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The Persistence of Stigma Linked with HIV/AIDS in Health-Care Contexts: A Chronic Social Incapacity

Oscar Labra and Daniel Thomas

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Abstract

The article presents an analysis of the stigmatization of people living with HIV/AIDS (PLHIV/AIDS) within health-care contexts. An overview of the short history of HIV/AIDS and of relevant literature reveals the extent and persistence of the stigmatization of PLHIV/AIDS through a variety of practices and attitudes among health personnel; various public policies have, however, produced a number of measures aimed at alleviating the stigma. The article proposes elements of analysis through which to examine stigma as it is present within the implementation of HIV/AIDS care: knowledge about nature and forms of stigmatization and consequences of practices on health services for PLHIV/AIDS.

Keywords: AIDS/HIV, PLHIV/AIDS, Stigma, Discrimination, health care, medical policy

1. Introduction

Stigma associated with various aspects of HIV/AIDS represents an important challenge for those attempting to mitigate the effects of the pandemic. As a social representation of collective fears surrounding HIV/AIDS and judgment of certain behaviors, this stigma forms a barrier that hinders access to health care and social services for many people living with HIV (PLHIV)/AIDS around the world. Indeed, "the history of illness – and epidemics in particular – is not solely one of viral spread and medical response: it is also a history of suspicion towards [PLHIV/AIDS], avoidance and exclusion" [1]. The relationship between health personnel and PLHIV-AIDS began to change after the outbreak of the pandemic, as has been noted also with reference to cancer and tuberculosis. Several studies [2, 3] have shown that caregiver-patient

relationships are significantly affected by social representations of the pandemic. Since the emergence of the pandemic, a significant proportion of the literature has studied the experience of stigma in such contexts as education [4], the family [5, 6], and health care [7–11]. Access to care for PLHIV/AIDS has been affected by discriminatory attitudes toward such dimensions as sexual practices, sexually transmitted infections, homosexuality, prostitution, and the use of hard drugs; indeed, HIV/AIDS was at one time known as the 4H disease (i.e., affecting heroin users, homosexuals, Haitians, and hemophiliacs) [12]. The scope of the pandemic, the medical challenges it presents, and the upheaval it causes in the lives of the infected are all factors contributing to set sufferers apart as a distinct social category. Thus, just as has been noted for handicapped individuals [13], cancer sufferers [14], and tuberculosis victims [15], a particular social significance is associated with PLHIV/AIDS.

It is essential to note that three major stages in the emergence of HIV-AIDS in the public consciousness during the 1980s were determinant for the development of negative (and potentially stigmatizing) significations. The first stage was that of an emerging crisis, approximately covering the years 1981–1982. This stage was characterized by growing fears within the male homosexual population, in particular in New York, Los Angeles, and San Francisco, where that population was especially sizeable, but also among Haitian communities in the United States, as well as heroin addicts and hemophiliacs [16]. In the three metropolitan areas mentioned, physicians at the time noted that the infection seemed to affect previously healthy men who had a known history of homosexuality. At the same time, exploratory medical research began attempts to define the epidemiological characteristics and implications of the new phenomenon. The mass media for its part reported on the disease under headlines such as "Mysterious new ill infects homosexual men and drug addicts" and "The gay plague" [17] as well as referring to the acronym GRID (gay-related immune disease) [12]. The terminology used to describe the symptoms underwent several permutations, notably including "the gay cancer," before the acronym AIDS was more widely adopted in 1982.

The second stage, covering the period 1982–1985, was that of moral panic. The marginality of those affected by the disease and its identification as a "gay plague" were major factors shaping social representations during this period. Characterized by the rapid escalation of alarmist reporting in the media and a growing hysteria surrounding AIDS in the broader population, this stage also coincided with the rise to prominence in the US of the New Right and Moral Majority movements as conservative social forces, whose discourses notably linked AIDS with notions of moral decline and divine judgment.

The third stage, which unfolded during the period 1985–1989, may be termed the management crisis stage, which resulted from a congruence of factors, of which the most publicized was the infection and death of actor Rock Hudson, which had a dramatic impact on the public at large. Overall, this period saw the deepening of the AIDS health-care crisis, as HIV infection, the scope of the spread of AIDS, and its costs for society became more widely understood.

By the 1990s, researchers noted that in the first years of the emergence of HIV/AIDS, health care had been characterized by conspicuous stigmatization and high levels of fear in relation to providing care to PLHIV/AIDS [18–23]. Stigma-inducing behaviors thus appeared very early in the history of PLHIV/AIDS health care needs and, since then, the

caregiver-patient relationship has progressively become of greater concern to the research community investigating various aspects of the pandemic.

On examining the 30-year history of the spread of the disease, it is clear that relations between health-care personnel and PLHIV-AIDS have undergone various changes. Yet, as studies have shown, people with HIV/AIDS continue to face stigmatization and discrimination in various facets of their lives [24, 25]. This stigmatization and discrimination, moreover, increase health risks for individuals who already face various other forms of discrimination that hinder their access to HIV tests and health-care services [26]. Other studies, in addition, suggest that stigmatization and discrimination tend to isolate the infected, compromise social support, raise anxiety levels, increase social risks linked with the disclosure of their HIV-positive status, impair housing and employment security, and give rise to obstacles along the health-care continuum [27–29].

2. Conceptualizing stigma

The literature produced in the first two decades of the pandemic did not develop an explicit conceptual basis for a definition stigma that would articulate a nuanced understanding of the phenomenon, referring rather to standard definitions ("mark of disgrace associated with a particular circumstance, quality, or person") or related concepts, such as stereotyping and rejection (e.g., "a distance in the social scale"). Yet even a dictionary, sufficiently perused, tells us that the concept of stigma connotes with manifestations that indicate the presence of something beyond view, superficial signs of a concealed phenomenon [30].

In seeking to define stigma more precisely, many authors cite the conceptualization proposed by Goffman (1963) in Notes on the Management of Spoiled Identity, a work that has engendered many subsequent inquiries into the nature, sources, and consequences of stigma. In ancient Greece, the word stigma designated physical marks "designed to expose something unusual and bad about [the bearer's] moral status [13]." As a social and cultural process, therefore, stigma carries an essentially moral significance that threatens the integrity of the stigmatized individual [6].

In a psychosocial perspective, Goffman's mark or sign is not in itself indicative, but acquires negative significances that are then transferred to the bearer in the course of social interactions [31]. Stigmatization arises when an individual possesses or is likely to possess certain attributes associated with a social identity perceived as devalued in a specific social context [32–36]. Goffman considered that stigma materializes through practice as a powerful social label that represents a severe critique of an individual's attributes in specific social interactions. The construction of stigma as a process dependent on the perception that there exists a normal or standard social identity that does not include those perceived as different or deviant, those who become stigmatized [13]. Researchers proposed that stigma "is the characteristic of a person who does not conform to a social unit in which the norm is defined as a common belief that a person must act a certain way in a given moment [37]." To summarize, these definitions have at their core the shared idea that stigmatized individuals have or may have certain socially

devalued attributes [38]. Such stigmatization has been studied in various contexts, including syphilis in the nineteenth century [39], cancer [40], epilepsy [41], poverty and social housing [42], and HIV/AIDS [30, 43–45]. To borrow from Goffman's perspective, therefore, the seemingly indelible mark borne by PLHIV/AIDS translates into an identity distorted by the pandemic.

3. Research into the nature and manifestations of stigma

Kelly et al. produced pioneering research into the relationship between health-care providers and PLHIV/AIDS, suggesting that physicians reacted with negative emotions toward AIDS diagnoses based on presumptions about patients' homosexual promiscuity rather than their sexual orientation as such [46]. Subsequently, a number of studies provided clear evidence of stigmatization within the health-care field in the early years of the history of HIV/AIDS and a fear of providing health care to PLHIV/AIDS [47, 48]. Authors also documented cases of refusal to provide care to PLHIV/AIDS [8] as well as instances of caregivers breaching patient confidentiality [49].

That the first known cases of infection were those of homosexual men tended to lend the disease a sensationalist aspect, not only in the public eye but also within the health-care field more specifically [7]. Homophobic attitudes among physicians thus acquired greater significance [46, 50, 51]. At the beginning of the pandemic, in fact, American physicians perceived HIV/AIDS as more closely related to homosexuality than to other diseases [52]. Research carried out through the early 1990s reveals highly negative attitudes on the part of doctors toward PLHIV/AIDS [8]. Throughout the 1980s and 1990s, a large proportion of health-care personnel remained unaware of the tremendous potency of stigma associated with HIV/AIDS. It was indeed during those two decades that prejudices and negative behaviors were most prevalent among health-care professionals in all affected regions. To be sure, there exists a clear consensus in the literature as to the difficulties PLHIV/AIDS have had to tackle in their relationship with health care during that period. In addition, the conservative public health policies in effect at the time reinforced negative social constructions and set in place marginalized social categories [53]. Clearly, therefore, the two decades that saw the outburst and multiplication of HIV/AIDS cases were characterized by a highly potent stigmatization of PLHIV/AIDS and prevalent fears among health-care personnel, both of which affected the delivery of care to PLHIV/AIDS. Experiences of discrimination and stigmatization in the provision of health care are documented in numerous studies undertaken at the time [9, 49, 54]. By contrast, only a small proportion of studies carried out during the 1990s noted an absence of discrimination toward PLHIV/AIDS on the part of caregivers [55, 56].

Furthermore, the literature provides evidence that behaviors stigmatizing HIV/AIDS observed during the second half of the 1980s continued to be present not only through the 1990s but into the 2000s, as well. Although negative behaviors toward certain marginalized groups in the delivery of HIV/AIDS health care were observed during the 1980s and 1990s [10, 57, 58], researchers all remarked on the presence of negative attitudes on the part of caregivers in relation to such factors as socioeconomic status, mental health, and race. Similar results were

also suggested in another study [57]. In the same vein, other researchers such as Parker [44] have described stigma and discrimination linked to HIV/AIDS as complex social processes that act on one another and reinforce preexisting stigma and discrimination toward sexuality, gender, race, and poverty. For their part [9], in their study of public hospitals in Belize, they found that stigmatizing attitudes and discrimination toward PLHIV/AIDS among health personnel correlated with religious and conservative outlooks, corroborating results reported by other researchers [59, 60] (1989). The most conspicuous components of stigma directed at PLHIV/AIDS were reproach and judgment; moreover, they found that in providing care to PLHIV/AIDS, physicians exhibited more stigmatizing attitudes than did nurses [9]. The authors suggest, furthermore, that the most discernible stigmatizing attitude among doctors was a perception of PLHIV/AIDS as entirely responsible for their own condition. Similarly, the study results [61] indicate that doctors exhibit more pronounced attitudes of refusal toward PLHIV/AIDS than do nurses and hospital support staff.

In a study concerned with Southeast China, they observed that caregivers were less inclined to provide health care to PLHIV/AIDS, corroborating both contemporary studies and others dating to the early 1990s [62]. Within the Chinese health-care system, in addition, regional disparities in HIV/AIDS education, as well as in material resources, appear especially acute and point to deep-rooted problems: the study found that the personnel of village health stations were particularly disinclined to provide services to PLHIV/AIDS. Overall, a significant number of studies covering the period 2000–2012 indicate that stigma directed toward PLHIV/AIDS persists within the health-care field [49, 53, 63–67] and continues to influence the relationship between health personnel and PLHIV/AIDS [11, 23, 68–71]. Ultimately, such attitudes contribute to keep PLHIV/AIDS anonymous and faceless in the eyes of broader society [48].

4. Archetypes as the source of HIV/AIDS stigma

Although the male homosexual population was the first to be targeted as responsible for the disease during the 1980s, researchers observed the presence of a persistent discourse, within the American public health context, attributing a measure of responsibility for the disease's transmission to prostitutes [50]. Such a discourse reproduces and perpetuates representations of deviance that, moreover, are closely linked with perceptions of women as "polluting." Another major theme implicit in significations attached to AIDS that emerges in reference to prostitutes and HIV-positive mothers is that of the self-control and self-discipline of one's body. These representations of the disease, therefore, carry the notion that HIV/AIDS can be avoided through "disciplined" behavior and that, by consequence, those who carry the virus are solely responsible for their infection. The discourse assumes that since there exist ways of avoiding infection, those who become infected are responsible (i.e., guilty) and, as such, undeserving of sympathy (Sacks, 1996). Infection is thus equated with undesirable behaviors, particularly as regards sexual practices. We cannot demonstrate that beliefs determine actions, because both beliefs and actions are expressions of fundamental representations [72]. Researchers [73], for her part, provided a clear illustration of this assertion in her observations of exclusion rituals

in homes where a family member suffered from mental illness, including the segregation of their clothing and linens from the rest of the family's laundry. Villagers had adopted these rituals as a way of accepting the mentally ill within the family home without risk of "infecting" their families; local representations held that madness was an infection born of false beliefs.

An analysis of three dominant archetypes at the root of negative significations attached to HIV/AIDS reveals the ways in which discourses, significations, and representations have changed over time [74]. The archetype of the victim of AIDS victim, which first emerged during the 1980s, continued to carry negative significations in the lives of the infected in the mid-1990s. The representations linked with this archetype held that PLHIV/AIDS were ravaged, disfigured, and debilitated by the syndrome, as well as alone, desperate, and condemned to inevitable death [75]. This pessimistic AIDS archetype was increasingly contested during the early 1990s by accounts that presented a divergent, more optimistic vision, culminating in the emergence of the archetype of the AIDS survivor. In contrast to the victim archetype, representations of AIDS survivors were linked with notions of fighting against disease and despair and found their most prominent public incarnation in Earvin "Magic" **Johnson**, the basketball star whose public announcement of his HIV-positive status and subsequent AIDS activism made him a rallying figure (Lupton, 1999). The third dominant archetype in the media in the early 1990s was that of the HIV carrier. The public availability of antiretroviral drugs by 1994 made it possible for people infected with the virus to stave off the development of the syndrome. The representations associated with this change centered on encouraging carriers to live their lives fully while keeping the virus under control through medicine.

In contrast with the archetype of the survivor, the figure of the homosexual was not frequently portrayed as representative of the HIV carrier. The media did, however, associate the HIV carrier archetype with women portrayed as morally suspect, in particular prostitutes and women from disadvantaged backgrounds [50, 76]. This alarmist perception of HIV/AIDS may be understood in terms of epidemic psychology, in which suspicion, fear, and panic emerge as reactions to possible infection when an epidemic is perceived as particularly dangerous to a society [59]. By the mid-1990s, media representations of HIV-positive women engaged in the struggle against AIDS began to show them as integral individuals unencumbered by guilt over their infection with whom the public could identify, rather than as those to be avoided, abused, or judged; in other words, as people living with AIDS, rather than dying from it [76]. This demonstrates the positive representation of women as having power over their situation and expresses the empowerment of HIV-positive women.

The three archetypal representations are linked with stigma, however. The victim of AIDS is represented as a victim also of discrimination and despair. The AIDS survivor is presented in a hopeful light. With the exceptions noted above, the AIDS carrier, by contrast, is represented in a negative light, as having a body that is a source of risk and having permeable boundaries through which the HIV virus can be transmitted to others. It is worth noting that the emergence of the negative archetype of the HIV carrier coincided with the development of the first antiretroviral drugs, which gave rise to a new, positive dimension in the lives of the infected, but, having extended their life, gave rise also to fears of a greater risk that they might pass the virus on to others.

5. The consequences of stigmatizing behavior in health care

A number of studies suggest that refusals to offer care based on prejudices can erect communication barriers and cause confidence to deteriorate, imposing additional limitations on HIV/AIDS medical care [22, 48, 69, 77]. Indeed, stigma is broadly recognized as an important barrier for prevention and treatment of HIV/AIDS [27, 66, 78–81] and as affecting the stigmatized individual's social situation and psychological health [82, 83]. Studies carried out in Thailand have noted that stigmatization of PLHIV/AIDS in the context of medical care constitutes a significant barrier to the delivery of services to PLHIV/AIDS [28]. Similarly, the work reveals points to intentional delays of medical appointments for PLHIV/AIDS, particularly for surgeries, as well as oral and dental care. The study notes that 43% of medical personnel would not consult a dentist who had tested HIV-positive, while 36% indicated a belief that an HIV-positive physician should not be allowed to perform surgeries and a full 65% of administrative personnel insisted on such a ban [64]. Thus, perceptions of PLHIV/AIDS influence their access to appropriate care. Other authors have in addition noted behaviors among medical personnel denoting stigma when interacting with PLHIV/AIDS, including refusal of care, reduced quality of care, as well as ignoring and intimidating patients, exhibiting anger and employing excessive precautions against infection [54, 68], other observed attitudes include pity and disillusion [69], as well as minimal eye contact, distance in conversation, devaluing attitudes, and excessive security measures [12, 68].

However, results reported [48] in a study of PLHIV/AIDS health care in the Maule region of Chile show that more recently health professionals, and physicians in particular, have pointed to a decrease in stigma toward PLHIV/AIDS in health center contexts and that there has been a positive change in the attitudes of physicians toward HIV/AIDS patients. In addition, the study shows that the majority of patient testimonies on the attitudes of caregivers indicate the latter's growing engagement and attention to a whole-person approach to care. These results point to positive changes over time in health-care provision to PLHIV/AIDS. The authors note, as well, that caregiver testimonies indicate that a similar positive change in attitudes toward patients has also permeated other areas of health care. Similarly, a study [84] involving eight HIV/AIDS-positive women of African origin in the city of Nottingham, England, shows that participants described health services as a safe social space and a source of positive support. Other results, however, suggest that when caregivers report experiencing positive emotions toward patients, it is overwhelmingly toward those who represent populations traditionally considered to be the pandemic's "innocent" victims, such as children or women infected by their partners [69] underlining a development over time in stigma directed toward those perceived as innocent [63] or faultless [80] in contrast to those seen as "guilty" patients [20, 50, 76, 85].

Our overview of the relatively short history of HIV/AIDS and the research literature concerned with various aspects of the pandemic underscores the scope and persistence of stigmatization across a range of practices. The stigmatizing attitudes described above are founded in specific discourses and representations, and can range from an indifferent gesture to a convinced decision, from passive negligence to violent rejection. We have also observed, however, that

positive attitudes appear to be progressing in certain HIV/AIDS health-care environments. The distance between caregivers and patients has lessened over time, as evidenced by patient testimonies of positive experiences in interactions with health services. The result is that the health-care space, which was once a source of concern for PLHIV/AIDS, has begun to acquire a more positive significance through more inclusive care practices and behaviors that better serve those in need. What is more, the concept of offering PLHIV/AIDS a care relationship that goes beyond strictly medical needs has also begun to take root among clinicians. Health workers increasingly view the disease as requiring a whole-person approach that is apt to more fully address a range of social and moral impacts in the lives of PLHIV/AIDS [48].

6. Conclusion

This review of the literature on the stigmatization of PLHIV/AIDS, in a variety of health-care contexts since the outbreak of the pandemic in the 1980s, provides evidence for the persistence of social stigma toward the infected, but also shows that stigma is attenuated or reduced in certain social settings and where specifically dedicated care is accessible [48, 84]. In the reviewed literature, the notion of stigmatization covers a wide range of psychosocial phenomena (attitudes and behaviors of caregivers) and perceptions (those of both caregivers and patients) that require a more comprehensive conceptual definition of stigma and the process of stigmatization than has been offered to date. The perspective developed by Goffman, which focuses on interaction frameworks, provides solid footing on which to develop an understanding of the nature and manifestations of stigmatization in the specific context of health services. Inquiries into the interactions between medical personnel and PLHIV/AIDS are likely to be particularly fruitful. At present, studies taking into account the perceptions of both PLHIV/AIDS and caregivers are exceedingly rare [86]. While existing studies rely primarily on analyses of respondents' testimonies of experiences, in vivo observations of interactions appear more apt to produce comprehensive results for understanding stigmatization processes.

In terms of the effects of stigmatizing behaviors on the provision of care to PLHIV/AIDS, although some studies show an improvement in attitudes on the part of caregivers PLHIV/AIDS [48, 84], the majority of the literature does not suggest a unilateral shift from a period of stigmatization to one of widespread compassion and social solidarity with the infected [4–6, 9–11]. The reduction of stigma toward HIV/AIDS and its consequences was identified as an important goal by the UN as far back as the year 2000 (Elliott, 2002). Yet, existing health policies still do not, or only inadequately, address PLHIV/AIDS stigmatization by health personnel. Many health policies remain framed in a population health perspective that only occasionally acknowledges the prejudices, stereotypes, and discrimination that PLHIV/AIDS may face in society.

Furthermore, the literature reviewed above is concerned largely with medical personnel in the context of modern health-care organizational structures in which work is divided along hierarchical lines of professional classification. Within this diversity of professions and areas of care, preventive and therapeutic interventions related to HIV/AIDS have varied consider-

ably since the first positive diagnoses and subsequent development of monotherapy treatments in the early 1980s. In order to better understand stigmatization, it is necessary to link the perceptions of health professionals on PLHIV/AIDS with broader social beliefs about disease, on both the social and individual levels, in relation to public policies and clinical interventions. While a majority of studies appear to consider categories of caregivers as mutually independent units, in practice interventions happen within multipurpose institutions staffed by multidisciplinary teams of caregivers. Preventive and therapeutic outlooks are elaborated within teams that span different professional categories, based on a number of shared postulates, in the course of discussions on specific courses of action in specific cases. It seems important therefore to further examine changes in the stigma and related behaviors associated with HIV/AIDS in specific professional contexts rather than in specific professional categories.

Thanks to biomedical research, HIV/AIDS has today become a chronic, rather than fatal, disease. Yet, indicators of the persistence of stigma directed at HIV/AIDS in health-care contexts suggest that the various components of caregiver-PLHIV/AIDS interactions are yet to be fully understood. Studies conducted in a range of social and cultural contexts demonstrate the persistence of negative (and potentially stigmatizing) behaviors toward PLHIV/AIDS in the field of health care. The results of the present examination of continuing stigma represent, therefore, a valuable contribution to the literature and point the way to further research.

Author details

Oscar Labra* and Daniel Thomas

*Address all correspondence to: oscar.labra@uqat.ca

Department of Human and Social Development, Université du Québec en Abitibi-Témiscamingue, Canada

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