

A comparative analysis of perceived stigma among HIV-positive Ghanaian and African American males

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ABSTRACT

The purpose of this paper was to address two questions: (i) Do Ghanaian and African American males with HIV/AIDS experience different types and degrees of stigma? and (ii) Is the impact of stigma associated with HIV/AIDS on the self different for Ghanaian and African American males? A quantitative method was used, and the four dimensions of stigma (social rejection, financial insecurity, internalised shame, and social interaction) were identified and measured using combination Likert-type questionnaires. Data regarding positive feelings of self-worth and self-deprecation, stress related to body image, and personal control were also collected in Ghana and the southeastern USA. The sample consisted of 55 men from Ghana and 55 men from the southeastern USA. Results indicate that values for the scales measuring stigma and self-perception were significantly higher for the Ghanaian sample than for the African American sample. Thus we conclude that the Ghanaian sample living with HIV/AIDS experienced a greater amount of negative self-perception and stigma-related strife than the African American sample.

Keywords: stigma, HIV/AIDS, social rejection, financial insecurity, internalised shame, culture.

RÉSUMÉ

Le but de cette communication est d'aborder deux questions, à savoir: (i) Est-ce que les hommes Ghanéens et Afro-Américains vivant avec le VIH/SIDA éprouvent de types et de degrés différents de stigmatisation? et (ii) Est-ce que l'impact de stigmatisation liée au VIH/SIDA sur le moi est différent chez les Ghanéens en comparaison aux Afro-Américains? Une méthode quantitative a été employée et les quatre dimensions de stigmatisation (le rejet social, l'insécurité financière, la honte intériorisée et l'interaction sociale) ont été identifiés et mesurés grâce à une combinaison des questionnaires Likert-type. Des données concernant des sentiments positifs de la valeur personnelle et d'auto-dénigrement, le stress lié à l'image corporel et le contrôle de soi-même ont été recueillies au Ghana et au sud-est des États Unis. L'échantillon consistait de 55 hommes du Ghana et 55 hommes du sud-est des États Unis. Les chiffres des barèmes utilisées pour mesurer la stigmatisation et la perception de soi-même étaient sensiblement élevés pour l'échantillon ghanéen par rapport à l'échantillon afro-américain. L'échantillon ghanéen vivant avec le VIH/SIDA a davantage de perception négative de soi-même ainsi que la lutte liée à la stigmatisation par rapport à l'échantillon afro-américain.

Mots clés: stigmatisation, VIH, SIDA, rejet social, insécurité financière, honte intériorisée, culture.

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Introduction

Stigma has long been known to have negative connotations, especially among those with life-changing, devastating illnesses. This phenomenon is particularly observed among those individuals who are personally confronted with the HIV/AIDS illness. These individuals are not only exposed to life-altering changes in their activities of daily living, but they must also contend with the hurtful actions of others who feel they should be further ridiculed for their stereotypical 'deviant behaviour.' 'People living with HIV/AIDS face discrimination and stigma that are associated with the disease' (AIDS Action, 2001, p.1), which results in further reduction in their quality of life and physical well-being. Much research has been conducted about HIV-related stigma, but there are few, if any, cross-cultural studies.

The purpose of this paper was to compare and differentiate the effects of stigma associated with HIV/AIDS and four dimensions of the self (self-worth, self-deprecation, body image, personal control), among Ghanaians and African Americans of the southeastern USA. It is hoped that this study will elucidate how stigma may manifest itself within different cultural groups and hence provide bases for differential intervention approaches. In accordance with the quantitative method of research, four dimensions of the self and four dimensions of stigma (self-rejection, social isolation, financial insecurity, internalised shame) are analysed for each culture, to determine the relationships which exist between stigma and the self. The analysis is guided by the theory of symbolic interactionism.

Background

HIV/AIDS is one of the most crippling and devastating diseases infecting people throughout the world. The total world population affected by HIV/AIDS was estimated to be around 40 million at the end of 2003 (National Institute of Allergy and Infectious Disease [NIAID], 2004). The highest HIV prevalence is in the sub-Saharan regions of Africa. Africans comprise only 10% of the total global population, but make up nearly 70% of the total HIV/AIDS cases worldwide (Ameyibor, 2002). Prevalence in Ghana remains low, with only 3% of the adult population living with HIV/AIDS (UNAIDS/WHO, 2004). However, that rate is steadily climbing, with 360 000 cases reported in 2002 (Avert, 2003). The USA, on the

other hand, is estimated by the Centers for Disease Control and Prevention (CDC) to have approximately 900 000 residents living with HIV, and 25% of them are unaware of their infection (NIAID, 2004). African Americans comprise only 12% of the total US population but accounted for almost half of all new HIV/AIDS cases reported in 2003 (CDC, 2004). AIDS is the leading cause of death among African American men ages 25 - 44 (NIAID, 2002), with the south accounting for over 35% of total AIDS-related deaths reported from 1993 to 2001 (Avert, 2003). It is not surprising, then, that both Africans and African Americans are major targets for HIV/AIDS prevention efforts.

Much of the HIV/AIDS focus has been on prevention efforts, but some programmes in the community now address stigma related to HIV/AIDS. Stigma is not a simple phenomenon commonly expressed and felt in the group. It is a complex interaction which is both covert and overt, and is subjectively experienced in various ways. Goffman (1963, p. 3) describes the general term 'stigma' as being 'an attribute that is deeply discrediting', with the stigmatised individual being reduced 'from a whole and usual person to a tainted, discounted one' (p.3). Link (2001) purported that 'we apply the term stigma when elements of labelling, stereotyping, separation, status loss, and discrimination co-occur in a power situation that allows them to unfold' (p. 2). Thus, labelling persons with undesirable characteristics such as being morally unjust, somehow justifies stigmatising behaviour for the stigmatising individuals (Link, 2001). Persons who have been stigmatised are diminished in social standing (Cumming & Cumming, 1965). In the eyes of others they are discredited and their identities are tainted or spoiled (Goffman, 1963). In addition, they are often isolated from others, assumed to be inferior and a threat to society (Goffman, 1963; Jones, Farina, Hastorf Markus, Mella & Scott, 1984; Link, Cullen, Struening, Shrout & Dohrenwend, 1989). Empirical studies have shown that stigma negatively affects self-perception, emotional well-being, social interaction and life chances (Link, Struening, Rahav, Phelan & Nuttbrock, 1997; Miles, Burchinal, Holditchp-Davis, Wasilewski & Christian, 1997). It is assumed that individuals who feel stigmatised will also experience low self-esteem and limited personal control.

Many people infected with HIV/AIDS must contend with the social repercussions of stigma. AIDS-related

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Stigma refers to a 'pattern of prejudice, discounting, discrediting, and discrimination directed at people perceived to have HIV/AIDS, their significant others and close associates, and their social groups and communities' (Cogan & Herek, 1998, p. 1). Many common misconceptions regarding HIV/AIDS contribute to the ostracism and ridicule received in the face of ignorance regarding the disease. Several researchers have found that many people feel that those who have contracted HIV are deserving of their illness (AIDS Action, 2001). This represents the overwhelming number of people who think HIV is only transmitted via contaminated needles or as a result of homosexual intercourse. These beliefs are contrary to the widely published statistic that worldwide, approximately 80% of HIV cases are transmitted through heterosexual intercourse (NIAID, 2002). 'People with the most correct knowledge about HIV infection are least likely to believe that HIV patients got what they deserved' (CDC, 2000, p.1). Preexisting prejudices, as well as fears of contagion from HIV, further contribute to stigmatisation of the inflicted individuals (Cogan & Herek, 1998). Furthermore, the CDC found that HIV prevention efforts are hindered due to a reluctance to talk about the risk factors of its transmission, which is a result of the stigma associated with the disease (AIDS Action, 2001). The African Commission of Health and Human Right Promoters (ACHHRP) discovered that the predominant attitudes found in Ghana were negative, due to the overwhelming belief that persons living with HIV/AIDS are immoral and promiscuous. A large majority of people in Ghana felt that 'anyone who contracts AIDS becomes dangerous and must be feared,' (Clotey-Sefa, 2001, p.4) and thus, should be isolated from others. Nadine France Health and Development Networks revealed that the most frequently cited setting for HIV/AIDS stigma in Africa was in health care. 'Nurses were frequently cited as being the perpetrators of stigma' (France, 2001, p.14). The reasons cited for stigma in the health care setting included negative attitudes from knowledge deficit of HIV/AIDS, fears of contagion, personal judgmental attitudes, constantly being reminded of the high risk of acquiring HIV due to increased exposure, work overload, fear of assisting in patient coping, and feeling helpless due to limited resources (France, 2001). These findings suggest that health care providers should also be targets of educational review on HIV/AIDS, with an emphasis on learning more effective coping strategies.

Stigma of the self arises out of symbolic expressions and symbols that aid in the derivation of meanings that one attaches to ideals of the self and others. Cooley's (1956) contention of the 'looking-glass self' suggests that 'the thing that moves us to pride or shame is not the mere mechanical reflection of ourselves, but an imputed sentiment, the imagined effect of this reflection upon another's mind' (p.184). Mead (1934) felt that symbolic meanings are a product of social interaction. Stigma symbols contribute to identity debasing, resulting in subsequent devaluing of individuals, thus affecting social interactions (Goffman, 1963). Generally speaking, due to limited social interaction, individuals are exposed to a great deal of social isolation and alienation. Likewise, stigma can alter one's ability to cope, leading to exacerbation of the present illness with subsequent presentation of other stress-induced illnesses and reduction of self-esteem and self-efficacy (Link, 2001). The effects of stigma are similar across cultural variations, but to understand the extent to which stigma affects individuals, one must delve directly into the social system from a cultural perspective.

There is no apparent difference in the defining elements of HIV/AIDS-related stigma between Africans and African Americans. Both cultures have fear regarding the social isolation and ridicule that accompanies exposing their serostatus (Horizons, 2002). Shame associated with the taboo of the derivation of the illness and deviant moral judgments are other common factors associated with HIV/AIDS stigma (Piot, 2001). One major difference that exists between the Ghanaians and African Americans regarding HIV illness is Ghanaians' reliance upon traditional and spiritual healers for healing. The reasoning behind this is two-fold. First, many Ghanaians often feel that 'the outbreak of a disease with no known cure or origin may be attributed to the commission of an offense against one's spirits, the ancestors of the gods, or an omission of duty on the part of an infected person' (Anarfi & Awusabo-Asare, 1997, p. 244). Secondly, these healers often claim to hold curing powers, which allows individuals to avoid exposing their HIV status to the professional health care environment, minimising the potential stigma associated with their disease (Anarfi & Awusabo-Asare, 1997).

It is evident that the effects of illness-induced stigma are profound, and contribute to the overall stress

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associated with illness, undermining one's psychological, social, and physical well-being. Stigma related to HIV/AIDS needs to be explored further from a cultural standpoint to develop educational programmes and interventions that are culturally appropriate.

Method

Design

This study was conducted using the quantitative method. No variables were manipulated in this non-experimental research. Statistical data between two different cultural groups were objectively examined and compared, to determine the relationship between stigma and the self among HIV-infected individuals. Data were analysed to determine the associations which exist between the independent variable (culture) and the dependent variables (dimensions of stigma and self). Similarities and differences between the two cultures were studied.

Sample

The Ghanaian sample was taken from a hospital-based clinic in Accra, Ghana. The African American sample was recruited from one community-based clinic located in Nashville, in the southeastern part of the USA. The first two authors reside in these two cities respectively. The measure was targeted at the HIV-positive adult male population aged 15 - 49 years attending respective HIV/AIDS clinics during the study period. The expected sample size for the Ghanaian site was 150 with an acceptable minimum of 50. The expected sample size was based on the estimated HIV prevalence in the local Ghanaian male population, a confidence interval of 95%, a 5% acceptable margin of error and the need for a sample size large enough to enable comparative analyses. The sample size was to be the same for both Ghanaian and African American samples.

Procedures

The sampling was undertaken between September and December 2001. Pre-sampling activities began in June with site selection, procurement of measuring instruments, training of staff, followed by trials in July. Administration of questionnaires began on 1 September and ended on 31 December - a period not exceeding 16 weeks. Consecutive sampling was used, consisting of sampling every HIV-positive male patient attending the HIV/AIDS clinic who met the inclusion criteria, until the required sample size was obtained or

the sampling period was over. Inclusion criteria were that all HIV-positive adult male clients within the prescribed age attending the clinics during the survey period were eligible for inclusion. HIV-positive clients for repeated visits who had earlier completed the questionnaires during the period were excluded. The participants either self-completed or were helped by trained staff to complete four questionnaires, after they received the details of the study. Four dimensions of the self (self-worth, self-deprecation, body image, personal control) and four dimensions of stigma (social rejection, financial discrimination, internalised shame, social isolation) were measured.

Questionnaires

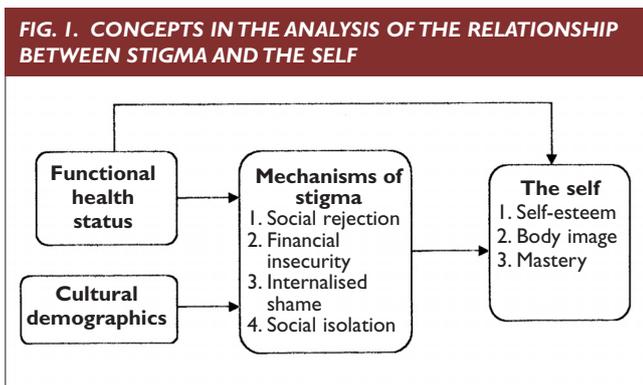
Measures of self-perception. The Rosenberg Self-Esteem Scale, a widely utilised and highly regarded instrument, is a ten-item questionnaire using a four-point, Likert scale ranging from 'strongly agree' to 'strongly disagree'. It measures self-esteem in relation to positive feelings of self-worth and self-deprecation (Fife & Wright, 2000). Original scoring was revised for this study so that higher scores indicate higher self-esteem. Silber and Tippett (1965) reported the stability reliability of the instrument after 2 weeks as 0.85 and found a correlation of 0.56 - 0.83 with similar measures and with clinical assessments. Crandall (1973) observed a correlation of 0.60 with Coopersmith's Self-Esteem Inventory. Rosenberg's scale has been cross-culturally validated and utilised world-wide for over 25 years.

We measured personal control using the Mastery Scale (Pearlin & Schooler, 1978). This instrument, initially developed for stress research, is an eight-item measure which has a four-point Likert scale ranging from 'strongly agree' to 'strongly disagree'. The validity and reliability of this frequently used scale is well demonstrated (Turner & Wood, 1985; Schieman & Turner, 1998; Fife & Wright, 2000; TCU, 2002). The Mastery Scale has also been cross-culturally validated and used worldwide for over 25 years. The scale for body image was developed to take into account physical changes and related concerns specifically for HIV/AIDS victims (Fife & Wright, 2000). It is a seven-item, Likert-type questionnaire.

Measures of stigma. The Social Impact Scale was devised specifically to measure the impact of stigma related to illness. It was developed for this study's

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previous counterpart, which was a comparison of HIV/AIDS and cancer (Fife & Wright, 2000). Its conceptualisation is based on the Modified Labeling Theory, which suggests that stigmatising beliefs become meaningful once the person(s) being stigmatised realises that he/she is part of a stigmatising category. This theory suggests that once negative beliefs become internalised, 'stigma can lead to negative self-conceptions and life experiences' (Fife & Wright, 2000). Key stigma components were taken from this theory, derived with the assistance of consulted clinical experts. These measures of stigma were then presented to seven individuals living with HIV/AIDS, who ranked and gave input on the key stigma identifiers. The end result consisted of a 24-item, Likert-type questionnaire that addressed four dimensions of stigma. These are social rejection, financial insecurity, internalised shame, and social isolation. Fig. 1 depicts the components of the relationship between stigma and the self, also taking into account functional health status and demographic information.



Data analysis

The consecutive sampling method yielded 55 Ghanaians (during the whole period) and a comparable 55 African Americans (first 55 during the period). Demographic characteristics between both groups demonstrated no significant disparities. All participants lived in a large metropolitan area. Age ranges for both African Americans and Ghanaians were between 18 and 48, with the mean for African Americans being 24 and the Ghanaian mean 24.5. Years of education for both samples ranged from 9 to 16 (African American mean = 11, Ghanaian mean = 10). Both samples were in the lower to lower middle class income bracket. All Ghanaians were Black Africans and USA participants were African Americans.

Again, there were no major differences between the two samples to account for any differences that were identified post-analysis.

Comparison of means and *t*-tests were used for the data analysis. The two cultures being compared represent the independent variables, and the measures of stigma and self-perception were the dependent variables. The results for the dependent variables in each group were given numerical values using interval-scale measurements. Scale means were calculated for each culture. The means were then compared for both stigma and self-perception, to address questions regarding the comparative relationships. The standard deviation was computed to account for the average deviation of scores from the mean in each sample for each item. *T*-tests were then used to test for significance in the differences for the 2 samples.

Results

Tables 1 and 2 show mean responses for summated measures of stigma and self-perception for each sub-sample. Table 1 shows the mean differences for each dimension of stigma (social rejection, financial insecurity, internalised shame, social isolation). The means were significantly greater among Ghanaians, indicating a higher level of experienced stigma. The *p*-values in Table 1 indicate that the differences between the means were significant at the 0.001 level.

Table 2 shows the mean responses for the sub-samples on the factor weighted self-perception measures. The results varied in levels of significance. Means were lower in the Ghanaian sample with regard to self-worth (mean = 4.03 v. 4.35) and higher in the Ghanaian sample with regard to self-deprecation (mean = 2.95 v. 2.29) compared with African Americans. The *p*-values showed that these differences were significant.

TABLE 1. MEAN RESPONSES ON FACTOR-WEIGHTED STIGMA SCALES FOR GHANAIAN AND AFRICAN AMERICAN SUB-SAMPLES*

	Ghanaian Mean (SD)	African American Mean (SD)	t, p-value
Social rejection	2.97 (0.81)	2.12 (0.56)	6.89, <i>p</i> ≤ 0.001
Financial insecurity	3.15 (0.94)	2.10 (0.82)	6.71, <i>p</i> ≤ 0.001
Internalised shame	3.52 (0.73)	2.08 (0.69)	12.71, <i>p</i> ≤ 0.001
Social isolation	3.54 (0.78)	2.77 (0.89)	5.41, <i>p</i> ≤ 0.001

*The scale items were weighted by their respective factor weights prior to calculating summary statistics.

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TABLE 2. MEAN RESPONSES ON FACTOR-WEIGHTED SELF-PERCEPTION MEASURES FOR GHANAIAN AND AFRICAN AMERICAN SUB-SAMPLES*

	Ghanaian Mean (SD)	African American Mean (SD)	t, p-value
Self-worth	4.03 (0.75)	4.35 (0.61)	-2.26, $p \leq 0.021$
Self-deprecation	2.95 (0.90)	2.29 (0.82)	5.18, $p \leq 0.001$
Body image	18.65 (3.39)	19.22 (3.64)	-.26, $p \leq 0.841$
Personal control	22.46 (3.79)	23.59 (3.86)	-1.38, $p \leq 0.151$

*The scale items were weighted by their respective factor weights prior to calculating summary statistics.

The means for body image and personal control, however, were higher among African Americans, but the p -values determined these differences were not significant.

Discussion

The findings from this study indicate that Ghanaians in the study experienced a greater amount of stigma and negative self-perceptions as a result of having HIV/AIDS than the African Americans living in the southeastern USA. This finding could be attributed to a number of factors. The first that comes to mind is culture, the learned complex of knowledge, beliefs, art, law, and custom within a specific society (Tylor, 1871) to explain and understand the differential impact of stigma and negative self-perceptions as a result of having HIV/AIDS. For example, it appears that there may be a stronger negative perception about HIV/AIDS within the Ghanaian community. Negative epithets used to describe HIV/AIDS in Ghana include: 'imminent death', 'untimely death', 'disgraceful death', 'shameful death', 'long-suffering death', and 'abominable disease'. Locally the disease is described as 'ko ankoro' (incurable disease), 'yadee bone' (abominable disease), 'owuo yadee' (death disease), 'yadee huhuu' (dreadful disease), and 'babaso weremfoo' (dangerous gonorrhoea). Ghanaians dread the thought of becoming ill and dying from AIDS.

Related to this is the fear of the mode of death, i.e. 'good death' versus 'bad death'. A 'good death', from the Ghanaian perspective, is one which complements rather than clashes with the vision of oneself or themselves. It is death with dignity or a dignified death that befits the stature of the individual such as dying at old age, in sleep, at home, with family members and not on a 'forbidden bad' day. For example, no one wants 'bad death', such as dying from abominable

conditions like blindness, suicide, without the body being seen or a long drawn-out death from HIV/AIDS. It would appear that it is not death *per se* that Ghanaians are afraid of, but death associated with HIV/AIDS. Thus the interplay between Ghanaian culture, HIV/AIDS and stigma may certainly yield the differential degree of stigmatisation. It is assumed that Ghanaians by self-definition are culturally different from Black Americans.

Secondly, it is probable that these findings can be attributed to lack of exposure to educational resources and knowledge concerning HIV/AIDS. Ghana is a developing country with limited fiscal resources, which hinders its ability to dispute misconceptions regarding HIV/AIDS and minimises prevention efforts. Also, the fact that there are many more traditional healers in Ghana than professional physicians may contribute to the knowledge deficit, as traditional healers may not have the educational background or necessary knowledge for accurate information dissemination. It is also possible that not all professional health care workers in Ghana have been exposed to all the facts concerning HIV, which may contribute to greater stigmatisation in the health care environment toward people with the illness.

Thirdly, the variations of race in each country should also be examined. The USA has a much more diverse population in terms of race and ethnicity. Historically, African Americans have been exposed to a great amount of racial stigma and discrimination and, therefore, may be better prepared to adjust to the social implications of stigma. Ghanaians, on the other hand, comprise the overwhelming majority of the population in Ghana, reducing the racial stigma and discrimination within their own country, possibly lending them fewer coping strategies due to lack of exposure to stigma. Many Ghanaians additionally hold beliefs that certain illnesses are exclusively attributed to sins against the gods, which translates into those with HIV/AIDS being perceived as immoral. This morality issue associated with stigma further prevents Ghanaians from seeking professional treatment for fear of greater stigmatisation. Moreover, since Ghanaians with HIV/AIDS are more prone to being excluded in society due to the moral implications associated with the origin of the illness, they are more likely to hold more negative self-perceptions and experience more damaging stigma-related consequences than African Americans.

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Health professionals and HIV/AIDS educators have the capacity to mitigate the effects of HIV/AIDS-related stigma. The most obvious way is through enhancing education efforts and spreading knowledge of HIV/AIDS, especially to high-risk communities. Addressing misconceptions of transmission, relaying information and assisting in resource allocation for prevention efforts, and exposing the public to the superficial normalcy that many HIV/AIDS victims possess are some ways in which knowledge about HIV/AIDS can reduce stigma. Education should be targeted at the community level, in schools, religious institutions, or community events, and should be culture-specific. Additionally, since traditional healers are regarded so highly by many in Ghana, it is important that they also be targets for enhancing knowledge of HIV/AIDS transmission, prevention, and treatment options.

Next, social support programmes should be instituted to aid in facilitating healthy coping strategies among people living with HIV/AIDS, their families, and supporters. Health professionals and HIV/AIDS counsellors should educate communities and facilitate support groups to promote more positive coping mechanisms. It may also be beneficial for health educators and counsellors to develop support groups for families who are constantly exposed to the HIV/AIDS population.

Furthermore, in order for persons living with HIV/AIDS to feel less stigmatised, it is essential that they become empowered to eliminate HIV/AIDS-related stigma and discrimination. HIV/AIDS educators should play a supportive and facilitative role in encouraging these people and others to take an active role in legislation to fend for their rights. Singling out specific, powerful political leaders or prominent names in society to gain support will certainly aid in reducing negative, stigmatising attitudes. Pushing for government subsidisation to ensure specific monies are allocated for the prevention and treatment of HIV/AIDS would be especially beneficial in Ghana.

Recommendations for future research on HIV/AIDS-related stigma should be directed at identifying the effects of stigma among other cultures throughout Africa. Certainly, other areas in Africa have a higher incidence of HIV/AIDS and, therefore, should be

targets for future studies. Also, increasing the sample size and discreetly disclosing specific sample characteristics, such as how individuals presumably became exposed to the disease or its mode of transmission, may aid in identifying the reasoning behind individual-specific stigma. It is important to identify the causes of stigma, as well as the potent effects of stigma. Future studies should definitely focus on identifying these cause-effect relationships in culturally-specific contexts, concentrating on their impact on illness progression and quality of life. Education and prevention efforts should not be ignored. Future research should focus on the trends in HIV/AIDS prevention efforts and how these aid in reducing stigmatising attitudes and beliefs. Success of prevention efforts should be assessed in culturally-based contexts.

Finally, coping strategies and support groups for HIV/AIDS should be assessed to establish whether social integration and support are consistent, and whether they enhance the quality of life and well-being of persons living with HIV/AIDS. Having a better grasp of the dynamics underlying the psychosocial aspects of stigma on the self may bring about a better understanding of illness-induced stigma, thereby enhancing intervention efforts to promote quality of life among stigmatised individuals.

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