtenstein, 2003) and a higher level of social rejection (Neff & Husaini, 1985; Phillips, 1966; Purvis et al., 1988). There is something else that ties all of these health problems together—they all have direct or indirect ties to HIV/AIDS.

One of the problems with the AIDS epidemic is that our society has grown blasé about infectious disease. HIV follows a pattern that is similar to the infectious disease outbreaks that preceded it, but it appears that we need to be reminded of the social responses to other plagues. An analysis of the public’s panic response to AIDS and to the infected person shows the influence of pre-existing attitudes toward contagious disease within our cultural stock of knowledge, specifically, fear of out-of-body control and fear of death (Murphy, 1989). More than any other disease in recent history, AIDS is first a social disease, then a biophysical one. This is evident in the way we are repeating some of our past mistakes, such as
demands for mass testing and quarantine (Risse, 1988). Since Leprosy, TB and VD are infectious diseases, fear of contagion is the obvious link to AIDS. The skin lesions of Kaposi’s sarcoma call to mind the images of individuals with leprosy pustules. *Pneumosystis carinii* pneumonia, though not airborne, is a respiratory illness that appears similar in nature to TB. STDs (VD) remind us of the stereotypically dirty or morally lax person spreading disease. Despite the fact that cancer and mental illness are not infectious diseases, they have their own connection to HIV. People with cancer and people with AIDS often look ravaged, or wasted, by their disease, while both mental illness and AIDS can lead to dementia and unusual behavior.

The negative judgments common to all of these stigmatizing health conditions are insidious for other reasons. When STDs or TB co-occur with HIV infection, there is evidence that people delay health-seeking behavior, do not adhere to treatment regimens (Lichtenstein, 2003; Weiss et al., 2006) and increase their risk of transmission and drug resistance (Heijnders & Van Der Meij, 2006) for any of the diseases. Conversely, people may be more willing to seek treatment for the non-HIV conditions, but not for the more life-threatening HIV infection (Lichtenstein, 2003). Fear of exposure often leads people to avoid disclosing their status to the detriment of their own and other’s mental and physical health (Daftary, Padayatchi & Padilla, 2007). The disadvantage accruing to those regarded as shameful through stigmatization is often mixed in with, even secondary to, exploitation and oppression (Scambler, 2006). All of these conditions affect to a greater degree the poor, powerless and marginalized members of society. The result is a vicious cycle in which marginalized groups become more vulnerable to health problems because they are identified with other conditions and situations that are stigmatized, such as poverty, ethnicity, gender and sexual preferences (Weiss et al., 2006).

**THEORY BEHIND THE BEHAVIOR**

Because health care is a by-product of the culture in which it is generated, we can use theory as a broad explanation for the behavior and attitudes that arise out of a particular *zeitgeist*. Each health-care worker is a member of a society, a class and an ethnic, cultural and religious group (Evans, 2001), all of which create a certain weltanschauung for each person. Becoming a health-care provider does not eliminate a person’s values and beliefs, nor does it mean that the provider will be nonjudgmental and accepting of all viewpoints and lifestyles once he or she enters the health-care setting (Hunter & Ross, 1991). The theoretical perspectives presented here provide a lens through which we can examine the issues of gender, race and class that arise in relation to HIV-positive women and pregnancy. These same perspectives can be used as tools for improving the health care that HIV-infected, pregnant women receive.

Recognizing that public health practitioners often work with pop-
ulations that are stigmatized for a variety of reasons, Erving Goffman’s discussion of stigma can help us understand how we react when we encounter people who are different from ourselves, thus illustrating why HIV-positive women who become pregnant experience discrimination and stigmatization. Looking at Michel Foucault’s examination of cultural change through history, we can begin to comprehend the way in which power and knowledge define social situations and what the effect of power is in relation to medical knowledge and the medical encounter. His treatise on power and knowledge can offer suggestions for breaking the pattern of suppression of people with HIV, specifically for pregnant HIV-positive women.

Stigma

The Greeks originated the term stigma to refer to bodily signs meant to expose something unusual and bad about the moral status of an individual. Visible markings were cut or burnt into the body and signified that the bearer was a blemished person, “ritually polluted,” and should be avoided (Goffman, 1963). Goffman defines stigma in its current usage as “an attribute that is deeply discrediting” within a particular social interaction, suggesting that it constitutes “a special discrepancy” between reality and social expectations (Goffman, 1963, p. 3). Herk (1990) elaborates on this concept, explaining that stigma arises during a social exchange when an individual’s appearance or behavior does not meet the normative expectations about that individual. The individual is perceived to be unable to fulfill the role requirements of ordinary social interaction with ‘normals’. Thus, in instances of stigma, the individual possesses an ‘undesired differentness’ that interferes with the normal social interactive process (Goffman, 1963). Goffman states:

We believe the person with a stigma is not quite human. On this assumption we exercise varieties of discrimination, through which we effectively, if often unthinkingly, reduce his life chances. We construct a stigma-theory, an ideology to explain his inferiority and account for the danger he represents, sometimes rationalizing an animosity based on other differences, such as those of social class (Goffman, 1963, p. 5).

Goffman believes that our tendency to isolate differentness leads to an environment in which “identity norms breed deviations” (p. 129). He defines a deviant as someone who does not adhere to his group’s social norms regarding conduct; his peculiarity is a deviation (Goffman, 1963). An important kind of deviation is one presented by “individuals who are seen as declining voluntarily and openly to accept their social place and who act irregularly and somewhat rebelliously in connection with our basic institutions” (Goffman, 1963, p. 143), such as family and
the stereotyped roles of the sexes. Prostitutes, drug addicts, homeless people, homosexuals and the unrepentant urban poor are among the types who constitute the core of social deviants (Goffman, 1963). It is believed that these people are engaged in some kind of collective denial of the social order and flaunt their refusal to accept their place in society. They are perceived as failing to take advantage of life’s opportunities, they show disrespect for their social superiors and they represent failures in the larger scheme of society (Goffman, 1963).

According to Quam (1990), ‘illness’ itself is portrayed as a kind of social deviance in which the individual is held responsible for his condition because of some transgression from established societal norms. Sexually transmitted diseases are a classic example of this conceptualization of deviance. It is not the physiological manifestations of STDs that cause people to suffer, but promiscuity, a behavior that violates the idealized moral standard. The stigma is applied more to the disgrace than to the bodily evidence of it. When personal responsibility for the stigma can be imputed to the individual, the severity of stigmatization increases (E. E. Jones, 1984). HIV as an STD preordains its inclusion in this category of aberrant illnesses. Using Goffman’s model, Herek (1990) discusses the creation of a new category of stigma that he calls AIDS-related stigma, referring to all unfavorable attitudes, beliefs, behaviors and policies directed at persons perceived to be infected with HIV, whether or not they actually are. The fact that many people become infected through drug and needle use or sexual behavior further excludes AIDS from the realm of socially acceptable diseases and places it in the category of deviant (Hunter & Ross, 1991).

Goffman’s stigma typology (Goffman, 1963, p. 4)—abominations of the body, blemishes of character and tribal conditions of race, nation and religion—can easily be correlated to conditions associated with HIV: a) the physical manifestations of HIV, such as the skin lesions caused by Kaposi’s sarcoma, b) the moral transgression of becoming pregnant through unprotected sex and c) the transmission of HIV from the poor woman of color to her infant, thereby contaminating all members of the ‘risk group’. This notion of risk group rather than risk behavior draws attention to already stigmatized persons, while the use of the phrase ‘the general public’ as a counterpart to ‘risk groups’ characterizes the distinction between the dominant social group and the stigmatized, deviant group (Herek, 1990). HIV-positive, pregnant women are thus cast as not being members of the general public.

When the opposition between ‘us’ and ‘them’ solidifies into value-laden social constructs, it can quickly disintegrate into prejudicial views and actions relating to the devaluation of the ‘other’ (Whitehead et al., 2001). A further consequence of this us/them categorization is that it allows the rest of society to establish their innocence and assign blame. Persons who did not contract HIV through sexual behavior or drug use, but were infected through contaminated blood transfusions or perinatal
transmission, have often been described as innocent victims (Boshier, 1992; Cournut & Trotot, 1997). The opposite of a blameless victim is a blameworthy victim (Herik, 1990). Patients infected through sex or drug use are ‘blameworthy’ (Hunter & Ross, 1991). By extension, children of HIV-infected mothers are innocent while the mothers themselves are to blame, even though they may have had no way to avoid being infected through sexual intercourse with their infected husbands.

Herek (1990) suggests that an individual’s hostility toward people with HIV is best understood through psychological and sociological perspectives on stigma, prejudice and disapproving attitudes. AIDS gives many people a convenient excuse for prejudice, a kind of pre-existing hostility toward social deviants. In delineating a community of pariahs, AIDS-related stigma may have offered society a false sense of security about individual risk for infection with HIV. The serious effects of this stigmatization have created an environment in which public health is at risk. Fear of retaliation has led to a certain amount of silence about HIV that threatens everyone’s health. Avoiding prenatal care poses a substantial health risk to HIV-positive women and to their children (Markson et al., 1996; Newschaffer et al., 1998).

The current focus on poor women of color having babies has its root in history. At different times, American society has overtly attempted to control women’s reproductive decisions. There have been specific social policies aimed at sterilization of criminals, mentally retarded women and, in some cases, African American women (Diamond, 1976). The issue of forced sterilization has been raised in the case of drug-abusing women, many of whom are HIV-positive. A health department official in Oregon was quoted as saying that “we must up the ante to criminalize or impose reproductive controls on people who are out of control... people are talking about sterilization” (Bays, 1989, E5). Some believe that women who abuse substances while pregnant are unfit mothers and are undeserving of their children (Carter, 1992).

Stigma is a complicated issue that is linked to gender, race, ethnicity, sexuality, class and culture (Valdiserri, 2002). The target group is disproportionately poor, HIV-positive women of color (Faden & Kass, 1996) or women cast as promiscuous in relation to an arbitrary moral standard, so issues of equality and fairness must be addressed. Chung and McGraw (1992) describe HIV-positive women’s feelings of shame and stigma that result from public discourse that categorizes them as “promiscuous and dangerous” (p. 892) and as vehicles for transmission of the virus. Lawless et al. (1996) discussed the negative evaluation that positive women received from health-care providers based on the assumption that the infected women were injection drug users or sexually promiscuous: they were often subjected to probing questions about their drug use and sexual history and have found it difficult to convince health-care workers that they have not personally engaged in any high-risk activities that would account for their positive serostatus. Copeland (1997) described a
situation of double deviance, in which women drug users were perceived to be promiscuous because of their addictions. Likewise, Hunter and Ross (1991, p. 953) were told about health-care workers who exhibited “stigmatizing and derogatory attitudes … [toward] … patients infected through sexual contact.”

Because a large percentage of HIV-positive women in the U.S. who become pregnant are African-American or Hispanic and come from a lower socioeconomic class, they are confronted with a double-layered stigma normally shared by such marginalized populations: they are ‘people of color’ and they are ‘the poor’. As females, they fall into the segment of the population assigned second-class status by the dominant patriarchy. HIV infection provides its own category of stigma, as Herek pointed out. Finally, by choosing to become pregnant or to continue a pregnancy, HIV-infected women place themselves squarely within the realm of a stigmatized group. By carrying through a high-risk pregnancy, the deviance label is justified because they are voluntarily declining to accept the social place assigned to them and they are acting rebelliously according to existing social rules (Goffman, 1963). Levine and Dubler (1990, p. 323) speculated that the public response to HIV-positive pregnant women would be different “if the majority of HIV-infected women were white wives of hemophiliac men, a group that is numerically smaller but equally at risk for giving birth to seropositive babies.”

In summary, the values, norms and standards regarding social identity are often so strong that a society can reward conformists and punish rebels. While there are certain profiles that society feels are permissible for any given individual to maintain (Goffman, 1963), there are others that are consequently considered unacceptable. Adherence or non-adherence to these roles determines the type of treatment that a person receives within the social context. When women cross these socially defined boundaries, they not only challenge dominant norms of behavior, but they also threaten the moral foundation of society (Hodgson & McCurdy, 2001). By denying the social order and becoming pregnant, the HIV-positive woman finds herself surrounded by argument and discussion concerning what she ought to think of herself and what she ought to do (Goffman, 1963). The result is that women face a routine cycle of restrictions regarding social acceptance (Goffman, 1963). The experience of stigma can then have “a profound effect both in its emotional impact for the individual and in its social repercussions for the marginalized group as a whole” (Whitehead, Mason et al., 2001, p. 29).

**Power & Knowledge**

One of the most valuable aspects of Michel Foucault’s work has been to sensitize us to the pervasive operations of power and to highlight the problematic aspects of knowledge and the production of social norms (Best & Kellner, 1991). By examining changes in the power structure that have occurred throughout history, Foucault tried to determine what
brings about social change, the manner in which changes influence the lives of individuals of every socioeconomic stratum and how particular individuals come to be in and out of power (Wuthnow et al., 1984). He asserted that each age has its own “codes of knowledge” (Foucault, 1970) and that proprietorship of knowledge enables certain members of society to increase their own status. Those in power then make the laws governing behavior for the general public according to their own political ideologies and, in that way, maintain social control (Conrad & Schneider, 1992). What makes this power acceptable is that it not only creates a force that says no, it also produces the corpus of common knowledge (Foucault, 1972).

Because the power/knowledge theme affords the view that all knowledge reflects some social or power class, there is no such thing as objective knowledge. According to Link and Phelan (2001), power is essential to the production of stigma. “Stigmatization is entirely contingent on access to social, economic and political power that allows the identification of differentness, the construction of stereotypes... and the full execution of disapproval, rejection, exclusion and discrimination” (p. 367).

Those in power use their self-generated definitions of normality to regulate behavior: “only through abnormality do we know what normal is” (Fillingham, 1993). The normal/abnormal dichotomy can easily be expanded to include an analysis of deviant versus nondeviant behavior. Of particular interest is the way deviance designations are defined by a society because these classifications are by-products of the society in which they exist. What is considered deviant in a given society is a product of a political process of decision-making. The power/knowledge base would naturally have a controlling influence in specifying exactly what constitutes deviant behavior. This power base would then be the one to legitimate and enforce their definitions onto the less powerful (Conrad & Schneider, 1992).

Scientific advances not only increase general knowledge, but more importantly, they give power to those who possess the knowledge. Psychiatric knowledge has allowed medical authorities to justify and expand their own power, shrouding it under legal codes they themselves have created. As doctors have asserted their ideas, they have further strengthened their own privileged positions and because the marginalized and disadvantaged lack medical knowledge, they are placed in a position of powerlessness when they seek medical care. Echoing Goffman’s views on deviance, Foucault argues that only law and medicine have the “right” to construct and promote deviance categories and that the medical profession actively influences definitions of deviance. Medical practice leads to the creation of new medical norms whose violation is deviant (Conrad & Schneider, 1992).

The stigma attached to AIDS is layered upon a priori stigma so
that public perceptions of AIDS become inextricably tied to perceptions of
the groups among which it is more prevalent (Herek, 1990). In relation to
HIV, Foucault would easily conclude that STDs have become a disrep-
utable disease of marginalized groups precisely because of the definitions
generated by the power/knowledge structure of white, heterosexual,
middle-class males. Accordingly, reactions to HIV are reactions to gay
men, drug users, minorities (Herek, 1990) and HIV-infected women, all
marginalized groups. Because HIV infection is now a disease of the poor
and disenfranchised, those who are infected are socially marginalized and
are kept outside of the power/knowledge matrix. Portraying people
infected with HIV as deviant and abnormal gives those in power a legiti-
mate justification for the confinement and exclusion from society of those.

As the ‘second sex’ women are brought up in a world defined by
men and are themselves defined by men (de Beauvoir, 1949). Feminist
critics see the medical profession as a patriarchal institution that uses their
definitions of illness and disease to maintain the relative inequality of
women. By drawing attention to women’s weaknesses and susceptibility
to illness, medicine has taken control over certain areas of women’s lives,
such as pregnancy and childbirth (Lupton, 1997). Throughout history, the
medicalization of women’s bodies, as described by Foucault, has gone so
far as to turn pregnancy into a disease (Diamond & Quinby, 1988). This
has meant that for much of medical history, women’s health issues have
been set apart in the context of the male-dominated medical profession
and the patriarchal nature of social life (Douard & Durham, 1993).

The outcome of this second-class status is that women have had
an obscure role in the unfolding of the HIV epidemic, ranging from
insignificant players, to carriers of a deadly disease, to vectors of trans-
mision of the virus to children. Despite the staggering statistics showing
that rates of HIV infection are increasing among women (Davis, 2003) and
the medical fact that females are more susceptible to HIV infection than
men (Burger & Weiser, 2001; Denenberg, 1997; Sutton, 2000), women with
HIV infection have become scapegoats in an attempt to classify the abnor-
mal. By considering the labeling of HIV-positive women as profane and
immoral, we can better understand how health-care providers, in this
case, physicians, exert power over them. The physicians use demoniza-
tion as a mechanism for discouraging pregnancy and for keeping these
women on the fringes of defined normality.

If, as Havighurst (1972) suggests, parenthood is one of the devel-
opmental tasks of adulthood, the outcome is that motherhood becomes an
important, if not primary, source of identity for women. This pronatalist
consciousness imposes on women a need to fulfill societal expectations
(Caron & Wynn, 1992). However, based Foucault’s theories of the med-
icalization of women’s bodies, pregnancy is a form of bodily weakness, if
not illness, requiring medical regulation. The medical profession is
charged with monitoring health/normality, detection of abnormality,
medical intervention and identification of risk factors with the express objective of delivering healthy babies (Phua & Yeoh, 2002). Within this context, women do not have full control over their choice to have children. Consequently, the inability to reproduce challenges a woman’s femininity since motherhood is the only real path to normality (Sandelowski, 1986). Within Goffman’s conceptualization of stigma, childlessness would be abnormal and would place women outside of the social norm.

Ingram and Hutchinson’s (2000) double bind applies equally to women with HIV infection and women with fertility problems. HIV-positive women are considered deviant if they become mothers but find themselves condemned by the same society that encourages HIV-negative women to embrace motherhood. An infertile woman becomes tainted because of her inability to fulfill her motherhood role but the use of fertility treatments confers its own level of shame (Baker, 2004).

The birth of children with genetic disorders emphasizes a striking difference between the treatment of HIV-positive women and HIV-negative women. Overall, the risk of an American woman having a child with a major birth defect is 2% to 3% (Villarosa, 2001); for a woman with HIV infection, it is less than 1% (Cooper et al., 2002). This risk is far less than the norm for certain genetic conditions, such as Tay Sachs disease and yet, women who are carriers of genetic defects often decide to reproduce without public outcry about the risk of transmission. Society has never considered condemning women or limiting a woman’s reproductive rights in the face of such tragic consequences. Further, “when women with chronic diseases and some who are dying, choose to become pregnant, even at considerable risk to themselves, they are treasured by their families and admired by society for doing so” (Levine & Dubler, 1990, p. 323). Similarly, more HIV-negative, older women are choosing to become pregnant after the age of 45, even though the risks to the fetus inherent with advancing maternal age increase considerably, specifically for Down syndrome. Those women who continue their pregnancies commonly find themselves supported and assisted in their quest for motherhood. Conversely, many in the medical establishment persist in discouraging HIV-positive women from becoming pregnant. “HIV-positive women are considered [to be] irresponsible for having babies who may face early death and whose future care may be a burden to society” (Levine & Dubler, 1990, p. 323).

All of these conditions influence how our society deals with HIV/AIDS and how individuals react personally and collectively to the issues. If we accept Foucault’s construction of illness as deviance and relate it back to Goffman’s definition of stigma, it is simple enough to recognize the way in which victims of illness are transformed into a stigmatized class (Goldstein, 1989). It is therefore easier to remain apart from the debate and rationalize HIV as an affliction that affects only certain, very specific and marginalized groups. Personal responsibility for the stigma can be imputed to the individual and the severity of stigmatization thus
increases (Jones, 1984).

What is required in public health is a change in the power/knowledge structure, which, according to Foucault, can only be accomplished through some degree of revolution. Health education has traditionally contributed to the maintenance of the power status quo, since health-care providers are entitled by their possession of scientific knowledge and power (Gastaldo, 1997). Health educators could adopt ‘discourses of participation and empowerment’, thus turning from ‘repressive approaches to constructive ones’ (Gastaldo, 1997). By transforming health education into an empowerment tool to increase informed decision-making regarding pregnancy, HIV-positive women could become advocates who champion their own social and personal factors and challenge the attitudes and knowledge of the health-care workers, especially physicians, during the medical encounter. The goal is to avoid the imposition of certain ‘truths’ about what constitutes health, in which women lose control over their bodies and their own health care (Gastaldo, 1997).

**USING THEORY TO CHANGE BEHAVIOR**

The value of stigma theory from a public health perspective is that it provides a paradigm for research on the attitudes of society toward marginalized individuals. It also helps us understand social exclusion and its role in social interaction in contemporary society, or why some individuals experience stigma and others do not (Whitehead, Carlisle et al., 2001). The sometimes-subtle processes that arise because of stigma can impact the provision of health care to HIV-positive women. If the perpetrator of stigma believes that the target of his or her stigma is of less value, bad, or dangerous, it can be difficult to conceal such feelings of condemnation (Whitehead, Carlisle et al., 2001).

Providing nonjudgmental prenatal care to pregnant women with HIV infection means confronting a host of personal and social issues that arise from deeply held beliefs and values about sexuality and deviance. The attitudes of health-care providers can determine how others react to a woman’s situation or problem and how a woman feels about herself. If medical practitioners approach their patients with the misconception that only “some kinds” of women are at risk for HIV infection, the result may be that women are being under-tested or misdiagnosed, a circumstance that could result in poorer health outcomes overall. In light of this reality, it is vital that the health-care establishment devise ways for health professionals to recognize and manage their attitudes about HIV and pregnancy so that HIV-positive women do not have to deal with the added burden of stigma when making pregnancy decisions. As long as the medical establishment continues to treat women paternalistically, Goffman’s typology of stigma will prevail. The person with a stigma—in this case, the HIV-positive woman—remains not quite human (1963), so it is acceptable to exercise varieties of discrimination that lead to prejudicial views.
If this ‘them/us’ dichotomy becomes entrenched, it results in a devaluation of the ‘other’ that can eventually reduce a person’s life chances.

Regrettably, the medical profession’s tendency to encourage conformity and compliance creates an atmosphere in which judgmental attitudes prevail (Mason, Carlisle et al., 2001). Patients are expected to adhere to certain health-care rules, for example, quitting smoking while pregnant or avoiding pregnancy after being diagnosed with HIV infection. By defying the norm and becoming pregnant, HIV-positive women risk inviting stigma and punishment, which almost certainly leads to blaming the women for being infected and for passing the virus on to their babies (Jones, 1984).

The ongoing stigma faced by pregnant, HIV-positive women clearly emphasizes the element of power that Foucault described as a reflection of some social or power class (Foucault, 1972). In one sense, disclosure or nondisclosure gives women a sense of control and power over their own lives. On the other hand, the limited options that dictate what the women ought to do about pregnancy in the context of HIV infection confirm Goffman’s (1963) views on punishing those who rebel against social norms and values. The focus of public health programs should not reduce women to mere vectors or agents through which HIV is transmitted to children. Rather, such programs should regard women as deserving of the knowledge and skills that would protect them from HIV infection or as worthy of the treatment and care that would optimize their health after being infected with the virus. Moreover, the women should be viewed as having the capabilities to make decisions about their own lives and pregnancies. Health practitioners could use the ideas inherent in the power/knowledge matrix to overcome the classification of HIV infection as stigmatizing and deviant by empowering HIV-infected women to take back control of their health by engaging in preventive health activities and joining patient advocacy groups.

Since HIV-positive women are part of the same social climate that places great value on motherhood, they undergo the same socialization processes as HIV-negative women; they internalize the group’s norms about childbearing; they learn their role regarding pregnancy expectations; and they experience similar positive and negative reinforcements for childbearing behavior. Therefore, it should not be surprising that a diagnosis of HIV does not cause an infected woman to abandon all notions about motherhood that she has been developing since adolescence. Likewise, it also does not remove what seems to be for many women an innate desire to have and nurture children (Linn, 1995); on the contrary, it may actually increase their desire to bear children (Ross et al., 1992).

Reproductive decisions for HIV-infected women are more convoluted and multidimensional than they are for HIV-negative women. For infected women, reproduction is not an either/or choice between social and individual responsibility (Arras, 1990). Viewed from an anthropolog-
ical perspective, the reproductive choices of HIV-positive women are made first, within the context of broader family and social relations and cultural influences and second, within the framework of personal and social reactions to HIV and AIDS. The usual decisional factors surrounding pregnancy are magnified and HIV status is not the sole determinant of women’s pregnancy decisions (Ahluwalia, DeVellis & Thomas, 1998; Sowell & Misener, 1997). Despite the risks of perinatal infection, HIV is often far down on the list of immediate concerns for these women. Economic conditions, socioeconomic status and educational and familial structures affect human behavior to the degree that they influence people’s aspirations, personal standards and emotional states (Pajares, 2002). Very often, women at risk of HIV are also subjected to poverty, chronic unemployment, poor or nonexistent education, substandard housing, crime, drug abuse and spousal abuse and the lack of medical or social support (Arras, 1990).

Public health specialists must recognize the way in which HIV in its cultural and historical context is similar to past epidemics. They could utilize a Foucauldian approach to examine the social events that preceded the HIV epidemic and then use that information to understand what barriers must be circumvented to design effective treatment programs for HIV-infected women. The history of society’s response to leprosy, TB, STDs, cancer and mental illness should remind us that a diagnosis of illness can alter a person’s behavior patterns, the attitudes they take toward themselves and the attitudes of others to them. There will be a difference in the way others react to a sick person if the illness is attributed to external forces over which the person has no control versus how dangerous they seem and whether contagion, personal responsibility, or morality is involved.

The fact that some health-care professionals are questioning the appropriateness of childbearing by HIV-positive women raises important questions about the quality of care that these women are receiving. Rather than emphasizing the potential for harm in HIV-positive pregnancies, health-care workers should treat women with HIV infection the same way they would treat any woman facing a difficult pregnancy—with compassion and consideration. The alternative to continued hostility would be the fair and equitable treatment of HIV-positive women in a nonjudgmental atmosphere. The task is to change both the environment in which the women learn about pregnancy and HIV and the experiences or values that surround childbearing for HIV-positive women.

Because HIV-positive women are faced with a multiplicity of social norms when considering pregnancy, it is necessary to develop new approaches to understand better the women’s health behavior. Ideally, all people with HIV infection should seek health care from HIV specialists, since the knowledge level and commitment would contribute to better overall care. But for women who become pregnant, it is doubly important to help ensure acceptance and to guarantee optimal prenatal care.
Through positive peer and social support and explicit institutionalized norms about pregnancy (Ingram & Hutchinson, 2000), a woman can feel completely confident in her ability to succeed at being a mother, knowing that her decision will actually increase her self-esteem and feelings of worth within the community.

Reproductive choice is a contentious issue that permeates all levels of society and forces us to look at the social and cultural norms that stigmatize women, that create health risks for them and that decrease their ability to function independently (Bradley-Springer, 1994). Yet even in the context of AIDS, having children is a highly personal matter (Allen, 1996). Women’s desire to control their reproductive system is probably as old as human history. Early feminists argued for a “right on the part of woman to decide when she shall become a mother, how often and under what circumstances” (Davis, 1983, p. 207). For this reason, society’s response to HIV-positive women’s choices must be based on an understanding of the interplay of all the psychosocial and biomedical issues outlined above for adolescent and adult women. Ultimately, the final decision about childbearing must be left to the woman.

The two theories outlined in this paper—Goffman’s stigma and Foucault’s power/knowledge matrix—suggest that social norms in some way determine the behavioral decisions of women about whether or not to have children. The important value of these theories is that they can help researchers recognize the interactions and reactions of health-care workers and HIV-positive women to prevailing negative attitudes about pregnancy and HIV infection. They can also provide a useful structure for understanding HIV-positive women’s choices regarding pregnancy. In a hierarchical sense, decreasing stigma and increasing knowledge and power work as a combined force to move women into a sphere in which pregnancy and HIV would not be fraught with drama and hardship.
REFERENCES

ing HIV infection. *AIDS Education & Prevention*, 10(1), 90-97.


