

DESTIGMATIZATION OF HIV: PROGRESS OR REGRESS?

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Part I: Stigmatization

ABSTRACT

The HIV epidemic has resulted in a renewed interest by social scientists in stigmatization and in a corresponding need to reconceptualize stigma, especially its relationship to power. While the professions have some power to control stigma, the emergence of self-help and mutual aid groups such as those founded by the gay activists involved in the AIDS epidemic, has shown that patients are not simply passive victims in the process of stigmatization. This new approach to stigma raises the questions: does destigmatization occur? What would constitute evidence of such a process? This article examines the change from seeing HIV as an epidemic and as a fatal disease to seeing it as a chronic illness—a possible example of destigmatization in action, noting the basic problems and promise of this process.

INTRODUCTION

Maida (2003) has observed that prior to twentieth-century innovations, the healthy viewed hospitals as “houses of infection and contagion” (p. 58); in a sense

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regarding the hospital as an unclean place and stigmatizing patients who dwelled within it. He notes that these dynamics of moral labeling continue within contemporary health care settings. The “sick role,” as conceptualized by sociologist Talcott Parsons, is frequently attributed to today’s patients because “physicians are required to stigmatize the sick through diagnostic labeling . . .” (p. 63), thereby symbolically and instrumentally opening a pathway to a system of care.

The chronically ill are especially vulnerable because they require and rely on a number of services for a much longer period. While the professions have the power to control the stigma, the emergence of self-help and mutual aid groups, founded by feminists and the gay activists involved in the AIDS epidemic demonstrates that the patients are not simply passive victims in the process of stigmatization. “Clearly, the politicization of health has challenged notions of stigmatization for at least these specific subcultures and their supporting institutions” (p. 72).

Link and Phelan (2001) who reconceptualize stigma, have also highlighted the importance of power on the part of those doing the stigmatizing, stating “Stigma is entirely dependent on social, economic, and political power—it takes power to stigmatize” (p. 375). They note, “The patients simply do not possess the social, cultural, economic, and political power to imbue their cognitions about staff with serious discriminatory consequences” (p. 376).

Parker and Aggleton (2003) have argued that the simplistic conceptual frameworks of sociology have hindered the understanding of stigma and HIV. For them, much of the historical work saw stigma as an attribute rather than as something that devalues relationships. Stigma must be examined in relationship to broader social processes of power and domination, as “stigma plays a key role in producing and reproducing relations of power and control” (p. 16). Therefore it should be examined in relation to inequality. “It is vitally important to recognize that stigma arises and stigmatization takes shape in specific contexts of culture and power” (p. 17).

Further, stigmatization can only be overcome by knowing the history and its consequences. Using Foucault’s work on knowledge and power and how the latter is embedded in the former, they argue that the cultural production of difference as described by Foucault also addresses the issue as stigmatization and asserts that both knowledge and power are central to the constitution of the social order.

Bourdieu’s work also addresses the issue as to how power is used to legitimize inequalities. He notes that symbolic violence (words, images, practices) not only promotes dominance (hegemony) but also seeks to convince the dominated to accept the inequalities inflicted on them. If, as Bourdieu suggests, all images, cultural meanings and practices embody interests and social distinctions, then (as for Parker and Aggleton) few do so as clearly and as powerfully as stigma and discrimination. This approach broadens the conception of stigma to include the complex struggle for power. Doing something about stigma and discrimination

therefore requires doing something about the structures of inequality, hence calling into question the structure of social life.

These accounts of stigma raise issues of whether stigma can be altered, and how destigmatization can occur. More fundamentally, they raise the question: does destigmatization occur, and if so, under what conditions? The work also raises the question: Why would those in power allow it to occur? Maida asserts that, through the self-help and mutual aid groups, it did occur as participants gained self-mastery and emotional self-care skills' involving a sense of "taking action together." The question arises: how does a destigmatized person negotiate treatment in the health encounter? Link and Phelan say that this can only occur through a process that is multifaceted and multilevel. Changes in the labeling process involving stereotyping, setting apart, devaluing and discrimination also require changes in the power relations. These writers feel that HIV stigmatization must be situated within a broader political economy of social exclusion and related to social processes, such as globalization.

Parker and Aggleton suggest that a new research agenda would include conceptual studies, new investigative inquiry, and strategic and policy-oriented research. Intervention models would not simply include the currently preferred cognitive-behavioral and social-cognitive approaches which stress individual coping, but would include community mobilization and social transformation.

What is needed here is work that captures destigmatization in process. Do changes in labeling occur? Do they result in other related changes in stereotyping, separation, devaluing, and discrimination? Since stigma is about power, particularly power in the health encounter, what kind of changes would provide evidence that a process of destigmatization has begun?

Castro and Farmer (2005) in their study of AIDS in rural Haiti have taken up this challenge. They note that much of the work on stigma often "desocialized" stigma by removing the social context. This occurred partly because the methods used, such as surveys, do not capture the historical and social processes involved and focus instead on knowledge and attitudes of individuals. They also feel that the claim often made, that stigma in third world countries is a barrier to getting care, ignores the fact that good quality care generally is not available and that cost and availability are more likely barriers.

Using ethnographic data, they propose that structural violence needs to be considered as part of the process of stigmatization. Structural violence refers to those social forces such as racism, sexism, political violence, poverty, social inequalities that impact the distribution and outcome of HIV/AIDS. Not only does structural violence determine who gets services and care, but also who gets stigmatized and suffers discrimination. Using a single ethnographic case study, they illustrate how highly active antiretroviral therapy (HAART) has been able to impact stigmatization and discrimination of the individual, noting that the introduction of effective therapy had a profound and positive effect on HIV testing.

Castro and Farmer (2005) conclude that the study of stigma poses methodological problems: there is no agreement on what methods can best capture the diverse variables that must be considered. These variables clearly must have a biosocial basis but must also include the “patients’ voices.” The framework “must not only assess the impact of stigma on morbidity and mortality but also address questions of stigma and equity” (p. 57).

The problem with this investigation relates to the fact that while stigma clearly cannot be measured simply by attitudes and knowledge, the indicators (changes in the life circumstances of an individual and rates of testing in a community) in themselves are not evidence that a cultural change in attitudes and stigma has occurred, or that changes in “structural violence” have occurred. We have no way of knowing whether the changes they documented for an individual reflect something unique about that person or the circumstances surrounding him.

These writers note that the physical changes that occurred after therapy (in visible skin infections, weight loss, thrush, coughing, etc.) affected the response of those around the person. The therapy may have had no effect however on the stigma in the community, or regarding AIDS patients generally.

Stigma clearly shapes public perceptions of HIV, as Paltiel et al. (2005) acknowledge in an analysis of the cost-effectiveness of expanded HIV screening. They cite the need for more data on both the extent to which stigma limits acceptance to HIV testing and linkage to care and prevention, and the potential benefits of expanded HIV counseling, testing, and referral in reducing negative perceptions of the disease.

This article considers the move from seeing HIV as an epidemic to seeing it as a chronic illness. It poses the question of whether this is an act of destigmatization or a change in stigmatization to a less serious form of stigma, that of a chronic illness. It also examines the consequences of such a change, focusing on the era of HAART—that period following the introduction of the new antiretroviral drug therapies. Medically, this period marked a transition from seeing HIV as a terminal illness and AIDS as a death sentence, to seeing it as chronic illness requiring long-term care. Our inquiry looks for evidence whether this medical change in the nature of the disease was matched by conceptual changes on the part of physicians, other health care workers, and the wider public.¹ We begin with explication of the concept of stigma.

¹ This new interest in the concept of stigma has not been confined to HIV as evidenced by a timely symposium on this topic in the *Health Sociology Review* (Vol. 10:2, 2001). The four papers included there present a range of topics on stigma in chronic illness, in the funeral business and with reference to doctors performing abortion.

STIGMA AND HIV

Stigma—a process of derogation of individual attributes and of blaming the person for the devalued attribute—has had a major impact on the reporting of instances of the HIV infection, the way patients seek care, and the type of preventive programs needed to change sexual behavior and drug use, two of the most significant means for transmitting the disease. There is an increasing recognition that for the patient, the process of stigmatization may be nearly as devastating as the disease itself. But as Coleman (1986) notes the concept of stigma has proven difficult to conceptualize because it reflects a process, a property, a social categorization, and an affective state.

While much work has focused on the psychological consequences of stigma, the phenomenon is sociocultural in nature. It is rooted in the fact that all and any human differences are potentially stigmatizable. Stigma stems from differences. Furthermore, what is stigmatized in one culture may not be stigmatized in another and what was once stigmatized may not be stigmatized at another time in a given culture. The essential feature of stigma therefore is that it is not an attribute of an individual. Essentially social norms and social context determine stigma. Therefore, stigma is a social construction and it is the society that validates a stigmatized identity (Sandstrom, 1990). The social norms in a given context thus will determine the stigma and its severity.

Most writers on stigma also accept Goffman's (1963) notion that stigma involves a trait that if hidden is discreditable, or if known is discredited (Quam, 1990). It involves a value judgment (Alonzo & Reynolds, 1995), and a social comparison (Coleman, 1986). It implies a relationship, and to the extent that stigmatization is successful, it involves the concept of power. "Power, social influence, and social control play a major role in the stigmatization process" (Coleman, 1986).

The HIV epidemic has provided a significant challenge to both epidemiologists and social scientists (Janes, 1986). As Gorman (1986) notes, the epidemic initially affected a subculture, namely gays, that was already stigmatized and about which little was known. It was the field of anthropology that was able to determine the social and cultural factors that influence behavior, and that placed certain groups at higher risk. Not only were anthropologists able to gain access to the groups, but this understanding of the disease contexts gave them a methodological research advantage: "The anthropologist's skill at gaining entry to the population(s) at risk, in identifying and gaining the confidence of key informants and serving as culture brokers between professional and lay communities can be vital in developing epidemiological research" (Gorman, 1986, p. 159).

By 1996, the face of the HIV epidemic in the United States had changed drastically. Data provided by the Harvard AIDS Institute (*New York Times*, 1996) showed that in 1986, 60% of those diagnosed with the disease were Caucasian,

24% African American, and 15% Latino. By 1995, the figures had become, 40% Caucasian, 39% African American, and 19% Latino. By the year 2000, African Americans accounted for half of all newly-diagnosed AIDS cases. The Centers for Disease Control and Prevention calculate “that in 1994, one of every three deaths among black men between the ages of 25 and 44, and one of every five deaths among women in the same age group, resulted from HIV-related illness. African-American men are already 5.5 times more at risk of contracting AIDS than white men. African-American women are now 16 times more likely to contract AIDS than white women (*New York Times*, 1996).

The early HIV epidemic was concentrated largely among the middle-class, gay, male population. It rapidly moved into other sub-populations and communities, for example, women, communities of color, drug users, and youth. As the epidemic attacked new communities and populations within diverse geographic areas, these groups of people living with HIV whose *a priori* health tended to reflect their members’ traditional lack of access to care have posed new challenges to the health care system. For the most part, the emerging groups were positioned among the more disenfranchised segments of American society.

At the same time, a second transformation had also occurred with respect to the AIDS epidemic. From 1996, for the first time, the numbers infected with HIV have shown a decrease (*Los Angeles Times*, 1997). This decrease was attributed to increased resources devoted to treatment, prevention and particularly improved therapies. The new drug regimens have shown great promise for at least keeping the disease in remission. However, the patterns have varied among gender, ethnic groups, and risk groups with the numbers dying shifting to the most vulnerable groups. The decline in deaths was 15% among men but deaths increased 3% among women. Deaths declined 18% for gay men and 6% among drug users but increased 3% for those infected through heterosexual contact.

Some areas such as New York, reported a 30% drop in AIDS-related deaths. Again, the drop varied by region with an 18% drop in the Western states but only an 8% decrease in the South. Although the decrease occurred in all ethnic groups it was greatest among whites (21%) compared to African Americans (2%) and Latinos (10%). Furthermore, the numbers diagnosed as having AIDS also increased by only 2% from 1995 to 1996 compared to 5% for 1995 and 1994. However, for the first time, in 1996 African Americans accounted for the larger proportion of AIDS cases (41%). Women with AIDS also increased and made up one-fifth of all newly reported AIDS cases. Thus, AIDS continued to ravage communities of color and women. Furthermore, other groups already stigmatized were emerging as populations-at-risk, such groups as intravenous drug users, and the severely mentally ill. Stigma, therefore, would *continue* to be a significant factor in HIV illness and in the treatment of HIV, and for the newly emerging groups, would have *increased* significance.

THE IMPORTANCE OF STIGMA FOR HIV PATIENTS

There is an increasing recognition among those researching the AIDS epidemic and HIV patients that in addition to being a disease epidemic, HIV/AIDS also had unleashed a psychosocial epidemic of stigma (Herek & Glunt, 1988) that derived much of its force from being embedded in culturally determined beliefs and symbols of illness and deviance in our society (Conrad, 1986). Furthermore, there was an increasing recognition that for the patient, the process of stigmatization may be as devastating as the disease itself (Bennett, 1990).

Research has shown that for other stigmatized patients, notably those with epilepsy, being sick is less salient than being stigmatized (Scambler & Hopkins, 1986). Research has also established the salience of stigma for HIV patients. Siegel and Krauss (1991) found that stigma rated second of the three most salient issues for males living with HIV. There is increasing evidence that for the newly emerging HIV populations, in particular women and drug users, stigmatization is a dominant feature of their encounters with health care providers (Herek & Glunt, 1988; Lawless, Kippax, & Crawford, 1996).

Studies to date have focused primarily on stigma as experienced by patients (King, 1989) and those stigmatized by association (Powell-Cope & Brown, 1992), and have been principally concerned with psychosocial consequences and methods of coping (Stahly, 1988). These have also sought the correlates of stigma among the population-at-large, and to a lesser extent, among care providers (Green, 1995; Kelly, Lawrence, Smith, Hood, & Cook, 1987; Pryor, Reeder, Vinacco, & Kott, 1989). There has been far less research on the role that providers have played in the process of stigma, either negative or positive, the salience of the patient's experience with stigma in care-giving organizations, or the ways in which treatment facilities intervene in, or contribute to, the process of stigmatization or its amelioration.

The question of why AIDS in particular has been strongly singled out for stigma has been extensively discussed in the literature. Quam (1990) examines three social boundaries that are symbolically evoked by the threat of AIDS: the issue of personal safety, faith in science and technology to find solutions, and a crisis in ambiguity in moral codes. Part of the explanation must also be the role that mass media have played in bringing the epidemic to the public, first largely ignoring it, then labeling it as the "gay plague" (Markova & Wilkie, 1987). This has ensured that the AIDS epidemic is "freighted with profound social and cultural meaning" (Paicheler, 1992).

As Crawford (1994) notes, the symbolism for AIDS condenses several significant metaphors in our culture: the unhealthy, the contagious, the sexually deviant, and the addicted. Finerman and Bennett (1995) draw attention to the fact that in contemporary Western societies, theories of illness have become increasingly responsibility- and blame-focused. That is, the disease is seen as an outcome of the behavior of the afflicted. These blame-oriented models are

“more accusation than they are explanation” (p. 1). However, as Lawless, Kippax, and Crawford (1996) note, HIV seems to have elicited judgments of responsibility and blame far stronger than other illnesses. In a society with a well-developed AIDS phobia (Mariner, 1995), the HIV patient had good grounds for concern, for “in a sense, stigma represents a kind of death, a social death” (Coleman, 1986). The pervasiveness of the stigma also extended to groups that are themselves stigmatized in society. Early in the epidemic, gay men, for example, have been shown to stigmatize those among them that have AIDS and to distinguish between themselves and such people (Kowalewski, 1988). Further, their attitudes toward such patients were markedly similar to the society-at-large, for example, holding the HIV patient responsible for their condition because of promiscuity. Attitudes toward AIDS patients are related to a general anti-permissive attitude toward non-traditional lifestyles (Nisbet & McQueen, 1993; Peruga & Celentano, 1993).

A significant type of stigma identified by Goffman (1963) is “courtesy stigma,” that is, stigma by association. This refers to the fact that stigma may not only be applied to a person with the defined attribute, but it is also extended to those associated with the person. So those who are involved with the HIV patient, namely family members, spouses or lovers, friends, and associates, may all suffer some of the stigmatization. One of the groups that may be stigmatized by association consists of those providing care to HIV patients. In one survey of attitudes during the early epidemic, 35% of the public indicated they would change dentists if they knew their dentist was treating AIDS patients (Cohen, Grace, & Ward, 1992).

Taylor, Eakin, Skinner, Kelner, and Shapiro (1990) found that 38% of physicians believed that if they treated HIV patients, others might conclude that they were gay and 33% thought they would be stigmatized by having these patients. Brefeldt, Dardeau, Wesley, Vaughan-Wrobel, and Markland (1991) found that 40% of physicians thought having HIV patients would affect their ability to attract and retain patients. Gerbert, Blecker, Coates, and McPhee (1991) found 1 in 4 patients reported that they would change doctors if they knew HIV patients were being treated by their provider. Nashman, Hoare, and Heddesheimer (1990) found that among nurses, stigma ranked as the fourth most important stressor in dealing with HIV patients. Bennett, Mitchie, and Kippax (1991) report that nurses feel they are stigmatized both socially and at work because they treat patients with AIDS. In an interesting twist, Reutter and Northcott (1993) found that those nurses who do provide care for patients with AIDS stigmatize those who oppose such care. Studies have also shown that nurses may derive satisfaction from assisting stigmatized patients (Breault & Polifroni, 1992).

STIGMA AND ILLNESS

Our culture has had a long history of stigmatizing illnesses as evidenced with polio, tuberculosis, epilepsy (Scambler, 1984; Schneider & Conrad, 1986),

leprosy (Gussow & Tracey, 1968; Opala & Boillot, 1996), mental illness (Phelan et al., 2000), and cancer (MacDonald & Anderson, 1984; Fife & Wright, 2000). HIV illness, however, has a combination of elements that make it quite unlike previous manifestations of stigmatized illness. In discussing leprosy, Gussow and Tracy (1968) identified the features that make leprosy an ideal candidate for stigma: 1) be externally manifested; 2) be progressively crippling and deforming; 3) be nonfatal and chronic, running an unusually long time; 4) have an insidious onset; 5) have a fairly high endemicity but not be epidemic; 6) be associated with low standards of living; 7) appear to be incurable; and 8) have a long incubation period. However, a case could be made that HIV is an even more telling exemplar than leprosy as a stigmatized illness. Not only does it share most of the same characteristics as leprosy, it has additional unique elements. It is often terminal, so it has the additional stigma of death; it is an epidemic; it is contagious (even if by limited means); it has been associated with behavior considered by many to be immoral and deviant; and it is increasingly identified with minority groups.

The fact that it was initially identified as a gay disease in North America has significantly contributed to the stigma. Those who become infected can be severally stigmatized; for example, an individual may simultaneously be female, gay, a member of a minority group, a drug user, and dying. Stigma from HIV illness therefore may be additive.

The matter is complicated by the existence of groups of “innocents,” such as hemophiliacs, persons infected through blood transfusions, heterosexual persons unwittingly infected by partners whose HIV status was either unknown or unacknowledged, and the unborn and newly-born child. In these instances, no blame is attributed because of their behavior or stigmatized group membership (such as being gay). However they may still share the stigma of the illness.

Although stigma is particularly associated with contagious diseases, such as sexually transmitted diseases, leprosy, etc., the experience of cancer patients (Sontag, 1977), those with epilepsy (Jacoby, 1992, 1994; Scambler & Hopkins, 1986), and obesity (DeJong, 1980), it is evident that stigma can be as powerful even when contagion is not the issue (Gerhardt, 1985). As Conrad (1986) notes, while AIDS may be contagious, so is the fear and stigma that surrounds it. In fact, the fear of the disease may have had as great an impact as the disease itself.

THE IMPACT OF STIGMA

The more extreme examples of stigma's social impact on HIV patients have been well-documented in the press (Conrad, 1986). Children have been barred from school, hospital workers have refused to treat HIV patients, families have had their homes fire-bombed, and families have been driven from communities. Many of the studies in sociology and anthropology investigating the impact of stigma on the patient have used qualitative methods and small groups of patients. Much of this work has tried to capture the meaning of stigma for the patient. Some

of the major impacts identified by stigmatized patients include fear, shame and guilt (Cohen & Weisman, 1986), discrimination, social isolation, alienation and rejection (Bennett, 1990; Cassens, 1985; Dilley, Ochitill, Perl, & Volberding, 1985; Doherty, 1986), exclusion (Bickelhaupt, 1986; Nicols, 1985), derogation of the individual (DeJong, 1980; Triplet & Sugarman, 1987), and loathing (Green & Platt, 1997).

Stigma is also a process of blaming the victim for the devalued attribute. Pryor, Reeder, Vinacco, & Kott (1989) were able to demonstrate that a general attitude toward homosexuals (the symbolic factor) was a better predictor of both attitudes and behavior toward HIV patients than concern about contacting AIDS or having your child contact it (the instrumental factor). In HIV patients' attributions of blame and responsibility have been shown to be positively correlated with a combined measure of depression, anxiety, and negative mood. Those attributing improvement in these areas also made more behavior changes (Moulton, Sweet, Temoshak, & Mandel, 1987). A further distinction has been made between felt and enacted stigma (Jacoby, 1992, 1994; Scambler & Hopkins, 1986), where the latter refers to episodes of discrimination while the former refers to the shame associated with the stigma and the fear of enacted stigma. While discrimination is related to stigma, it is, however, distinct. Clearly, stigma also involves stereotyping to the extent that it applies to, but is not limited to, a category of individuals; it establishes psychological and social distance.

One consequence of stigma for HIV-infected individuals is the fear of disclosing their HIV status. Because of stigma, HIV patients must be judicious in deciding to whom they will reveal their status. Hays et al. (1993) found that gays will disclose their status to gay friends and lovers first, and to their families and colleagues only when they become symptomatic. This may result in HIV patients denying themselves important sources of social and medical support although this denial is driven by the need to safeguard themselves against stigmatization and discrimination.

Another consequence of stigma may be a reluctance to get tested for the virus resulting in infecting others and later entry into care. Yet a further consequence for HIV patients involves an increase in uncertainty. HIV status already confronts them with the problem of dealing with uncertainty (Weitz, 1989): the uncertainty of diagnosis, prognosis, when they contacted the disease, when they might actually get AIDS, when they might die, and whether they can live or die with dignity. Stigma adds to this burden an additional strain of uncertainty regarding how others will react to disclosure of the illness.

From a health policy perspective, the significance of stigma is the impact it is likely to have on preventive behavior. As noted by Valdiserri (2002), stigma is a continuing impediment to programs of HIV prevention and care. Those fearing stigmatization are less likely to be tested, less likely to reveal their health status, less likely to behave in a way that might identify them as HIV positive, including the practice of safe sex.

RESPONSES TO STIGMA

A major area dealing with reaction to stigma has been coping studies which fall into three major categories: those concerned with individual responses (Sandstrom, 1990), those that examine collective or group responses (Siegel & Krauss, 1991; Stahly, 1988), and those that examine intervention strategies for providers. Sandstrom (1990) identified four coping strategies: passing (by suppressing knowledge by others); covering (attributing symptoms to some other less stigmatized illness, e.g., cancer); isolation; and insulation (interacting with a select group only). In addition to rejection and isolation, Coleman identified lowered expectations as a result of the stigma (Coleman, 1986).

Alonzo and Reynolds (1995) have proposed that HIV patients are confronted both by the stages of the disease and by socially determined stages in which they are restigmatized. The authors have provided an articulate, theoretical framework for examining the relationship between the stages of the disease and the stages of stigma. They identify four stages of disease: transient, asymptomatic, symptomatic, and opportunistic. For the stages of stigma, they distinguish the following: at risk, diagnosis, latent, and manifest. The essential feature of their theory is that the experience of HIV patients and their reactions and coping strategies cannot be understood except in the context of the process of stigmatization that is occurring concurrently with the disease. Stigma is a social construction but is not a static attribution. It is emergent during the course of HIV illness and provides each individual patient with a series of challenges every bit as demanding, and perhaps as debilitating, as the disease itself. At each stage, both the demands and the responses differ.

Evidence for the separation of stigma and the disease comes from a study by Crandall and Coleman (1992) that found that not all persons with HIV experience stigma, but for those that do, it is not correlated with the diagnostic severity of the disease. Stigma was correlated with anxiety, distrust of others, and depression, but not with health care satisfaction. Few patients were alienated from their providers. Both stigma and severity of disease predicted days of work loss. Those who reported losing social support after diagnosis also reported higher levels of stigma. As noted by Valdiserri (2002), the good news from national surveys is that the overt expression of stigma about HIV/AIDS has decreased during the 1990s, but the bad news is that at least one in five American adults still express some element of it.

The proposals for intervention strategies have varied widely but all start with the need for more research and the need for providers to recognize the importance of stigma (Bennett, 1990). Recognizing the importance of stigma also involves recognizing the different forms of HIV-related anxiety (Fullilove, 1989). Providers can play a role in reducing such anxiety by relabeling the illness, for example, as HIV not AIDS, and as a chronic illness rather than a terminal illness. Counseling can assist the patient in acquiring skills for managing

the illness, including problem-solving and emotional skills. The qualities of the healer, such as empathy, concern, respect for the patient, cultural sensitivity, are seen as crucial.

Ideally, the best approach to HIV patients involves an integrated multidisciplinary team. The provider can help overcome stigma by building bridges between the individual and groups. "We cannot cure HIV disease yet but we can relieve the unnecessary rejection and suffering" (Fullilove, 1989). Crocker, Voeikl, Testa, and Major (1991) have shown experimentally that those who are stigmatized can protect their self-esteem by attributing the negative feedback to prejudice.

The use of support groups is a common recommendation, particularly for groups suffering the same stigma (Sandstrom, 1990; Saylor, 1990). Health care professionals have a key role in the redefinition of the individual as someone of worth. Other recommendations have included teaching about stigma in the nursing curriculum (Longo, Spross, & Locke, 1990). Since uncertainty is a major issue for HIV patients, Weitz (1989) recommends programs aimed at lowering their stress. This involves removing uncertainty where possible but also recognizing that some uncertainty is in fact useful, it is somewhat counterproductive to have patients learn their situation is hopeless.

All of these proposals, however, focus on individual responses and individual patients. The importance of social groups in fighting stigma is supported by the finding in Stahly's study (1988) that married patients scored lower on a stigma inventory. Furthermore she found that those who report highest hostility also report greater loss of social support and rate higher on the stigma inventory. As she notes, in cancer research those patients who report more anger and hostility, that is, "the more obnoxious patient," have a better prognosis. However, in the case of HIV patients, this may result in loss of social support and make the patient more prone to the effects of stigma. It should also be noted that one possible reaction to stigma is to become assimilated to it, that is, by accepting the devaluation of others (Siegel & Krauss, 1991).

As noted earlier, stigma is not an individual issue. Its effective solution, therefore, must be sought in changes to the ways health care is delivered so that good care does not simply depend on the luck of the individual in finding a good health care provider. The work of Singer (1991) takes the focus away from the individual and examines the significance of cultural factors in infection patterns. His review of the literature has established that even within the subcultures of drug users, ethnic culture has a significant impact on AIDS prevalence. Furthermore, institutions and interventions that do not pay attention to cultural discontinuities, including the cultural dissonance between the provider and the patient, will be largely unsuccessful in their intervention strategies. Singer's solutions go beyond the individual to social program designs and implementations that utilize ethnographic research for identifying discontinuities and other problems, as well as culturally sensitive and culturally specific

interventions. The latter involves use of existing cultural institutions and values for implementing programs to alter behavior.

THE ROLE OF HEALTH CARE PROVIDERS IN STIGMATIZATION OF PATIENTS

The role of providers in fostering stigma, and their potential role in the amelioration and negotiation of stigma, are significant topics for investigation. HIV is a chronic illness (Siegel & Krauss, 1991) whose stages will occur over 12 or more years during which time the individual will access both health care providers and institutions for a wide range of associated disorders. Furthermore, HIV is a multi-system illness in that those who suffer from it are likely to have several threatening health conditions simultaneously, which have an impact on a variety of bodily and mental functions. HIV, therefore, places tremendous demands on the health care delivery system. Like other chronic illnesses HIV is managed, not cured (Pierret, 1992). To the extent that stigma is a major component of the illness, it is imperative that health care providers come to understand the nature of stigma, at the very least to ensure that they do not contribute to the process.

In spite of its importance, relatively little is known about the role that providers play in stigma and the impact of stigma on the treatment of HIV patients. Do providers and clinics play a mediating role between the patient and society or do they in fact contribute to the process of stigmatizing patients, or both? In a very significant way, providers have stigmatized individuals by labeling them first as having GRID (gay-related immune deficiency), which identified HIV as a gay condition. This was later replaced by the label AIDS which in turn has been replaced by HIV-positive, and more recently, "persons living with HIV." Furthermore, the ambivalent attitudes and possible prejudices of providers may be powerful determinants of how the patient experiences the disease (Blumenfeld, Smith, Milazzo, Seropian, & Wormser, 1987; Hayward, Kravitz, & Shapiro, 1991; Kelly et al., 1987; Shapiro, 1989; Shapiro, Hayward, Guillemot, & Jayle, 1992; Yedidia, Barr, & Berry, 1993).

There is, however, an extensive literature on health care workers' attitudes about, and knowledge of HIV and AIDS. Horsman and Sheeran (1995) conducted a critical review of 164 articles. Their review shows there is great variation in the amount of knowledge that health care workers have about HIV/AIDS, with nurses appearing to be the least knowledgeable. Negative attitudes to AIDS were prevalent and appeared to be related to attitudes toward homosexuality. More recently, intravenous drug users were shown to be the most negatively perceived group of patients. Amount of HIV education does not predict attitudes; although education about HIV may reduce anxiety of the health care workers, it seems not to result in more positive attitudes. Religion has also been related to attitudes (both positive and negative), but no relationship occurs with regard to gender.

Although gay sexual orientation is related to greater knowledge and positive attitudes, the stress levels, anxiety, and depression of gay doctors treating AIDS is higher than that of non-gay doctors.

Shapiro et al. (1992) show that culture does have an impact on attitudes particularly with regard to homosexuality. Blameworthiness of the patient also affects the attitudes of health care workers (hence intravenous drug users were viewed more negatively than other groups). Haywood and Shapiro (1991) found that 42% of medical residents would not provide care for intravenous drug users (IVDUs) with AIDS and 41% would not provide care for IVDUs whereas only 11% would refuse care to homosexuals. Similarly, attitudes toward prostitutes with AIDS appear to be more negative (Breault & Polifroni, 1992). However, little investigation of providers' attitudes toward women or members of disadvantaged ethnic minorities with AIDS/HIV has been done. In the case of women, HIV shares the stigma traditionally associated with sexually transmitted disease. For Lawless, Kippax, and Crawford (1996), this includes notions of indiscriminate promiscuity, pollution, and uncleanness. As sources of infection, women have become positioned as "dirty, diseased and undeserving" (p. 1371). The results of their interviews with women suggest that the first assumption of health care providers is that the women were infected either by drug use or by sexual promiscuity, and this leads to almost immediate stigmatization.

The reaction of health professionals toward HIV during the epidemic's first decade has often been no more enlightened than that of the general public. In one study of a large urban hospital (Barrick, 1988), 25% of nursing staff thought patients with AIDS should be quarantined. Lester and Beard (1988) found 49% of the nurses preferred not to work with AIDS patients. Blumenfeld et al. (1987) found that nurses had a fear of treating gay patients and prisoners. One-half of the nurses thought they would request a transfer if they had to care for HIV patients on a regular basis. Kelly et al. (1987) used a series of vignettes to demonstrate the stigmatization of HIV patients by physicians. The negativity of the physicians was directly correlated with the lifestyle of the patient. Yedidia, Barr, and Berry (1993) have shown that physician attitudes vary according to the stage of their career and their specialty. House staff was more negative than senior medical students and faculty, and surgeons were more negative than internists.

An extreme response on the part of health professionals occurred in Dallas where a group of physicians and dentists formed Dallas Doctors Against AIDS and campaigned to have sodomy laws reinstated (Conrad, 1986). Quam (1990) notes that in the early period of the AIDS epidemic, many physicians refused to have their names on referral lists for HIV patients. Not only have homophobic attitudes been demonstrated among physician groups (Mathews, Book, Turner, & Kessler, 1986) but the degree of discomfort with treating gay patients has been shown to be related to competence measures for dealing with AIDS (Lewis, Freeman, & Corey, 1987).

Horsman and Sheeran (1995) note that the attitudes and beliefs of health care workers must be seen in the context of general social and cultural beliefs. Given that a major source of knowledge, for nurses at least, is the media (Armstrong-Esther & Hewitt, 1990; Reed, Wise, & Mann, 1994), it should not be surprising that they share many of the same attitudes as the general public. However, the work of Berkowitz and Nuttall (1996) on pediatric nurses shows that the attitude does vary with the type of patient involved. In their study, most of the nurses held positive attitudes and only 1.4% were unwilling to care for such patients.

The response of dentists to HIV has been widely noted (Gerbert, 1989; Gerbert, Sumser, Chamberlin, Greenblatt, & McMaster, 1989; Scheutz, 1990). In many communities it was impossible to find a dentist to treat HIV patients. Dentists have seen themselves at considerable risk from HIV (Gerbert, 1987; Hazelkorn, 1989; Kunzel & Sadowsky, 1991, 1993; Moretti, Ayer, & Derefinko, 1989). This problem has given rise to considerable ethical debate in dentistry (Davis, 1989). The attitude of dentists may also result in less disclosure by HIV patients to their dentists. Perry, Moffat, and Card (1993) found only 53% of the patients had informed their dentist of their HIV status but 85% had told their physician. On the other hand, dentists may be more at risk from stigma than other providers if they treat HIV patients. As noted earlier, household surveys have indicated that some of the public would change their dentist if they knew he/she was treating HIV patients. May, Murry, and Blinkhorn (1990) found that 25% of dentists in Scotland said they were unwilling to treat people with HIV not because of antipathy but because it would be "bad for business."

Horsman and Sheeran (1995) point out numerous methodological weaknesses in the work on health professionals: lack of theoretical frameworks; over-reliance on survey methods; reliance on convenience samples; use of cross-sectional studies; focus on doctors, nurses, and dentists with the exclusion of other care givers; focus on attitudes and knowledge with few studies of actual behavior; and few studies of the impact on quality of care. The issue of quality of care is important. Cleary et al. (1992) found that although patient satisfaction varied significantly between a special ward for AIDS patients and patients in the general wards, overall the patients were satisfied with their care. Some patients felt that they got even better care than non-HIV patients. Medical providers within the VA also report that HIV patients may get better care (Coulter, Maida, Wellenkamp, & Gifford, 1997).

THE NEGOTIATION OF STIGMA

The essential feature of stigma is that it is not an attribute of an individual. Stigma is determined by social norms and social context. Virtually any socially defined attribute can be the grounds for stigmatization. Stigma is therefore a social construction, and it is the society that validates a stigmatized identity (Sandstrom,

1990). Stigma involves a value judgment (Alonzo & Reynolds, 1995) and a social comparison (Coleman, 1986). It implies a relationship, and to the extent that stigmatization is successful, it involves the enactment of power. The fact that stigma can be negotiated has considerable significance for developing intervention strategies because it clearly demonstrates that stigma can be ameliorated. Through contextual analysis, social scientists will be able to gain an understanding of the specific circumstances that allow stigmatized groups and those who treat them the option of intervening. By learning more about the attitudes and practices of individual providers, the contexts within which they work, and the patients' experiences with care, we will learn a great deal about the factors that facilitate and or inhibit stigmatization.

However, stigma theory has tended to ascribe passivity to those stigmatized (Kleinman, Wang, & Li, 1995). While it is clear that many who are stigmatized are passive victims, persons are able in some situations to renegotiate the labels and stigma applied to them. There are numerous examples of groups confronting stigma, renegotiating the social constructions, and in some instances removing the stigma. The civil rights, feminist, and disability rights movements have all changed the ways we speak of and label ethnic groups, men and women, and people with disabilities. The American Civil Rights Movement in the United States changed forever the labeling of blacks (e.g., "black is beautiful") as has the more contemporary, African-American designation. The move to new forms of designation such as the physically and mentally challenged and the moving away from the label "handicapped" reflects the same social process. Labels such as "mentally retarded" have virtually disappeared in the common lexicon of our culture. People with serious physical disabilities organized self-help groups to confront stereotyping, stigmatization, and increased dependency on professionals (Maida, 2003). Whether changes in the labels have resulted in changes in the stigmatization of such groups remains unclear. It is probably the case that it has lessened, but not eradicated.

What weaves together these diverse social action practices is the resurgence of populism in the social movements of the late twentieth century. Populism implies a reliance on self-initiated activity, based on both participatory democracy and experiential forms of knowledge. Most contemporary movement organizations emphasize the creation of social environments, such as self-help groups, support networks, and experiential learning situations, where participants solve problems by "taking action together." Within these settings, the change process is relational, rather than individualistic, emphasizing the connectedness and mutual involvement of participants in meaningful activities. This emphasis may account for the success of many voluntary social action initiatives, from neighborhood organizations to broad-based citizen coalitions. Similarly, the "social model" programs that frequently emerge from populist initiatives differ considerably from their professional counterparts (Borkman, 1976; Katz, 1993).

Regarding the AIDS epidemic, gay activists clearly indicated that passivity should not be taken for granted on the part of stigmatized groups (Epstein, 1995; Goldstein, 1990; Gorman, 1986). By the late 1980s, AIDS activists went beyond each of the considerable achievements of the other activist groups in spearheading policy advocacy on behalf of patients with a condition which the medical profession was virtually powerless to cure. In the epidemic, gay activists numbered among their members articulate individuals with considerable intellectual skills who also had experience in political activism. Their counterparts in the lesbian movement brought similar skills and experience, as well as feminism's fundamental questioning of the motives of health care providers (Epstein, 1995). Both groups share a fundamental ideology of personal empowerment and of control over their own health care. Together with constituencies, such as parents of HIV patients, they created a powerful coalition that could not only organize but also deliver funds, protesters, and votes. Clearly, the politicization of health care has challenged the nature of stigmatization for at least these specific subcultures and their supporting institutions.

Because of their involvement in, and access to, the cultural institutions of the arts, AIDS activists have developed the skills to present their definitions of the epidemic and to express what it means through powerful images (Goldstein, 1990). In the area of research, these activists have been uniquely able to influence all aspects of the research process from the funding to the conducting of clinical trials (Epstein, 1995). More significantly, they have been able to influence the very definition of what constitutes good science in AIDS research. They mobilized public interest in the ways HIV patients are treated, anti-retroviral therapies and other AIDS drugs are marketed, AIDS-related research is funded, even how the epidemic is defined. The powerful AIDS lobby convinced Wellcome to slash prices on the controversial drug, AZT, and persuaded the Food and Drug Administration (FDA) to speed up the release of drugs that were thought to be effective in treating AIDS. Advocacy groups obtained the release of information about experimental treatments "overcoming the FDA's insistence that to do it would violate commercial confidentiality" (Epstein, 1995).

These examples also point to the need to examine the process of stigma in terms of the social context. While it is clear that within specific institutions and within certain subcultures, it is possible for groups to aggressively negotiate the labels by which they are stigmatized, this is the result of a complex set of situational, historical, and political factors. Only through contextual analysis will we be able to gain some understanding of the specific circumstances that allow stigmatized groups this option. This is particularly the case for determining the patient experience of stigma with providers and provider institutions. Approaching the treatment of HIV patients only in terms of the epidemiology of the illness, or the organizational structure of the delivery system, fails to address the actual health encounter between the provider and the patient.

Although the delivery systems may resemble each other in terms of their organizational structures, the care is ultimately delivered within a provider-patient relationship. In organizational studies, the informal structure has been referred to as the organizational culture (Abell, 1996). It includes the quality of interpersonal relations and the informal norms. In the case of HIV care, we need to determine the essential ingredients of the informal structure and show how these affect the formal organization. Abell (1996) notes that two important ingredients of any organizational culture are help and trust. The organization must depend upon informal services rendered and this necessitates relations of trust. In this sense, the organizational culture is a mechanism for strangers to help and trust one another. In HIV health encounters such trust may be severely tested. On the other hand, some level of informal cooperation is needed for care to be rendered. Thom and Campbell (1997) have shown that trust is a concept specific to the patient-physician relationship and has more potential explanatory power than satisfaction for such things as adherence. They also concluded that it is a concept best captured by qualitative methods.

A second part of the organization involves systems of relationships. Such networks cannot only be observed, but by using network analysis can also be mapped (Eisenberg & Swanson, 1996). Wright and Shuff (1995) have used this type of sociometric analysis to examine program integration of services for HIV patients. Combined with the observations and in-depth interviews, network analysis can contribute to a comprehensive picture of what services are offered; what the informal and formal links are between the programs and the actors involved; the utilization of the services; and the experiences of the patients. Ethnographic data provide the interpretations for the more formal network analysis. At the informal level, an order is negotiated among the health care providers which may look quite different than the formal structure suggests. Recent work on the relationship between doctors and nurses (Svensson, 1996) suggests that a negotiated order perspective more accurately captures what happens on the wards than the traditional hierarchical model of authority.

In examining the experience of the HIV patient and stigma, it is necessary to examine the quality of the patient-provider relationship from the perspectives of both the patient and the provider. Health encounters should be conceived as negotiations (Blumer, 1969). What is required to direct this research, however, is a negotiated theoretical perspective (Strauss, 1978). It is part of the peculiarity of stigma that it is constructed and negotiated through such encounters. Patients perceive and experience stigma in the reactions of others to their disease. In the case of HIV patients, this reaction can be extremely negative. However, this may be indicated to the patient largely by covert body language or interactional cues rather than by overt language. Of particular interest here, is the nature of the relationship for both the patient and the provider in this process. HIV patients present a challenge to providers both because of the complexity of their illness (more correctly, their multi-system illnesses) and because of the social, political,

and moral climate that has come to surround this particular illness. This is an illness that has aroused a strong societal reaction and therefore carries with it, for both the provider and the patient, a large burden of emotional weight. Given this, it would be surprising if the provider/patient relationship for this illness were not somewhat distinct or that providers were immune to the social context.

Despite the importance of the health encounter, systematic study of it is a quite recent phenomenon. The literature indicates that satisfaction with the visit has the most consistent relation to provider behavior, and that this can be predicted by the amount of information given in the encounter. Social conversation that builds partnerships and positive conversation are also related to satisfaction. Patient adherence is related to the medical encounter (Roter, 1988), which involves both affective and task elements for both the provider and the patient, what Roter calls "a reciprocity." She distinguishes between intrinsic affect (verbal exchanges with socioemotional content), conveyed affect (carried by tone of voice), and interpreted affect (the total impression given).

The health encounter and its role in stigma, is accessible primarily through the use of qualitative observation methods. While observation of the encounter poses a challenge, work by Sleath, Svarstad, and Roter (1997) on prescribing in primary care demonstrates that it is possible to conduct such observation even when the discussion involves sensitive topics. Their study on whether the patient or the physician initiates the prescribing behavior could only be carried out either by observing or recording the encounter itself. Kelner, Hall, and Coulter (1980) were successful in obtaining an 84% compliance rate from patients in observing the encounter in chiropractic offices. In other studies on patient adherence, Coulter, Hays, and Danielson (1994, 1996) found that there is often a wide disparity between the patient's and the provider's immediate reports of what occurred in an encounter. Over 20% of the patients reported that the provider had not recommended a course of action when the provider reported to the contrary, and over 20% of the patients reported the provider recommending something when the latter reported to the contrary. Such results raise considerable concern about the accuracy of self-reports and the need for direct observation.

Roter, Hall, and Katz (1988) in reviewing the literature on patient-physician communication noted that such studies have used an array of methodologies and an array of analytic schemes for coding the content of the communication. Three of the most frequently used schemes are those of Bales (1950), Roter (1977), and Stiles (1978). Wasserman and Inui (1983) suggest that any system of interaction analysis should capture the salient features of the communications, deal with the distinctive features of the physician-patient interaction, and apply to health care system parameters. Each scheme has certain strengths but these cannot be judged independently of the actual content of the communication. One weakness of the coding schemes noted by Roter, Hall, and Katz (1988) is that none of them captures such things as the "eloquence" of patients or physicians. Reducing the content of the communication to frequency counts of such things as

“information” may not capture the significance of the communication. Coulter et al. (1997) found that HIV providers report that educated, assertive patients get better HIV care. Huby (1997) notes that in HIV care what is not said by the patient may be as significant as what is actually stated and that researchers should pay attention to silence. Using only audiotapes will not allow a researcher to assess this feature, but observation will at least apprise the researcher of the significance of silences.

LIMITATIONS OF STIGMA THEORY AND RESEARCH

There is an increasing body of work that has drawn on the construct of stigma to examine the experience of HIV patients (Bennett, 1990; Herek, 1999; Herek & Glunt, 1988; Kelly et al., 1987; Quam, 1990). Broadly speaking, sociologists have delineated the normative process of stigmatizing HIV; anthropologists have provided more ethnographic accounts of diverse populations and specific social and cultural systems (Ablon, 1981); while psychologists have looked at the impact of stigma on the patient, the individual’s coping strategies, and the perception of HIV by a variety of subjects.

The concept of stigma quite clearly involves behavior (e.g., discrimination), social relationships (e.g., reinforcement of status hierarchies and inequality), affective states (e.g., fear and dislike), and cognition (e.g., perception of differences). Brimlow, Cook, and Seaton (2003) in their review of work on stigma and HIV/AIDS, note that the quantity of literature varies by the topic area, and therefore, probably by academic discipline.

There is a considerable literature on the evolution of the stigma and on policy-related and legal initiatives but much less on programmatic solutions. The percentage of the public harboring HIV/AIDS-related stigmatizing thoughts has been shown to be as high as 28.8% (1997). These studies also note that work in this field is dominated by a few key leaders such as Gregory Herek (Herek, 1999; Herek & Capitanio, 1993, 1997, 1998, 1999; Herek, Capitano, & Widaman, 2002). In this context, stigma emerges as a concept that is of interest to anthropologists, sociologists, and psychologists, and that significantly involves each of their intellectual domains.

While considerable work has been done on stigma, and has contributed to our understanding of the phenomenon, in reviewing the literature certain conclusions can be drawn about the limitations of the work to date. Much of the work is non-empirical in nature. Stigma has been used extensively as an organizing concept but in an ad hoc way. For example, the use of stigma to understand epilepsy led to an exaggeration of the psychological impact of stigma and discrimination experienced by epileptic patients (Jacoby, 1994). There was little empirical support for the conclusion vis-à-vis discrimination or the psychological

impact of the disease. The theoretical and conceptual formulations of stigma have outstripped their empirical investigation.

A published meta-analysis on stigma and AIDS (Crawford, 1996) although identifying a database of 105 studies, found only 21 studies suitable for such meta-analysis. Of these 57% were samples drawn from students and 43% were samples drawn from health professionals. Based on these data, the following was found: students had a greater tendency to stigmatize AIDS patients than did the health professionals; there was no relationship between year of publication and the measure of stigma; and AIDS had higher stigma scores than other illnesses (such as cancer).

Although some studies (Fish & Rye, 1991) have shown that sexual orientation and gender of the subject affect stigma, there are insufficient studies available to reach a definitive conclusion. The data suggest that homosexuals with AIDS are more stigmatized than heterosexuals, and women are less likely to stigmatize HIV patients. However, while health professionals had lower stigma scores than students, the literature has documented that stigmatization of HIV patients does occur among this group.

In the psychological research, although many elegant and rigorous designs have been used to investigate predictors of stigma, the samples used (university students, etc.) do not allow for generalization. No attempt has been made to identify groups that might play a significant role in determining nature and process of stigma. By their very nature, these types of psychological studies do not capture the contextual nature of stigma, and are not intended to do so. The artificiality of the instruments (e.g., hypothetical vignettes) for measuring stigma in groups, such as physicians, is problematic. Many commentators have noted that, because a respondent indicates in a hypothetical situation that he perceives an individual in stigmatized terms, it does not mean he will therefore react negatively when confronted by an actual individual. LaPierre's work on hotel and restaurant owners (1934) clearly established the difference between what people say and what they will actually do when confronted by a minority group person. Psychological inquiry has also focused largely on issues related to psychological and interpersonal needs of those who are already victims of the disease (Triplet & Sugarman, 1987).

In the sociological and anthropological research, there has been an abundance of studies with small numbers of subjects (white, gay, young men) who do not represent the full range of HIV patients (Kaplan, 1989). Notable for their absence are the most marginalized groups: drug users and minority group members (particularly African Americans and Hispanics) and gays within these subcultures. The importance of the choice of samples even within the HIV community has been demonstrated in the work of Moulton et al. (1987) who compared self-blame among HIV patients and those of AIDS-related complex (ARC). The results show that these are two distinct groups with regard to the variable of self-blame. The work of Diaz, Chu, and Frederick (1993) on bisexual men was significant in

demonstrating the ethnic cultural differences in bisexual behavior and in behavioral differences between gay and bisexual men with regard to drug use. Although sociological studies have tended to emphasize the natural setting, the studies have usually selected convenience samples. This limits the usefulness of this work in describing the phenomenon of stigma.

Part of the problem of past studies in stigma is that they are unable to capture one of the most significant features of this phenomenon, the use of covert and subtle clues in interactions (Stahly, 1988). It is in non-verbal communication that the victim of stigma is often made aware of his/her status. Even with verbal communication there are important subtleties that can only be identified through close observational techniques. Green and Platt (1997) note that HIV infection differs from some other stigmatized conditions in that those interacting with the infected person, i.e., the health professionals, have access to discrediting information (the patient file). The reaction of the health care workers is potentially very damaging to the patient but this reaction is not well understood.

The research on health professionals illustrates, however, the importance of the situational context. Those who use the most invasive therapies also report the highest level of concerns about HIV patients (Dworkin, Albrecht, & Cooksey, 1991; Weyant, Bennett, Simon, & Palaisa, 1994). Green and Platt (1997) found in their study of HIV patients that stigma was identified as a core variable in interactions with health care providers. Seventy-two percent of specific incidents which dissatisfied the patient were related to stigma of HIV. This included acts indicating fear of contagion (refusing to touch the patient, exaggerated protection procedures, physical isolation of the patient), refusal to treat adequately (canceling non-essential surgery, refusing dental and medical care, trying to transfer the patient to other facilities, not changing bed linen). Importantly, their subjects report that much of this is done subtly although on occasions it could "be overt and brutal" (p. 79). Much of the stigma was experienced by the patients as loathing on the part of the health care providers (treating them with obvious distaste). The patients also reported gross violations of confidentiality. This study reflected that, although the situation had improved, stigmatization by health professionals remained a real concern for the patients. As noted by the authors, such studies fail to reach those patients whose fear of stigmatization prevents them from seeking care or results in their dropping out of care.

Use of individual methods also is problematic in HIV research. Taerk, Salle, Lancee, Coates, and Fanning (1993) in research on health care workers, found that, in group discussions, individuals disavowed the fear of contagion and homophobic attitudes that had been found in pre-discussion surveys. Horsman and Sheeran (1995) note: "There has been an over-reliance on survey methods at the expense of interview-based, observational, or quasi-experimental studies in research to date. This is an area of research where triangulation of research is particularly appropriate" (p. 1562). Crawford (1996), in her meta-analysis, concludes that the "theory-driven investigation of AIDS stigma would facilitate

the identification of important mediating or moderating variables associated with stigma” (p. 411), and that methods other than self-report should be used.

Most current studies do not include behavioral measures nor any contextual analysis; they do not explicate how the patient is made to feel stigmatized in actual encounters and the process by which enacted stigma is experienced. Future research needs to overcome the following: the artificiality of experimental studies by using natural settings; the weaknesses in previous designs by combining quantitative data with qualitative interviews; the problem of sample sizes in qualitative studies; the problem of relying on self-reports by using ethnographic observations of the health encounter; and the inherent assumption of passivity in the face of stigma by accepting a negotiated order perspective. Studies should also include the role of providers and provider institutions in the analysis of the attribution of stigma.

Finally, there is the problem of definition. Link and Phelan (2001), who in their attempt to re-conceptualize stigma, having also surveyed the various ways that the concept has been defined, come to the conclusion that stigma only occurs when several interrelated components converge. For them there must be: labeling, stereotyping, degrees of separation, status loss and discrimination, and these must occur in a situation where power allows the components of stigma to unfold. Without the power, one might get labeling and stereotyping, for example, but not stigma. This re-conceptualization of stigma leads to several significant implications. The first is that stigma is a matter of degree. The second is that the origins of stigma cannot be reduced to cognitive processes. The real question involves whose cognitions count most. Those stigmatized are not passive recipients. Stigma involves numerous outcomes. Discrimination can be individual, structural, and that caused by the stigmatized person’s own beliefs and behaviors. Link and Phelan believe that the process of changing stigma must be multifaceted. Either the deeply held attitudes and beliefs of the powerful must be changed, or we must change the circumstances to limit the power of these groups so that their cognitions are not the dominant ones. Finally, they suggest that stigma must be seen as a significant factor in determining life changes.

CONCLUSION

Western society has had a long tradition of stigmatizing illnesses. However, HIV/AIDS has unleashed what may be termed a psychosocial epidemic of stigma. This is partly the result of the profound social and cultural meanings associated with the epidemic that evoke issues of death, contagion, and morality. This is also heightened by the fact that the epidemic has struck marginalized populations who have already been stigmatized in this culture. While an extensive literature has established the salience of stigma for HIV patients, and has established a widespread negative response among health care workers to these patients, there has been far less research on the role that providers have played in the process of

stigma. The patient's experience with stigma in care giving organizations, or the ways in which treatment facilities intervene in, or contribute to, the process of stigmatization or its amelioration, has also been largely ignored.

This article has suggested that current studies have been unable to capture one of the most significant features of the phenomenon, the way in which stigma intrudes into the health encounter. The article has further suggested that work on stigma needs to be informed by a *negotiated order* perspective. Both of these aspects of stigma are accessible to social science only through ethnography and other qualitative research methods. Through them, researchers who engage in intensive fieldwork within health care settings can more fully understand the interactions that frame stigma and the social and psychological costs to the persons living with it.

The same holds for the analysis of destigmatization processes and the positive reframing of stigmatizing disease in the treatment setting and the wider society. Following Navon (1996), who calls for an "optimistic" approach to destigmatization studies, researchers will need to focus on the ways improvements in treatment serve to transform images of a condition. Analyses of destigmatization must differentiate between commonly held images of a stigmatizing condition and changes in the inherent characteristics of the labeled phenomena brought about by treatment innovations.

The introduction of HAART during 1996-1998 has had profound impacts on the course of HIV disease and public perceptions of the condition and its sufferers (Karon, Fleming, Steketee, & DeCock, 2001). Dramatic changes in the provision of medical care occurred at this time, as treatment options became more complex and much more expensive. With the advent of new drug therapies that increased survival and led to the reframing of HIV as a chronic condition, a process of destigmatization was begun, albeit initially among those with the resources, knowledge, and skills to access state of the art medical care. Early on in the era of HAART, Harris (1999) pointed to two distinct epidemics. The first affects predominately gay white males with education, health insurance, and access to care and resources. For this group, improved overall health and better quality of life came about through increased health encounters with clinical specialists engaged in HIV medication trials, thereby engendering more trust between providers and patients, and a change of view by the general public. The second epidemic affects disadvantaged communities where lack of services, including poor quality education and health care, is just one of many ongoing social concerns, including community violence, substance abuse, low-paying jobs and substandard housing.

The disproportionate effect of the HIV epidemic among more vulnerable groups (women, ethnic minorities, drug users) with less access to care, limited knowledge of their disease and treatment options, and less trust in medical and pharmaceutical innovations, has served to continue many of the stigmatization processes that characterized the early epidemic. Members of these groups are viewed as a

“problem,” and, according to Aggleton, Wood, Malcolm, Parker, and Maluwa (2005), a “stigmatizing social environment” to manage the problem emerges within and beyond their communities, and the resulting institutional arrangements pose barriers across the prevention-to care-to treatment continuum. The impact of HIV-related stigma and discrimination at each point along this continuum, further increases personal suffering, decreases counseling and support, hence limits treatment options and thereby undermines the chances of survival for the more vulnerable individuals. This cycle of stigma poses a challenge to those interested in carrying out an “optimistic” research program to document stigma-reduction, anti-discrimination, and the promotion of human rights for people living with HIV. To move beyond the “pessimistic” stance of many earlier studies of stigmatization, engaged researchers will need to look within the institutional settings that reinforce stigma, but also beyond them to examine the familial and community contexts where the ensuing isolation, depression, and powerlessness that characterize HIV-related stigma and discrimination are “enacted” in everyday life, and where local innovations to reduce these consequences have taken root.

REFERENCES

- Abell, P. (1996). A model of the informal structure (culture) of organizations: Help, trust, rivalry and team spirit. *Rationality and Society*, 8(4), 433-452.
- Ablon, J. (1981). Stigmatized health conditions. *Social Science and Medicine*, 15B, 5-9.
- Aggleton, P., Wood, K., Malcolm, A., Parker, R., & Maluwa, M. (2005). *HIV-related stigma, discrimination and human rights violations: Case studies of successful programs*. Geneva: Joint United Nations Programme on HIV/AIDS (UNAIDS).
- Alonzo, A. A., & Reynolds, N. R. (1995). Stigma, HIV and AIDS: An exploration and elaboration of a stigma trajectory. *Social Science and Medicine*, 41(3), 303-315.
- Armstrong-Esther, C., & Hewitt, W. (1990). The effect of education on nurses' perception of AIDS. *Journal of Advanced Nursing*, 15, 638-674.
- Bales, R. F. (1950). *Interaction process analysis*. Cambridge, MA: Addison-Wesley Press.
- Barrick, B. (1988). The willingness of nursing personnel to care for patients with acquired immune deficiency syndrome. *Journal of Professional Nursing*, 4, 366-371.
- Bennett, L., Mitchie, P., & Kippax, S. (1991). Quantitative analyses of burnout and its associated factors in AIDS nursing. *AIDS Care*, 3, 181-188.
- Bennett, M. J. (1990). Stigmatization: Experiences of persons with acquired immune deficiency syndrome. *Issues in Mental Health Nursing*, 11, 141-154.
- Berkowitz, N. F., & Nuttall, R. L. (1996). Attitudes of pediatric nurses facing HIV risk. *Social Science and Medicine*, 42(3), 463-469.
- Bickelhaupt, E. (1986). Psychological aspects of AIDS. *Kansas Medicine*, 87(3), 66-83.
- Blumenfeld, M., Smith, P. J., Milazzo, J., Seropian, S., & Wormser, G. P. (1987). Survey of attitudes of nurses working with AIDS patients. *General Hospital Psychiatry*, 9, 58-63.
- Blumer, H. (1969). *Symbolic interactionism: Perspective and method*. Englewood Cliffs, NJ: Prentice Hall.
- Borkman, T. (1976). Experiential knowledge: A new concept for the analysis of self-help groups. *Social Service Review*, 50, 445-456.

- Bourdieu, P. (1989). *Outline of a theory of practice*. Cambridge: Cambridge University Press.
- Breault, A., & Polifroni, E. (1992). Caring for people with AIDS: Nurses' attitudes and feelings. *Journal of Advanced Nursing*, 17, 21-25.
- Brefeldt, R., Dardeau, F., Wesley, R., Vaughan-Wrobel, B., & Markland, L. (1991). AIDS: Family physicians' attitudes and experiences. *Journal of Family Practice*, 32, 71.
- Brimlow, D. L., Cook, J. S., & Seaton, R. (Eds.). (2003). *Stigma and HIV/AIDS. A review of the literature*. U.S. Department of Health and Human Services Contract #231-01-0052.
- Cassens, B. (1985). Social consequences of the acquired immunodeficiency syndrome. *Annals of Internal Medicine*, 103(5), 768-771.
- Castro, A., & Farmer, P. (2005). Understanding and addressing AIDS-related stigma: From anthropological theory to clinical practice in Haiti. *American Journal of Public Health*, 95(1), 53-59.
- Cleary, P. D., Fahs, M. C., McMullen, W., Fulop, G., Strain, J., Sacks, H. S., Muller, C., Foley, M., & Stein, E. (1992). Using patient reports to assess hospital treatment of persons with AIDS: A pilot study. *AIDS CARE*, 4(3), 325-332.
- Cohen, M., & Weisman, H. (1986). A biopsychosocial approach to AIDS. *Psychosomatics*, 27(4), 245-249.
- Cohen, L. A., Grace, E. G., & Ward, M. A. (1992). Maryland residents' attitudes toward AIDS and the use of dental services. *Journal of Public Health Dentistry*, 52(2), 81-85.
- Coleman, L. M. (1986). Stigma: An enigma demystified. In S. C. Ainsley, G. Becker, L. M. Coleman (Eds.), *The dilemma of difference: A multidisciplinary view of stigma*. New York: Plenum Press.
- Conrad, P. (1986). The social meaning of AIDS. *Social Policy*, 17, 51-56.
- Coulter, I. D., Hays, R. D., & Danielson, C. D. (1994). The chiropractic satisfaction questionnaire. *Journal of Topics in Clinical Chiropractic*, 1, 40-43.
- Coulter, I. D., Hays, R. D., & Danielson, C. D. (1996). The role of the chiropractor in the changing health care system: From marginal to mainstream. *Research in the Sociology of Health Care*, 13A, 95-117.
- Coulter, I. D., Maida, C., Wellenkamp, J., & Gifford, A. (1997). *The transformation of HIV from epidemic to chronic illness*. Physician responses' presented at the Society for Applied Anthropology, Seattle, March.
- Crandall, C. S., & Coleman, R. (1992). AIDS-related stigmatization and the disruption of social relationships. *Journal of Social and Personal Relationships*, 9, 163-177.
- Crawford, R. (1994). The boundaries of the self and the unhealthy other: Reflections on health culture. *AIDS*, 38(10), 1347-1365.
- Crawford, A. M. (1996). Stigma associated with AIDS: A meta-analysis. *Journal of Applied Social Psychology*, 26, 398-416.
- Crocker, J., Voeikl, K., Testa, M., & Major, B. (1991). Social stigma: The affective consequences of attributional ambiguity. *Journal of Personality and Social Psychology*, 60(2), 218-228.
- Davis, M. (1989). Dentistry and AIDS: An ethical opinion. *Journal of the American Dental Association*, Suppl:9S-11S.
- De Jong, W. (1980). The stigma of obesity: The consequences of naive assumptions concerning the causes of physical deviance. *Journal of Health and Social Behavior*, 21, 75-87.

- Diaz, T., Chu, S. Y., & Frederick, M. (1993). Sociodemographics and HIV risk behaviors of bisexual men with AIDS: Results from a multistate interview project. *AIDS*, 7, 1227-1232.
- Dilley, W., Ochitill, H., Perl, M., & Volberding, P. A. (1985). Findings in psychiatric consultations with patients with acquired immune deficiency syndrome. *American Journal of Psychiatry*, 142(1), 82-85.
- Doherty, J. (1986). AIDS: One psychosocial response. *Quality Review Bulletin*, 112(8), 295-297.
- Dworkin, J., Albrecht, G., & Cooksey, J. (1991). Concern about AIDS among hospital physicians, nurses, and social workers. *Social Science and Medicine*, 33, 239-249.
- Eisenberg, M., & Swanson, N. (1996). Organizational network analysis as a tool for program evaluation. *Evaluation and the Health Professions*, 19(4), 488-506.
- Epstein, S. (1995). The construction of lay expertise: AIDS activism and the forging of credibility in the reform of clinical trials. *Science, Technology & Human Values*, 20(4), 408-437.
- Fife, B. L., & Wright, E. R. (2000). The dimensionality of stigma: A comparison of its impact on the self of persons with HIV/AIDS and cancer. *Journal of Health and Social Behavior*, 41(1), 50-67.
- Finerman, R., & Bennett, L. A. (1995). Guilt blame and shame: Responsibility in health and sickness. *Social Science and Medicine*, 40(1), 1-3.
- Fish, T. A., & Rye, B. J. (1991). Attitudes toward a homosexual or heterosexual with AIDS. *Journal of Applied Social Psychology*, 21, 651-667.
- Fullilove, M. T. (1989). Anxiety and stigmatizing aspects of HIV infection. *Journal of Clinical Psychiatry*, 50(11), 5-8.
- Gerbert, B. (1987). AIDS and infection control in dental practice: Dentists' attitudes, knowledge, and behavior. *Journal of the American Dental Association*, 114, 311-314.
- Gerbert, B. (1989). Patients' attitudes toward dentistry and AIDS. *Journal of the American Dental Association*, Supplement, 16-21.
- Gerbert, B., Maguire, B., Blecker, T., Coates, T. J., & McPhee, S. J. (1991). Primary care physicians and AIDS: Attitudinal and structural barriers to care. *Journal of the American Medical Association*, 266, 2837-2840.
- Gerbert, B., Sumser, J., Chamberlin, K., Greenblatt, R. M., & McMaster, J. R. (1989, November). Dental care experience of HIV-positive patients. *Journal of the American Dental Association*, 119, 601-603.
- Gerhardt, U. E. (1985). Stress and stigma explanations of illness. In U. E. Gerhardt, M. E. J. Wadsworth (Eds.), *Stress and stigma: Explanation and evidence in the sociology of crime and illness*. New York: St. Martin's Press.
- Goffman, E. (1963). *Stigma: Note on the management of spoiled identity*. Englewood Cliffs, NJ: Prentice Hall.
- Goldstein, R. (1990). The implicated and the immune: Cultural response to AIDS. *Milbank Quarterly*, 68(2), 295-319.
- Gorman, E. M. (1986). The AIDS epidemic in San Francisco: Epidemiological and anthropological perspectives. In C. R. Janes (Ed.), *Anthropology and epidemiology*. London: D. Reidel Publishing Company.
- Green, G. (1995). Attitudes towards people with HIV: Are they as stigmatizing as people with HIV perceive them to be? *Social Science and Medicine*, 41(4), 557-568.

- Green, G., & Platt, S. (1997). Fear and loathing in health care settings reported by people with HIV. *Sociology of Health and Illness*, 19(1), 70-92.
- Gussow, Z., & Tracy, G. S. (1968). Status, ideology and adaptation to stigmatized illness: A study of leprosy. *Human Organization*, 27, 316-325.
- Harris, P. (1999). The degaying of AIDS. *A & U AIDS*, 8, 46-49.
- Hays, R. B., McKusick, L., Pollack, L., Hilliard, R., Hoff, C., & Coates, T. J. (1993). Disclosing HIV seropositivity to significant others. *AIDS*, 7(3), 425-431.
- Hayward, R. A., Kravitz, R. L., & Shapiro, M. F. (1991). Program directors' attitudes towards residents' care of persons with AIDS. *Annals of Internal Medicine*, 115(4), 308-314.
- Haywood, R. A., & Shapiro M. F. (1991). A national study of AIDS and residency training: Experiences, concerns, and consequences. *Annals of Internal Medicine*, 114, 23-30.
- Hazelkorn, H. M. (1989). The reaction of dentists to members of groups at risk for AIDS. *Journal of the American Dental Association*, 119, 611.
- Health Sociology Review. (2001). Editorial. Symposium on stigma and health. *Health Sociology Review*, 10(2), 1.
- Herek, G. (1999). AIDS and stigma. *American Behavioral Scientist*, 42(7), 1106-1116.
- Herek, G. M., & Capitanio, J. P. (1993). Public reactions to AIDS in the United States: A second decade of stigma. *American Journal of Public Health*, 83(4), 574-577.
- Herek, G. M., & Capitanio, J. P. (1997). AIDS stigma and contact with persons with AIDS: Effects of direct and vicarious contact. *Journal of Applied Social Psychology*, 27(1), 1-36.
- Herek, G. M., & Capitanio, J. P. (1998). Symbolic prejudice or fear of infection? A functional analysis of AIDS-related stigma among heterosexual adults. *Basic Applied Social Psychology*, 20(3), 230-241.
- Herek, G. M., & Capitanio, J. P. (1999). AIDS stigma and sexual prejudice. *American Behavioral Scientist*, 42(7), 1130-1147.
- Herek, G. M., Capitanio, J. P., & Widaman, K. F. (2002). HIV-related stigma and knowledge in the United States: Prevalence and trends 1991-1999. *American Journal of Public Health*, 92(3), 371-377.
- Herek, G. M., & Glunt, E. K. (1988). An epidemic of stigma: Public reactions to AIDS. *American Psychology*, 43, 886-891.
- Horsman, J. M., & Sheeran, P. (1995). Health care workers and HIV/AIDS: A critical review of the literature. *Social Science and Medicine*, 41(11), 1535-1567.
- Huby, S. (1997). Interpreting silence, documenting experience: An anthropological approach to the study of health service user's experience with HIV/AIDS care in Lothian Scotland. *Social Science and Medicine*, 44(81), 1149-1160.
- Jacoby, A. (1992). Epilepsy and the quality of everyday life: Findings from a study of people with well-controlled epilepsy. *Social Science and Medicine*, 34(6), 657-666.
- Jacoby, A. (1994). Felt versus enacted stigma: A concept revisited. *Social Science and Medicine*, 38(2), 269-274.
- Janes, C. R. (Ed.). (1986). *Anthropology and epidemiology*. London: D. Reidel Publishing Company.
- Kaplan, H. B. (1989). Methodological problems in the study of psychosocial influences on the AIDS process. *Social Science and Medicine*, 29(3), 277-292.

- Karon, J. M., Fleming, P. L., Steketee, R. W., & DeCock, K. M. (2001). HIV in the United States at the turn of the century: An epidemic in transition. *American Journal of Public Health, 91*(7), 1060-1068.
- Katz, A. H. (1993). *Self-help in America: A social movement perspective*, New York: Twayne.
- Kelly, J. A., St. Lawrence, J. S., Smith, S., Hood, H. V., & Cook, D. J. (1987). Stigmatization of AIDS patients by physicians. *American Journal of Public Health, 77*(7), 789-791.
- Kelner, M., Hall, O., & Coulter, I. (1980). *Chiropractors. Do they help?* Toronto: Fitzhenry and Whitesides.
- King, M. B. (1989). Prejudice and AIDS: The views and experiences of people with HIV infection. *AIDS Care, 1*(2), 137-142.
- Kleinman, A., Wang, W.-Z., & Li, S.-C. (1995). The social course of epilepsy: Chronic illness as social experience in interior China. *Social Science and Medicine, 40*(10), 1319-1330.
- Kowalewski, M. R. (1988). Double stigma and boundary maintenance: How gay men deal with AIDS. *Journal of Contemporary Ethnography, 17*(2), 211-228.
- Kunzel, C., & Sadowsky, D. (1991). Comparing dentists' attitudes and knowledge concerning AIDS: Differences and similarities by locale. *Journal of the American Dental Association, 122*, 55-61.
- Kunzel, C., & Sadowsky, D. (1993). Predicting dentists' perceived occupational risk for HIV infection. *Social Science and Medicine, 36*(12), 1579-1586.
- LaPierre, R. T. (1934). Attitudes versus actions. *Social Forces, 13*, 320-327.
- Lawless, S., Kippax, S., & Crawford, J. (1996). Dirty, diseased and undeserving: The positioning of HIV positive women. *Social Science and Medicine, 43*(9), 1371-1377.
- Lester, L., & Beard, B. (1988). Nursing students' attitudes towards AIDS. *Journal of Nursing Education, 27*, 399-408.
- Lewis, C. E., Freeman, H. E., & Corey, C. R. (1987). AIDS-related competence of California's primary care physicians. *American Journal of Public Health, 77*(7), 795-799.
- Link, B. G., & Phelan, J. C. (2001). Conceptualizing stigma. *Annual Review of Sociology, 27*, 363-385.
- Longo, M. B., Spross, J. A., & Locke, A. M. (1990). Identifying major concerns of persons with acquired immunodeficiency syndrome: A replication. *Clinical Nursing Specialist, 4*(1), 21-29.
- Los Angeles Times*. (1997, February 28). p. A1.
- MacDonald, L. D., & Anderson, H. R. (1984). Stigma in patients with rectal cancer: A community study. *Journal of Epidemiology and Community Health, 38*, 284-290.
- Maida, C. A. (2003). Campaign against stigma: Patients and the ongoing therapeutic revolution. *International Journal of Self-Help and Self-Care, 2*:1, 57-83.
- Mariner, W. K. (1995). AIDS phobia, public health warnings, and lawsuits: Detering harm or rewarding ignorance. *American Journal of Public Health, 85*(11), 1562-1568.
- Markova, I., & Wilkie, P. (1987). Representations, concepts and social change: The phenomenon of AIDS. *Journal for the Theory of Social Behaviour, 17*(4), 389-409.
- Mathews, W. C., Book, M. W., Turner, J. D., & Kessler, L. (1986). Physicians' attitudes toward homosexuality: Survey of a Californian medical society. *Western Medical Journal, 44*, 106-110.

- May, E., Murray, K., & Blinkhorn, A. S. (1990). AIDS and human immunodeficiency virus: A preliminary investigation into Edinburgh general dental practitioner views and behaviors. *Health Education Research, 5*, 321-328.
- Moretti, R. J., Ayer, W. A., & Derefinko, A. (1989). Attitudes and practices of dentists regarding HIV patients and infection control. *General Dentistry, 37*, 144.
- Moulton, J. M., Sweet, D. M., Temoshok, L., & Mandel, J. S. (1987). Attributions of blame and responsibility in relation to distress and health behavior change in people with AIDS and AIDS-related complex. *Journal of Applied Social Psychology, 17*(5), 493-506.
- Nashman, H., Hoare, C. H., & Heddeshimer, J. C. (1990). Stress and satisfaction among professionals who care for AIDS patients: An exploratory study. *Hospital Topics, 68*, 22.
- Navon, L. (1996). Beyond constructionism and pessimism: Theoretical implications of leprosy destigmatisation campaigns in Thailand. *Sociology of Health and Illness, 18*(2), 258-276.
- New York Times*. (1996, November 4). p. A26.
- Nicols, S. (1985). Psychological reactions of persons with the acquired immunodeficiency syndrome. *Annals of Internal Medicine, 103*(5), 765-767.
- Nisbet, M., & McQueen, D. (1993). Anti-permissive attitudes to lifestyles associated with AIDS. *Social Science and Medicine, 36*, 893-901.
- Opala, J., & Boillot, F. (1996). Leprosy among the Limba: Illness and healing in the context of world view. *Social Science and Medicine, 42*(1), 3-19.
- Paicheler, G. (1992). Society facing AIDS. *Current Sociology, 40*(3), 11-23.
- Paltiel, A. D., Weinstein, M. S., Kimmel, A. D., Seage, G. R., Losina, E., Zhang, H., Freedberg, K. A., & Walensky, R. P. (2005, February 10). Expanded screening for HIV in the United States—An analysis of cost-effectiveness. *New England Journal of Medicine, 352*, 586-595.
- Parker, R., & Aggleton, P. (2003). HIV and AIDS-related stigma and discrimination: A conceptual framework and implications for action. *Social Science and Medicine, 57*(1), 13-24.
- Perry, S. W., Moffatt, M., & Card, C. (1993). Self disclosure of HIV infection to dentists and physicians. *Journal of the American Dental Association, 124*(9), 51-53.
- Peruga, A., & Celentano, D. D. (1993). Correlates of AIDS knowledge in samples of the general population. *Social Science and Medicine, 36*(4), 509-524.
- Phelan, J. C., Link, B. G., Stueve, A., & Pescosolido, B. A. (2000). Public conceptions of mental illness in 1950 and 1996: What is mental illness and is it to be feared? *Journal of Health and Social Behavior, 41*(2), 188-207.
- Pierret, J. (1992). Coping with AIDS in everyday life. *Current Sociology, 40*(3), 66-84.
- Powell-Cope, G. M., & Brown, M. A. (1992). Going public as an AIDS family caregiver. *Social Science and Medicine, 34*(5), 571-580.
- Pryor, J. B., Reeder, G. D., Vinacco, R., & Kott, T. L. (1989). The instrumental and symbolic functions of attitudes toward persons with AIDS. *Journal of Applied Social Psychology, 377*-404.
- Quam, M. D. (1990). The sick role, stigma, and pollution: The case of AIDS. In D. A. Feldman (Ed.), *Culture and AIDS*. New York: Praeger.
- Reed, P., Wise, T., & Mann, L. (1994). Nurses' attitudes regarding acquired immunodeficiency syndrome (AIDS). *Nursing Forum, 21*, 153-156.

- Reutter, L. I., & Northcott, H. C. (1993). Making risk meaningful: Developing caring relationships with AIDS patients. *Journal of Advanced Nursing, 18*, 1377-1382.
- Roter, D. L. (1977). Patient participation in the patient-provider interaction: The effects of patient question asking on the quality of interaction, satisfaction and compliance. *Health Education Monographs, 5*, 281-315.
- Roter, D. L. (1988). Reciprocity in the medical encounter. In D. S. Gochman (Ed.), *Health behavior. Emerging research perspectives*. New York: Plenum Press.
- Roter, D. L., Hall, J. A., & Katz, N. R. (1988). Patient-physician communication: A descriptive summary of the literature. *Patient Education and Counseling, 12*, 99-119.
- Sandstrom, K. L. (1990). Confronting the deadly disease: The drama of identity construction among gay men with AIDS. *Journal of Contemporary Ethnography, 19*(3), 271-294.
- Saylor, C. (1990). The management of stigma: Redefinition and representation. *Holistic Nursing Practice, 5*(1), 45-53.
- Scambler, G. (1984). Perceiving and coping with stigmatizing illness. In R. Fitzpatrick, J. Hinton, S. Newman, G. Scambler, & J. Thompson (Eds.), *The experience of illness*. New York: Tavistock.
- Scambler, G., & Hopkins, A. (1986). Being epileptic: Coming to terms with stigma. *The Sociology of Health and Illness, 8*, 26-43.
- Scheutz, F. (1990). HIV infection and dental care: Views and experiences among HIV-seropositive patients. *AIDS Care, 2*(1), 37-42.
- Schneider, J. W., & Conrad, P. (1986). In the closet with illness, epilepsy, stigma potential and information control. In P. Conrad & R. Kern (Eds.), *The sociology of health and illness*. New York: St. Martin's Press.
- Shapiro, J. A. (1989). General practitioners' attitudes AIDS and their perceived information needs. *British Medical Journal, 298*, 1563-1566.
- Shapiro, M. F., Hayward, R. A., Guillemot, D., & Jayle, D. (1992). "Residents' experiences in, and attitudes toward, the care of persons with AIDS in Canada, France, and the U.S." *Journal of the American Medical Association, 168*(4), 510-515.
- Siegel, K., & Krauss, B. J. (1991). Living with HIV infection: Adaptive tasks of seropositive gay man. *Journal of Health and Social Behavior, 32*, 17-32.
- Singer, M. (1991). Confronting the AIDS epidemic among IV drug users: Does ethnic culture matter? *AIDS Education and Prevention, 3*(5), 258-283.
- Sleath, B., Svarstad, B., & Roter, D. (1997). Physician vs. patient initiation of psychotropic prescribing in primary care settings: A content analysis of audiotapes. *Social Science and Medicine, 44*(4), 541-548.
- Sontag, S. (1977). *Illness as metaphor*. New York: Farrar Straus Giroux.
- Stahly, G. B. (1988). Psychological aspects of the stigma of cancer: An overview. *Journal of Psychological Oncology, 6*(314), 3-27.
- Stiles, W. (1978). Verbal response-modes and dimensions of interpersonal roles: A method of discourse analysis. *Journal of Personality and Social Psychology, 36*, 693.
- Strauss, A. (1978). *Negotiations: Varieties, processes, contexts, and social order*. San Francisco: Jossey-Bass.
- Svensson, R. (1996). The interplay between doctors and nurses—A negotiated order perspective. *The Sociology of Health and Illness, 18*(3), 379-398.
- Taerk, G., Sallo, R. M., Lancee, W. J., Coates, R. A., & Fanning, M. (1993). Recurrent themes of concerns in groups for health care professionals. *AIDS Care, 5*(2), 215-222.

- Taylor, V., Eakin, J., Skinner, H., Kelner, M., & Shapiro, M. (1990). Physician's perception of personal risk of HIV infection and AIDS through occupational exposure. *Canadian Medical Association Journal, 143*, 493-500.
- Thom, D. H., & Campbell, B. (1997). Patient-physician trust: An exploratory study. *Journal of Family Practice, 44*(2), 169-176.
- Triplet, R. G., & Sugarman, D. B. (1987). Reactions to AIDS victims: Ambiguity breeds contempt. *Personality & Social Psychology Bulletin, 13*(2), 265-274.
- Valdeserri, R. O. (2002). HIV/AIDS stigma: An impediment to public health. *American Journal of Public Health, 92*(3), 341-342.
- Wasserman, R. C., & Inui, T. S. (1983). Systematic analysis of clinician-patient interactions: A critique of recent approaches with suggestions for future research. *Medical Care, 21*(3), 279-293.
- Weitz, R. (1989). Uncertainty and the Lives of Persons with AIDS. *Journal of Health and Social Behavior, 30*, 270-281.
- Weyant, R. J., Bennett, M. E., Simon, M., & Palaisa, S. (1994). Desire to treat HIV-infected patients: Similarities and differences across health care professions. *AIDS, 8*, 117-125.
- Wright, E. R., & Shuff, M. I. (1995). Specifying the integration of mental health and primary health care services with HIV/AIDS: The Indiana Integration of Care Project. *Social Networks, 17*, 319-340.
- Yedidia, M. J., Barr, J. K., & Berry, C. A. (1993). Physicians' attitudes toward AIDS at different career stages: A comparison of internists and surgeons. *Journal of Health and Social Behavior, 34*, 272-384.

Part II: A Case Study

ABSTRACT

New drug therapy and aggressive management have changed both the nature of HIV and quality of care standards. This study examines practicing physicians' beliefs about exemplary care in HIV. They considered specialist involvement in HIV care, continuity of care between providers, and appropriate and timely use of aggressive medical therapy as important components of exemplary care, and saw fragmented care and reduced access to needed surgical consultations as non-exemplary. As they entered the era of Highly Active Antiretroviral Therapy (HAART), the physicians predicted that new drug therapies would transform HIV, from an acute to a chronic illness, but will raise new problems. A fundamental change would occur at the social cognitive level, with HIV being perceived differently and less negatively than it was at the beginning of the epidemic; stereotyping the disease has changed, the devaluing of the HIV patient has declined and the more excessive forms of discrimination have stopped.

INTRODUCTION

The introduction of the antiretroviral therapies has had two major impacts on the HIV epidemic. The first was that it provided those with the virus some element of hope. It transformed a terminal disease into a disease with the possibility of survival. For those with the disease this meant a transformation from preparing for death to learning to cope with a serious chronic illness. Secondly, for providers it offered hope in a therapy that might work, the possibility of managing the disease. Garrett (2001) has noted that for chronic illness, while cure is not possible, healing is, but this is highly related to the concept of hope. To the extent HIV has become a chronic condition, it poses the same challenges as other chronic illnesses for which there existed known and accepted protocols for management.

Within a very short time medicine seemed to shift, viewing HIV as a chronic disease. This was related, in part, to the judging of the quality of care for HIV patients. Bozzette and Asch (1995) suggested that constructing criteria for evaluating the quality of care for HIV can best be regarded as establishing criteria for *either* acute and mostly inpatient care, *or* for chronic outpatient care. Here, broad-based recommendations for care of acute HIV complications are generally not available so that "practical considerations . . . favor a focus on chronic care" (p. S47).

This inquiry was carried out as part of the HIV Cost and Services Utilization Study (HCSUS), conducted from 1996 through 1998 (RAND, 1998, 2000), the first comprehensive U.S. survey of health care use among a nationally representative

sample of HIV persons with a regular source of medical care (Bozzette et al., 1998). Both authors worked on this study (Coulter et al., 2002; Marcus et al., 2005).

The HCSUS consortium involved investigators from a score of institutions and organizations, an active community advisory board, and 13 research teams that focused on the costs associated with HIV care; barriers that affect access to HIV treatment as well as other health care services; the influence of HIV status on quality of life, productivity, and family life; and other related issues (RAND, 1999a, 1999b). Because the study participants were interviewed several times over a three-year period, it was possible to assess the effects of changes in HIV treatment. The HCSUS patient study was funded by the U.S. Department of Health and Human Services. The Robert Wood Johnson Foundation provided resources to study providers and sites of care. As part of the provider study, a “principal HIV physician” survey was administered to all physicians identified by study patients as their main or primary HIV physician (Cleary et al., 1992).

Focus groups were carried out in Boston, Massachusetts, and Los Angeles, California, at the time that the physician survey was being developed, and the results informed the survey design and revision process. This case study is based solely on the providers’ responses from the Los Angeles focus groups that were conducted by the authors. At the time of the focus groups, the physicians were entering the “Era of HAART” (Highly Active Antiretroviral Therapy), thus they were timely in that we could begin to see the impact of HAART on how physicians construct the illness.

Three physician focus groups were conducted in Los Angeles, California, in June 1996. High-potency protease inhibitor antiretroviral medications had recently been approved for general use and were widely incorporated into HIV providers’ practices. One group of eight infectious disease (ID) physicians, and a second group of ten general internal medicine physicians (GIM) were assembled from the staff of a large Veterans’ Administration Hospital. A third focus group of eight community-based physicians with substantial HIV care responsibilities (CB physicians) was also conducted. Of the eight community physicians who participated, five were infectious disease specialists; the other three specialized in general internal medicine, dermatology, and digestive diseases. A standard set of probes was used for all focus groups, to stimulate discussion by the participants.

It is important to note that the physicians were not asked directly about stigmatization or whether HIV had changed from an epidemic to a chronic illness. The topic was approached indirectly by asking the respondents to focus on exemplary and nonexemplary care. We wished to find out from their own narratives, without any prompts from the research team, whether this change in their thinking had already occurred.

All focus groups were facilitated by a medical sociologist (Ian Coulter—IC), and observed by a medical anthropologist (Carl Maida—CM) and a physician, and were tape-recorded. The audio recordings of the discussions and field

observation notes by the medical anthropologist form the basis of this report. All quotations cited in the text are those of the focus group participants. Analyses to identify the major themes of the focus group's discussions were conducted by the two social scientists separately, and reviewed jointly, and by the physician for completeness and accuracy.

MANAGED CARE COMMUNITY-BASED PHYSICIANS

Exemplary Care Organization

While some of the physicians described specific incidents of “exemplary” care, most discussed general factors that in their view promote good outcomes. “Team” approach, continuous treatment, supporting sub-structure were emphasized, but patient access to providers was a “big pan” of exemplary care—patients should be encouraged to contact staff so that patients “are in control of things as much as possible.” Exemplary care results in as little disruption to a patient’s life as possible, and not in care that drains the person’s financial resources. Exemplary care “has expectations of management, including the relief of anxiety, a good contract, and an excellent communication system.” Good lab support is also needed, along with compassionate staff members who are sensitive to alternative lifestyles. According to the physicians, many of the patients “are scared, many are from the inner city, are uneducated, and need hand-holding.” Compliant patients are a necessity.

Organizational Barriers and Non-Exemplary Care

Examples of “non-exemplary” care and barriers to care included: having to wait three to four weeks for a committee to decide whether or not to give approval for a test or a shift to different medication. Physicians should be able to say, “This is what the patient needs.” Other barriers to care (or solutions to these) included supporting the idea that this is “not a disease you can handle by committee” and confronting a system that is not flexible enough to accommodate individual patient’s needs. Additionally, dealing with the rationing of care at a county hospital, dealing with stigmatization by other providers, lack of consensus among different providers, difficulty of working as a specialist consultant need to be addressed.

Managed Care vs. Other Organizations of Care

When asked to comment on the quality of treatment for HIV patients in managed care settings, it was common to note the delays in getting authorization, which can seriously affect patient care. In one instance, the physician spent three to four days waiting for a response and talked to “seven different providers asking me questions.” The physicians identified the need to “work the system” and how this has become a necessary evil and has redefined their role as doctors.

Another physician said that he had two patients with the same problem: the patient who belonged to an HMO waited six weeks and lost 40 pounds before getting authorization for one month's worth of medication; the second patient had Medicare with Medi-Cal and was given meds right away. Other difficulties include the small number of consultants to choose from; one "needs a team that functions (well)" and the requirement that certain labs are used where the "turnaround time is usually not as good." In addition, "not a day goes by" without a physician reviewer asking what is going on.

One physician suggested that after providers have been at an organization for a while, problems that were at first very obvious to them are perceived as less so. According to the physician, the system hadn't changed, *he* had: "I shut off the alarm for things I can't change." Managed care was thought to be generally much more "cost responsive" than was the county system. The county health care system and the VA are "an entirely separate culture" from managed care. When asked to comment on the importance of financial constraints in the treatment of HIV in a managed care setting, one physician related that a meeting was held at a local medical center to discuss the fact that too much money was being spent on Total Parenteral Nutrition (TPN), or intravenous complete nutrition (containing fats and protein), rather than the usual intravenous solution (containing glucose), to HIV patients who cannot eat normally. A decision was made to try to stop this, and "two patients simply didn't get (the TPN)." The physician believes that the decision was made beforehand by someone who is not an HIV specialist, and was based on cost, not on considerations of appropriate care.

Another problem is that the frequency of changes in HIV care means that guidelines, protocols, and restrictions are always "a step behind," while patients and their advocates have up-to-date information. This "raises the issue of what is research and what is up-to-date care" and with HIV, there is a "really narrow boundary" between the two. HIV patients are seen as a disenfranchised group (more so than mothers with breast cancer), and thus, are not able to put pressure on the system. However, when asked whether care provided to HIV patients was worse in managed care settings, compared to fee-for-service, physicians said "No." One said, "everyone is managed these days."

Physician Characteristics

Physician experience in diagnosing an opportunistic infection was considered important, as was generalists' faith that specialists will not "drive up the bills" with unnecessary tests. The importance was confirmed for clinical trials that focused upon how best to use subspecialties in the care of HIV patients. The results from such trials save "months of deteriorating quality of life." Several physicians seemed to feel that specialists who provide exemplary care to HIV patients are functioning as "primary care" providers.

Patient Characteristics

According to the physicians, patients who are educable and able to identify problems and communicate them to their providers make a clinician's job easier. One physician described a case where a patient's access to services was affected. The case involved a patient who was "extraordinarily compliant" and "extraordinarily reliable," keeping appointments and following regimens. As a consequence of this, he—and later his lover, on his behalf—were able to "prod the system" and thus, obtain a visit with a specialist in a few days instead of two weeks. The "educated and educable patient" is "one who is able to 'spy' problems, to show up and to engage in a dialogue of science, myth, and hearsay, especially about alternative medicine." Being a good provider involves having empathy and understanding for one's patients; being available to them and rapidly responding to their perceived needs are important components of quality care.

Several of the physicians seemed to take a relativistic, case-by-case approach to defining "exemplary" care or a "good outcome," with one's treatment goal varying depending on the patient's desires and needs. The provider should give patients enjoyment, health, life, or "whatever that individual needs on an individual basis." The "bottom line" is that care is rendered to a patient who then gets some survival benefit and quality of life; whatever it takes to accomplish that is "exemplary care."

Exemplary care also depended on whether or not the patients' expectations were met, their anxiety was relieved, and they felt they were better now than they were two years ago. While a "good outcome" does refer to quality of life, it also is defined, in part, by provider restraint regarding the over utilization of services.

Views about Future Prospects for HIV/AIDS Treatment

At the time of focus groups, the group felt very positive about recent advances in the treatment of HIV/AIDS. The optimism was expressed by such statements as: "There have been quite dramatic improvements," "This is the best time to have HIV," "We are in the 'summer' of the protease inhibitors," and "It's an exciting time in the treatment of HIV." The physicians were much less sanguine, however, about the delivery of care to HIV patients; the situation was "terrible," and many patients do not have access to recent treatments.

Summary

Table 1 (column 1) provides a summary of the major findings from the managed care providers. For this group, exemplary care requires organization, formal or informal; experience on the part of the provider; assertiveness on the part of the patients; and the availability, integration, and coordination of a wide range of services and specialists. Providers see the care as requiring both generalists and specialists but also that in treating HIV the latter must act more like the former. On

Table 1. Physician Perspectives Regarding the Elements of Quality Care for HIV Patients

Community-based providers	Infectious disease specialists	General internal medicine
Characteristics of Exemplary Care Organization		
Coordinated	Coordination	Continuity
Continuous	Specialized clinic	Specialized clinic
Case management	Integration	Access to specialists
Easy access	Comprehensive	Stopping infections
Medications	Quick diagnosis	Timely screening
Laboratories	Aggressive therapy	Aggressive therapy
Supporting services	Wide range of services	Supportive services
	Computerized records	Prophylaxis
	Experimental drugs	Social/spiritual care
	Follow-up	Psychological care
	Resource allocation	Prolonging life
		Providing a good death
Physician Characteristics		
HIV experience	HIV experience	HIV experience
Informal networks	Training	Training
Generalists and specialist	Interest in HIV	Diagnostic skills
Good communicator	Involvement of ID	Involvement of ID

the negative side they see that making decisions in managed care based on economics (demanding physician reviews, administrative delays, formularies that do not include the latest drugs, etc.) are a major barrier to care. The existence of stigma, the disenfranchisement of many of the patients, and lack of education and assertiveness are also thought to contribute to less than exemplary care.

INFECTIOUS DISEASE, VA-BASED PHYSICIANS

Exemplary Care Organization

Institutional access to a wide range of medical services through the VA was considered crucial. A good record-keeping system that allows physicians greater

access to patient records over several years' time was an element stressed by this group. This allowed a greater degree of follow-up than with other patients, including other infectious disease patients, e.g., tuberculosis patients. The respondents also felt that a separate clinic for treating HIV patients allowed for a better relationship between the patient and the provider. This made possible continuity in care. While other patients may be admitted to the hospital "without us knowing," whenever an HIV infected patient is admitted or uses the emergency room, the Infectious Disease (ID) physicians are informed. The special clinic has taken the lead in establishing continuity of care, which is especially important since "some things might be missed by other staff."

Comprehensiveness of patient care was considered crucial and the ideal. During the early stages of HIV infection, an internist or family practitioner could function adequately as a provider for a patient and might be in a better position to address the non-medical ("social," e.g., case management) needs of the patient.

Organizational Barriers and Non-Exemplary Care

According to some, the need for greater financial resources affects the speed with which providers are able to obtain test results and consults from other providers. While it is possible to obtain services for patients, it may take a lot of personal energy for the doctor and the staff to do so; a case for the patient's need is required. A patient with acute need might be seen on the same day, while for someone who merits an outpatient MRI scan, "good luck in accessing it on a timely basis."

The institution's decreased participation in large, clinical trials has resulted in decreased access to experimental therapies. The VA does not have access to "cutting edge experimental therapy." Unlike outpatient services, the quality of care provided to hospitalized HIV patients "varies" due among other factors, to the high workload and lower level of motivation of the staff. The staff has a more "nihilistic" view of what can or should be done for HIV patients.

The ID providers also play a more limited role in the provision of care to hospitalized patients. The ID staff is "important," but they do not have the final say regarding in-patient care, e.g., diagnostic procedures. House staff treatment, without adequate supervision/consultation by an ID specialist is a problem, as is assistance from colleagues in other specialties. Colleagues from whom providers receive assistance in treating HIV/AIDS include oncologists, dermatologists, psychiatrists, pulmonary specialists, surgeons, neurologists, ear/nose/throat specialists, and ophthalmologists.

The VA vs. Other Organizations of Care

The care provided to HIV patients was thought to be better than that provided to other patients. When asked to compare the VA with other facilities having different organizational structures, the physicians thought the HIV clinic was

much more “organized” than a county facility but that there was not much difference between the two in terms of the coordination of effective care; the county facility does not have continuity of care.

Now that protease inhibitors/viral load measures are being proven effective, the VA is generating guidelines in these areas, as well as for antiretroviral treatment and prophylaxis. This contrasts with 1991, about five years before these focus groups were convened, when the VA Central Office provided a “broad and bland” set of recommendations for HIV care. There have also been frequent meetings to rework the guidelines, and address variability in treatment among attending physicians. Non-VA guidelines have been slightly modified for purposes of the ID clinic.

Physician Characteristics

Physician characteristics were thought to be of particular importance, especially the expertise of the infectious disease physicians to notice subtle changes, pursue appropriate laboratory work, and thus make accurate and timely diagnoses of disorders that may have eluded those with less skill and experience. It was felt that most of the complications of HIV infection are infectious diseases, and thus ID physicians are at an advantage when treating these patients, particularly after the early stages of infection.

Likewise, as most complications of HIV are infectious diseases, knowledge of infectious disease pathogenesis and treatment strategies is crucial; providers must also keep current with the HIV literature. Provider training, an interest in treating HIV, experience in seeing many patients (especially advanced cases) were felt to be major components of good care. In the hospital setting, the stigma of the patients was felt to be a “remarkably minor issue,” in part because of a separate clinic for HIV patients. There was no “overt” stigmatization, but some house staff might make decisions about the allocation of care to HIV patients, especially if the patient is in the advanced stages of illness.

Patient Characteristics

In terms of patient characteristics it was felt that a cooperative patient was essential for successful management of HIV. Patient characteristics were thought to be an important barrier to care. It is difficult working with patients who “strike out on their own” by, for example, obtaining drugs in Mexico and seeing other doctors without the physician’s knowledge. According to the providers, the fact that more treatment drugs have become available recently has “calmed them down” and patients are more willing to go to a better doctor and “stick” with them. Drug users were more difficult to manage in terms of preventative practices; the lower socioeconomic and educational levels of some patients sometimes lead to lack of compliance. For some patients, living situations are so precarious that it is

an imposition to conduct another diagnostic test or prescribe another medication. They seem to be looking for “simpler” therapy.

Views about Future Prospects for HIV/AIDS Treatment

A majority of the physicians said that they were optimistic about future treatment possibilities. However, despite encouraging short-term prospects of the new treatments, HIV is still a frustrating disease; the benefits have a better impact but have not made a huge advance in the field. The optimism is about an eventual discovery that will “turn things around” and about the natural history of disease approach inherent in the rationale for triple therapy, based upon David Ho’s physician-instigated investigation of the replicatory cycle of the virus within a patient, coupled with laboratory work (Ho et al., 1995). This work was viewed as “a turning point.” There was also optimism about prolonged survival and cure. The breakthroughs in the development of more potent anti-retroviral agents, demonstrated experimentally and clinically, will take about 10 years before the effects of these advances are seen.

Summary

Table 1 (column 2) provides a summary of the major findings obtained from the ID providers. The examples given of “exemplary” and “less-than-exemplary” care suggest that in the view of the infectious disease specialists “quality” care involves: expertise; quick and accurate diagnosis; rapid initiation of treatment; access to expensive treatment drugs and to new, experimental therapies; aggressive therapy; a wide range of medical services; coordination and integration of medical care; computerized record keeping; follow-up care; good patient/provider rapport; continuity of care; and a “comprehensive” approach that includes attention to the patient’s living situation and non-medical needs. The examples provided by the infectious disease physicians tended to emphasize the more “technical” aspects of care, such as accurate and timely diagnosis and rapid initiation of treatment.

GENERAL INTERNAL MEDICINE, VA-BASED PHYSICIANS

Exemplary Care Organization

The examples provided of “exemplary” care suggest that, in the view of the general internal physicians, quality care involves minimizing the occurrence of opportunistic infections by providing appropriate prophylaxis, timely screenings, and mental health support; combining excellent technical care with supportive care from house staff; having good support from peripheral health care professionals such as dietitians and psychiatrists; good diagnostic abilities on the part of the physician; and having a center for HIV care.

Many examples of exemplary care provided by the physicians focused on the interpersonal components, i.e., the provider-patient relationship, and the psychological and spiritual needs of the patients. One physician related a case involving a “difficult” patient with “many psychological manifestations” who was nevertheless treated well by providers. Each time the patient came in, however, he did not stay to complete his treatment. A priest then talked to the patient, whereupon the patient became fully compliant and has remained so up until now (two years later). One physician felt that a psychiatrist should follow every patient’s case, even the ones not exhibiting overt symptoms of depression; he believes every HIV patient experiences depression. Whoever is the main provider for a patient must maintain a professional attitude of compassion toward the patient, and not, for instance, decide to not assist the patient because “the guy will be dead in a week anyway.”

Another example of exemplary care provided by the group-involved providers helping their patients to die a “good” death.

Organizational Barriers and Non-Exemplary Care

HIV patients may be “bumped off the schedule” for a needed invasive procedure. Nurses, cardiologists, surgeons, and others can be reluctant to treat HIV patients, for fear of becoming infected and because they feel “it’s not an investment in the future.” One physician noted that, before he came to the VA, he would hear HIV referred to as a terminal disease. While the physician has seen a few HIV patients die since coming to the VA, many more patients suffering from other disorders have died.

Although there is an attending physician assigned to each patient in the HIV clinic, different residents and fellows treat any given hospital patient on a discontinuous basis. In HIV there is need for building a relationship between a patient and one particular provider. Providers’ fears about HIV are often experience-related, often based either intuitively, or subconsciously in the worst case. However, because HIV patients are living longer, this changes one’s perception of the disease and the patient.

At the VA, HIV testing is only available through the HIV nurse (requiring patients to register themselves). While hospital protocols aim to centralize post-test counseling, patients often do not now receive adequate counseling. Patients should be able to go to a lab to have blood drawn, and then register with the HIV nurse. Moreover, a patient’s designated primary care provider should be allowed to perform the HIV test.

The VA vs. Other Organizations of Care

Physicians felt that VA HIV patients are getting better care than they might receive relative to non-VA patients of similar socioeconomic status. In fact, HIV patients get better care than other patients, sometimes as good as the private

sector, and certainly up to community standards. The VA is very aggressive in caring for acute medical problems of HIV patients. For example, it is easier to get a CT head scan for HIV patients, and easier to get new medications approved for HIV patients. There is a multidisciplinary approach, including good guidelines for screening, and attention to psychosocial issues through immediate referrals. When HIV patients are admitted, the ID Consultation Service is routinely alerted.

The existence of the HIV clinic, operated by the ID service, assures state of the art care with respect to therapies, continuity, support, and knowledgeable nurses; a separate HIV in-patient ward has closed because of a significant decline in admissions. The internal medicine physicians stated that the VA is attuned to the problems of HIV patients, and staff is constantly made aware of these patients' special needs. Providers reference work and social issues when dealing with a HIV patient within the VA. HIV patients tend not to be stigmatized at this institution; patients discuss their status in the lobby. The hospital's HIV clinic is a protected environment for providing "private time" between a patient and a physician, and thus is not a "forum for public acceptance."

Physician Characteristics

This group of physicians also stressed the importance of provider training, seeing it as paramount. For an internist to provide good care for HIV patients, ongoing exposure to HIV cases is required. The physician's utilization of HIV-related resources is related to knowledge of, and identification with, community resources, especially psychotherapy, self-help, and self-care. "HIV is a proactive disease, we have to know what to look for." There are limitations in medical training to providing practitioners with ways to deal with the emotional aspects of the disease.

The internal medical physicians saw the ID specialists as primary care providers for HIV patients' at the VA and in Los Angeles. In other places there are groups of internists who are specializing in HIV; all are experience-based. They felt that the ID service is the appropriate place to focus on the problems of HIV, because ID specialists know the HIV patient better than others, they are technically more sophisticated, and they keep current with the literature. Moreover, internists believed that the ID specialists feel the responsibility for treating HIV, and therefore have a greater commitment to HIV patient care: "HIV is the climax of ID." The general internists feel better when experts view their work with HIV patients. Thus, GIM have great expectations for the ID service. Other colleagues found especially helpful and most frequently consulted include those in dermatology, hematology, oncology, psychiatry, social work, nutrition, and pharmacy.

Patient Characteristics

HIV patients with relatively advanced illness and for whom little can be done in terms of technical care, and who are seen as "not the greatest personality" can

find themselves in a room that is physically remote from the provider and will be “left out.” The provider will have little interaction with the patient. If there is a systematic exemplar of bad care, it is the providers not giving patients the “same type of care we’d want to receive.”

Views About Future Prospects for HIV/AIDS Treatment

This group of physicians displayed guarded optimism about the future. They were optimistic about the drugs on the market that work exponentially better than those offered previously. “In the next 5-10 years, AIDS will be a disease like diabetes.” However, they expressed a concern for the human factor in AIDS: “as we make it better—like diabetes—people are not going to worry about it.”

They were also optimistic about prolonged survival and quality of life. Any pessimism centered on the increased prevalence among adolescents and drug abusers; a cautious optimism about the ability to fight the virus was due to a healthy respect for the virus and the way it mutates. There was a belief that anti-retroviral drugs will “fall by the wayside” and a concern that an emergent infectious disease, such as multi-drug resistant TB, could be a significant problem for both the HIV and non-HIV-infected patient. The physicians were also pessimistic in that the virus is spreading quickly into the Third World: “We are not living by ourselves.”

Summary

Table 1 (column 3) summarizes the general internal physicians’ attitudes. They stressed the importance of specialty care within a specialty clinic in infectious diseases; supportive care; continuity of care; aggressive therapy; a compassionate attitude of the providers; and experienced providers. Many of the examples of exemplary care provided by these physicians focused on the interpersonal components of care, i.e., the provider-patient relationship, and the psychological and spiritual needs of the patients.

DISCUSSION

Providing medical care to persons with chronic conditions requires a range of clinical and non-medical services. High quality care is defined as appropriate general and specialty physician and nursing care. Furthermore, it is extremely important that such care be coordinated to maximize the potential benefit of different providers. The care of persons living with HIV also exemplifies the difficulty of providing care for persons with complex medical conditions. Such persons need extensive primary care yet also require very specialized care at different points in their illness. Furthermore, in order to meet the needs of patients, a wide range of non-medical services is required. To that extent, care of HIV patients might provide an important model of care for other chronic conditions.

It is possible to compare characteristics of exemplary and non-exemplary care, between HIV and other chronic illness. Wagner, Austin, and Von Korff (1996) have found that successful intervention programs for chronic illness shared common characteristics, noting that wide variation occurs from the available standards in the medical care of patients with chronic illness. Surveys have documented repeated failures to comply with guidelines for such conditions as hypertension, diabetes, frailty in the elderly, and asthma. While this is due, in part to deficient training . . .

. . . a more critical factor derives from the culture and structure of medical practice, which limits caregivers' ability to meet the clinical and self-management needs of chronically ill patients. Medical practices, especially those in primary care, are generally organized to respond to acute and urgent needs of their patients. The emphasis is on diagnosis, ruling out serious disease, and curative or symptom-relieving treatments.

This may lead to a failure by primary care providers to differentiate their approaches to patients with acute or chronic illnesses. Wagner et al. (1996) conclude that high quality programs for chronic care contain the following elements: 1) use of explicit plans and protocols; 2) reorganization of the practice to meet the needs of patients who require more time, a broad array of resources, and follow-up; 3) systematic attention to the information and behavioral change needs of the patient; 4) ready access to expertise; and 5) supportive information systems.

Use of guidelines moves the focus away from thinking of cases as unique and idiosyncratic with highly individualized care, but guidelines by themselves have been shown to have little impact on care. Reorganizing practices involves determining responsibility for the care and allocating tasks to the team involved. Specialized programs give ready access to specialists and other resources such as pharmacists, nutritionists, and social workers. There is strong evidence to show that those providers who are more knowledgeable, and who have the most experience with chronic illness, tend to have better outcomes, and adopt new approaches more readily. However, the debate over whether chronic care should be provided by a primary care physician or by a specialist has not been settled. Wagner et al. (1996) note that a key element of a successful program is the delegation of tasks, especially to non-physicians.

Comparing these characteristics of chronic care to the data in Table 1, it is remarkable that what the physicians in this study describe as exemplary care for HIV closely resembles what Wagner et al. (1996) describe as the elements of successful interventions for chronic illness. Guidelines have emerged for the care of HIV patients. The care is multi-disciplined, combines specialists and generalists and an array of non-physician providers. Specific clinics have emerged to provide focused, integrated, comprehensive and coordinated services and case management has emerged as a key component of care. There are in place supportive information systems, at least within the VA. Although much of HIV care,

particularly in the earlier stages, is focused on diagnosis and aggressive intervention, as the illness progresses attention is paid to its mental and social aspects. There is considerable support for the thesis therefore that, increasingly, physicians came to view HIV as a chronic illness with the attendant challenges posed by this status. In this study, where the focus was not explicitly on HIV as a chronic disease, the data reveal indirectly the extent to which (what physicians describe as) exemplary care for HIV resembles that standard held to be the one for managing chronic illness.

One of the arguments put forward—for viewing HIV as a chronic disease—has to do with judging the quality of the care. Bozzette and Asch (1995) have suggested that constructing criteria for evaluating the quality of care for HIV disease can best be viewed as establishing criteria for *either* acute and mostly inpatient care, *or* for chronic outpatient care. For them, broad-based recommendations for care of acute HIV-complications are generally not available; “practical considerations . . . favor a focus on chronic care” (p. S47).

Available data sources are more suited to the assessment of the quality of chronic care. Great detail or precision is not necessary in assessing most outpatient interventions, and data sufficient to judge the adequacy of chronic treatment may be generally found in routine office charts, pharmacy records, and billing records. Many criteria, such as those regarding drug therapy or the performance of a procedure, might be assessed from computerized records with no chart abstraction whatever. In contrast, meaningful assessment of acute care requires detailed information, such as the exact time and rate of a drug infusion that is either unavailable or very expensive to obtain (p. S47).

By viewing HIV as a chronic illness, we may utilize the existing experience, and research on managing chronic illness as well as the standards for evaluating the quality of chronic care. Although unlikely to remove the stigma of HIV entirely, seeing the complex illness as a chronic condition may help reduce this stigma. The challenges facing HIV care will remain the same as they are for all chronic care; while our society does know how to manage it, it cannot be said that we have done so very well.

Transforming the HIV epidemic to a chronic illness is not without consequences; the sense of urgency that accompanies epidemics might be lessened. The latter are generally viewed as crises demanding attention and commanding the allocation of resources; often-heroic intervention measures are mandated by the state.

On the individual level, HIV might come to be perceived as less threatening which, in turn, may undermine preventive efforts to control the epidemic. It is therefore timely to examine whether seeing HIV as a chronic condition is the most appropriate way to view the illness and to ponder the consequences of such a view.

The shift, from seeing HIV as an epidemic and fatal illness, to seeing it as an epidemic and chronic illness, has opened the possibility of reducing the stigma

attached to HIV. While chronic illnesses may have some attached stigma, this is generally considerably less than either the amount of stigma or the strength of the stigma experienced by HIV sufferers. Nothing on this scale of burning persons' homes, exclusion from schools for children, cancellation of health insurance, and widespread refusal by some providers to treat HIV patients has been inflicted on those with chronic illness.

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REFERENCES

- Bozzette, S. A., & Asch, S. (1995). Developing quality review criteria from standards of care for HIV disease: A framework. *Journal of Acquired Immune Deficiency Syndromes and Human Retrovirology*, 8(Suppl 1), S45-S52.
- Bozzette, S. A., Berry, S. H., Duan, N., Frankel, M. R., Leibowitz, A. A., Lefkowitz, D., Emmons, C. A., Senterfitt, J. W., Berk, M. L., Morton, S. C., & Shapiro, M. F. (1998). The care of HIV-infected adults in the United States. *New England Journal of Medicine*, 339(26), 1897-1904.
- Cleary, P. D., Fahs, M. C., McMullen, W., Fulop, G., Strain, J., Sacks, H. S., Muller, C., Foley, M., & Stein, E. (1992). Using patient reports to assess hospital treatment of persons with AIDS: A pilot study. *AIDS Care*, 4(3), 325-332.
- Coulter, I. D., Heslin, K., Marcus, M., Hays, R., Freed, J. R., Der-Martirosian, C., Guzmán-Becerra, N., Cunningham, W., Andersen, R. M., & Shapiro, M. F. (2002). Associations of self-reported oral health with physical and mental health in a nationally representative sample of HIV persons receiving medical care. *Quality of Life Research*, 11, 57-70.
- Garrett, C. (2001). Sources of hope in chronic illness. *Health Services Research*, 10(2), 1-7.
- Ho, D. D., Neumann, A. U., Perelson, A. S., Chen, W., Leonard, J. M., & Markowitz, M. (1995). Rapid turnover of plasma virions and CD4 lymphocytes in HIV-1 infection. *Nature*, 373, 123-126.
- Marcus, M., Maida, C. A., Freed, J. R., Der-Martirosian, C., Liu, H., Freed, B. A., Coulter, I. D., Guzmán-Becerra, N., & Andersen, R. M. (2005). A longitudinal analysis of unmet need for oral treatment in a national sample of medical HIV patients. *American Journal of Public Health*, 95(1), 73-75.
- RAND Health Program. HIV Cost and Services Utilization Study (HCSUS): Provider survey. Santa Monica, CA: RAND. Fielded nationally in 1998 to 571 clinicians. <http://www.rand.org/health/projects/hcsus/index.html>
- RAND Health Program. (2000). Access to HIV care: Initial results from the HIV Cost and Services Utilization Study. Santa Monica, CA: RAND, RB-4530. www.rand.org/publications/RB/RB4530

- RAND Health Program. (1999a). Caring for HIV patients. Santa Monica, CA: RAND, RB-4525. www.rand.org/publications/RB/RB4525
- RAND Health Program. (1999b). A portrait of the HIV+ population in America: Initial results from the HIV Cost and Services Utilization Study. Santa Monica, CA: RAND, RB-4523. www.rand.org/publications/RB/RB4523
- Wagner, E. H., Austin, B. T., & Von Korff, M. (1996). Organizing care for patients with chronic illness. *Milbank Quarterly*, 74(4), 511-544.

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