

Managing AIDS stigma

W L Holzemer, L R Uys

ABSTRACT

According to anecdotal reports, AIDS stigma and discrimination continue to influence people living with and affected by HIV disease as well as their health care providers, particularly in southern Africa where the burden of AIDS is so significant. Stigma is perceived as a major limiting factor in primary and secondary HIV/AIDS prevention and care. It reportedly interferes with voluntary testing and counselling, and with accessing care and treatments, thereby increasing suffering and shortening lives. Many health care workers in southern Africa have come to the conclusion that unless stigma is conquered, the illness will not be defeated. While there is substantial anecdotal evidence of the impact of stigma on AIDS care, very little rigorous research has been conducted. This article explores three questions: What is AIDS stigma? What is the impact of AIDS stigma? How can health care providers help to manage AIDS stigma?

Keywords: HIV/AIDS stigma, management, measurement.

RÉSUMÉ

D'après des rapports anecdotiques, la stigmatisation et la discrimination liées au SIDA continuent à influencer les personnes vivant avec la maladie du VIH, ceux qui en sont affectés ainsi que leurs fournisseurs de soins particulièrement en Afrique Australe où le fardeau du SIDA est très prononcé. La stigmatisation est perçue comme un facteur majeur qui restreint la prévention et les soins primaires et secondaires du VIH/SIDA. Il est dit que la stigmatisation entrave la Consultation et le Dépistage Volontaires (VCT) et l'accès au soin et au traitement. Pour cette raison, la stigmatisation augmente la souffrance et raccourcit la vie. Beaucoup de personnel de soin, en Afrique Australe, ont tiré la conclusion qu'à moins que la stigmatisation soit conquise, la maladie ne sera jamais vaincue. Pendant qu'il y a une évidence anecdotique importante de l'impact de la stigmatisation sur le soin du SIDA, très peu de recherche rigoureuse a été faite. Cette présente communication étudie trois questions: Qu'est-ce que la stigmatisation? Quel est l'impact de la stigmatisation liée au SIDA? Comment est-ce que les fournisseurs de soin peuvent aider dans la gestion de la stigmatisation associée au SIDA?

Mots clés: VIH/SIDA, soigner, stigmatisation.

William L Holzemer (RN, PhD, FAAN) is Professor of Nursing, University of California, San Francisco. His work focuses upon care for people living with HIV/AIDS in the areas of medication adherence, symptom management, stigma, and quality of life. Together with Leana Uys, he is co-directing a 5-year project Perceived AIDS Stigma: A Multinational African Study, NIH R01 TW006395, in Lesotho, Malawi, Tanzania, South Africa, and Swaziland exploring and measuring the contribution of stigma to quality of life for people living with HIV/AIDS and to quality of work life for nurses.

Leana R Uys (RN, RM, D Soc Sc) is Interim Deputy Vice-Chancellor and Head of the College of Health Sciences at the University of KwaZulu-Natal. Her research in the past has focused on home-based HIV/AIDS care, and she is co-author of the book *Home-based HIV/AIDS Care*, published in 2003 by Oxford University Press.

Correspondence to: William Holzemer, School of Nursing, University of California San Francisco, 2 Koret Way, San Francisco, CA, 94143-0608 USA. E-mail: bill.holzemer@nursing.ucsf.edu.

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There is an extensive literature on the medical management of HIV/AIDS which often makes the assumption that people living with HIV infection want to be tested and, if found to be positive, want to engage with care. In the United States (USA), however, it is estimated that as many as one-third of the HIV-positive population do not know their HIV status (Kaiser Family Foundation, 2004). Even in countries where studies have documented high rates of HIV infection, many individuals are reluctant to get tested and often slow to access care (Newman, Grusky, Roberts & Rivkin, 2002). The stigma of HIV/AIDS is one factor affecting people's decisions to get HIV tested and seek care.

AIDS stigma and discrimination have a considerable influence on people living with and affected by HIV, as well as on their health care providers, particularly in southern Africa where the burden of AIDS is so significant (African Development Forum, 2000). Stigma has emerged as a major limiting factor in primary and secondary HIV/AIDS prevention and care (Weiss & Ramakrishna, 2001). It interferes with voluntary testing and counselling, and access to care and treatment, increasing suffering and shortening life (Newman *et al.*, 2002). Many health care workers in southern Africa have come to the conclusion that unless stigma is conquered, the illness will not be defeated (Uys, 2000).

This paper reviews the literature on the definitions of stigma, the impact of stigma on the lives of people living with and affected by HIV/AIDS, and proposes care strategies to help health care workers to support clients living with HIV in stigmatising environments. The article explores three questions: What is HIV/AIDS stigma? What is the impact of HIV/AIDS stigma? How can health care workers address stigma in ways that help clients manage their HIV in a stigmatising environment?

What is AIDS stigma?

'Stigma' is a Greek term denoting a mark that, in ancient times, was burned or cut into the flesh of an unsavoury character — a traitor, criminal, or slave (Harvey, 2001). Goffman (1963, p. 3) defined it as 'an attribute that is deeply discrediting within a particular social interaction', as a 'spoiled social identity' and 'a deviation from the attributes considered normal and acceptable by society' (Harvey, 2001, p. 175). According to Alonzo and Reynolds (1995, p. 304),

stigma is 'a construction of deviation from some ideal or expectation'. Stigmatised groups in the US include women; minorities, such as people of colour, homosexuals, and substance abusers, and people who are physically and/or mentally disabled (Corrigan *et al.*, 2003; Harvey, 2001). Today, Goffman's concept of stigma is the one most widely accepted (Harvey, 2001).

Herek *et al.* (1998, p. 36) used the term 'AIDS-related stigma' to mean 'prejudice, discounting, discrediting, and discrimination that are directed at people perceived as having HIV or AIDS, and at individuals, groups, and communities with which they are associated'. Those who experience stigma view it differently than those who stigmatise (Herek, Capitanio & Widaman, 2002). In health care, stigma is often described in the literature in relation to chronic illness and visible physical disability. One description of stigma in this context is 'a factor influencing the response of others to the chronically ill' (Jillings & Alexis, 1991, p. 62). People with HIV/AIDS may not have any visible signs of the disease, yet they are more likely to be stigmatised because others may view them 'as contributors to their own problems and unworthy of the care directed to more legitimate victims of illness' (Jillings & Alexis, 1991, p. 62). Alonzo and Reynolds (1995, p. 304) defined stigma as a 'powerful and discrediting social label that radically changes the way individuals view themselves and are viewed as persons'. Insideout Research (2003, p. 5) describes a large collaborative study on stigma in South Africa and reports that stigma 'can be **felt** (internal stigma), leading to an unwillingness to seek help and access resources, or **enacted** (external stigma), leading to discrimination on the basis of HIV status or association with someone who is living with HIV/AIDS'.

A conceptual model proposed by Weiss *et al.* (1992) recognises an insider's perspective (emic) and an outsider's perspective (etic) of the consequences of any illness studied. They developed an emic interview to elicit explanatory models of patients in their own terms, rooted in local cultural concepts and reflecting the way people think about their world, themselves, their health and their health problems. Originally applied to leprosy, this conceptual view of illness claims to study the relationship between culturally defined experiences (the emic perspective) and professionally defined outcomes/consequences (the etic perspective) related to the coping strategy of

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denial, emotional sequelae, and compliance with treatment. Health care workers quickly see the consequences (the etic view) of perceived stigma (the emic view), such as the decision not to be tested or not to visit an AIDS clinic. However, such workers cannot assume they understand their patients' perceived views of stigma and discrimination unless they ask.

In August 2001, staff at the US National Institutes of Health commissioned a series of papers that reviewed the significance of stigma on health status and access to care and offered suggestions on how to manage stigma. Link and Phelan (2001) proposed that stigma contains five elements. First, differences are identified and labelled. Second, differences (labels) are linked to undesirable attributes. Third, a separation of 'them' and 'us' occurs. Fourth, the resulting discrimination and loss of status lead to devaluation, rejection, exclusion, and blame, which Fife and Wright (2000) described as social rejection, financial insecurity, internalised shame, and social isolation. Fifth, this process can take place only if a group is able to enforce the stigma. Breaking down the process of stigmatisation into these steps provides a framework for a better understanding of the concept and target interventions to reduce stigma.

Link and Phelan (2001) articulate three mechanisms of stigma. One is direct discrimination at a person-to-person level, where activities devalue, reject, exclude or blame the other person. A second is structural discrimination in which social contexts, such as a sign identifying an HIV/AIDS clinic, enforce stigma without person-to-person actions. The third mechanism is self-stigmatisation, a socio-psychological process that operates through the stigmatised person. Stigmatised persons apply labels to themselves, believe in these labels, and live accordingly. Evidence of stigma appears in three forms in nursing and patient care, according to Jillings and Alexis (1991, p. 62-63): '(1) the labels and stereotypes attached by society to particular illnesses; (2) the patient's behaviors toward others as a result of feeling stigmatised; and (3) the values and assumptions of nurses themselves in relation to selected illnesses'. Nurses and other health workers who care for persons living with HIV/AIDS have their own emic view of stigma that may lead them to promulgate prejudice and discrimination toward their patients. The impact of this type of stigma on patients is unclear. At the same time, nurses and health care

workers are the recipients of stigma from their families, friends and patients. It is unclear how such received stigma affects the quality of work life for HIV/AIDS care providers.

The HIV/AIDS literature in recent years has devoted considerable attention to the concept of AIDS stigma, particularly after the XIII International AIDS Conference in Durban, South Africa in 2000. Herek *et al.* (2002) traced the prevalence of AIDS stigma in the US for the period 1991 - 1999. They concluded that although support for extreme, punitive measures — such as putting HIV-positive persons in camps — had decreased, AIDS remained a significantly stigmatised condition. Apparently, similar studies have not been done in southern Africa.

De Bruyn (1999) identified factors contributing to HIV/AIDS stigma. These include the fact that AIDS is life-threatening, that people fear it, that it is associated with behaviours (for example drug use) already stigmatised by many societies, and that people with HIV/AIDS are viewed by others as responsible for contracting the disease. What is stigmatised and how stigma is manifested may vary among different cultures (Weiss & Ramakrishna, 2001). Some authors have noted that stigma may also be different for men and women (Bunting, 1996; Vlassoff *et al.*, 2000). In addition, the degree to which a person with HIV or AIDS actually feels stigmatised may depend on individual differences.

Although stigmatisation is associated with membership of a group, not all members of the group necessarily feel stigmatised (Harvey, 2001). Fife and Wright (2000) explored the difference between the impact of stigma on persons with cancer and on persons with HIV/AIDS, and found that HIV+ people experienced significantly more stigma. A study of stigma against persons with HIV/AIDS in Uganda demonstrated a strong gender bias (women were more stigmatised than men), rejection by their families, increased suspicion and gossip, and isolation in communities (Aggleton, 2000; Monico, Tanga & Nuwagaba, 2001).

The Siyam'kela Project (Insideout Research, 2003) recently completed a series of interviews and focus groups in South Africa with persons living with HIV/AIDS, faith-based organisations and leaders, and governmental groups. They reported several stigma factors based upon a content analysis of their

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interview and focus group data. The themes related to external or enacted stigma included: avoidance, rejection, moral judgment, stigma by association, unwillingness to invest in persons living with HIV/AIDS, discrimination, and abuse. The themes related to internal or felt stigma included: self-exclusion from services and opportunities, perception of self, social withdrawal, overcompensation, and fear of disclosure.

Sandelowski, Lambe and Barroso (2004) reported on a metasynthesis of 93 qualitative reports on stigma among women living with HIV/AIDS in the USA. They stated that none of the reports were excluded for reasons of methodological quality, a strategy that may significantly have limited their observations. Extractable stigma findings were defined as 'any interpretation pertaining to stigma that could be separated from other elements of the research report (p.123). Using Herek and Capitano's (1993) definition of stigma, these were databased events pertaining to prejudice, discounting, discrediting, and discrimination. They organised their key findings into a taxonomy based upon some 2 000 statements of stigma findings. Their taxonomy focuses upon information management, principally related to the data elements and outcomes of disclosure of HIV status. Because it focuses primarily upon an individually received view of stigma, this taxonomy provides some insight into the issues related to disclosure but little help regarding the issues of stigma in high-prevalence countries, the context of stigma or community-based stigma. They suggest their results support a gender-linked intensification of stigma yet they only reviewed studies of women so it is unclear how such a conclusion could be drawn.

Nyblade (2003) recently reported on the results of 700 interviews with community members, persons living with HIV/AIDS, youth, caregivers, religious leaders, NGOs, and employers in Ethiopia, Tanzania and Zambia. Their objective was to disentangle stigma and thus provide a four-part framework based upon the content analysis of their interviews. They suggested that stigma could be best understood from the perspective of (i) causes of stigma; (ii) context of stigma; (iii) experiences of stigma; and (iv) effect of stigma on programmatic efforts. This macro-level framework is helpful to begin an understanding of the complexity of stigma.

Five instruments have been reported in the literature designed to measure HIV/AIDS stigma.

- Herek and Capitano (1993) developed a 10-item instrument to measure the USA public's stigma regarding HIV/AIDS. The instrument measures four factors: negative feelings toward persons with AIDS (three items); support for coercive AIDS-related policies (two items); blame of persons with AIDS (one item); and intentions to avoid a person with AIDS (four items). It enables calculation of a single stigma score. No item analysis was reported. Subsequent studies (Herek *et al.*, 2002) used this instrument to monitor changes in attitudes towards stigma and results showed significant AIDS-related stigma among a notable minority of the USA public.
- Sowell, Lowenstein, Moneyham, Demi, Mizuna and Seals (1997) reported on a 13-item scale used with rural HIV-positive women in the southern USA. The report provides little background information on the scale, number of items, or its psychometric properties. They reported a significant difference between older and younger respondents with respect to two items: younger participants perceived a higher level of stigma regarding being blamed and for losing friends, and African Americans felt more afraid of rejection by their families than did Caucasians. There were no differences by level of income.
- Fife and Wright (2000) reported on the development of a 24-item, Likert scaled instrument based on labelling theory that expresses stigma in terms of four dimensions: social rejection, financial insecurity, internalised shame, and isolation or anomie. Scales for the four factors had Cronbach alpha reliability coefficients ranging from 0.85 to 0.90. Using this scale, Fife and Wright (2000) compared stigma associated with HIV/AIDS versus stigma associated with cancer and found that the aggregate stigma of AIDS was significantly higher than that of cancer for all four dimensions. This difference was true even when the background of respondents and the severity of illness were controlled. Very few demographic variables were significantly related to overall measure of stigma, although some subtle patterns emerged. Older people, for example, showed more internalised

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blame than younger participants, while women felt more social isolation and anomie than men.

- Berger, Ferrans and Lashley (2001) reported on the psychometric properties of the 101-item HIV stigma scale, which was tested on 318 HIV-positive persons (19% women). The resulting factor analyses supported four subscales: personalised stigma, disclosure concerns, negative self-image, and concern with public attitudes toward persons with HIV. Cronbach alpha reliability coefficients for the subscales ranged from 0.90 to 0.93. The instrument uses a 4-point Likert scale, from 'strongly disagree' to 'strongly agree'. Construct validity was further supported by significant negative correlations between stigma and self-esteem and social support, and by significant positive correlations between stigma and depression and social conflicts.
- Bauman, Silver and Camacho (2000) reported on use of the perceived stigma scale. Its two factors — personal view and public view — measured stigma among 237 mothers with HIV/AIDS. The instrument has 48 items (24 per factor) and uses a 4-point Likert scale to assess participants' level of agreement with items measuring attitudes toward stigma and discrimination. The personal view portion of the scale (Cronbach alpha = 0.87) purports to measure respondents' personal beliefs and attitudes about HIV. Items reflect shame, guilt, blame, embarrassment, self-worth, and attitudes about self. The public view portion of the scale (Cronbach alpha = 0.90) targets respondents' perceptions of others' beliefs and attitudes about HIV.

Researchers have not used these scales to measure stigma as an outcome measure in intervention studies designed to reduce stigma. Also, none of these scales have been used in countries with very high HIV prevalence data such as South Africa, where stigma has a significant impact on people's lives. It is not clear if the scales would be culturally appropriate for this region because issues of sexuality, gender, race and ethnicity, and class are intimately linked to HIV/AIDS stigma (Parker & Aggleton, 2002). Madru (2003, p. 48) recently reviewed the theory and historical background of stigma, and concluded that: 'Perhaps the most devastating effect of stigma on the HIV epidemic is the willingness and ease with which societies use it to assign blame to individuals, their behaviors, and the

groups they belong to - usually the poor and minority or those seen as morally deficient'.

This paper hopes to provide a greater understanding of stigma for nurses and other health care workers and suggest some strategies for dealing with these devastating effects.

What is the impact of HIV/AIDS stigma?

Few articles have investigated the impact of AIDS stigma on quality of care. While limited data are available, numerous testimonials from several countries document the effect that stigma has on reducing access to care. In a study of women who refused to be tested for HIV at Ethiopian antenatal clinics, Kumbi, Bedri, Abashawl, Isehak, Coberly and Ruff (2002) concluded that fear of, and the stigma associated with, HIV were significantly related to the women's decision. Munhenga, Chiwara, Jena, *et al.* (2002) reported similar results regarding antenatal clinics in Zimbabwe. At an Indian clinic that focused on men who have sex with men (MSM), fear and stigma were the reasons MSM cited for not using the clinic's services (Chakrapani, Govindan, Joseph & Balasubramaniam, 2002). Donini, Tunala, Castanheira, Melchior, Basso and Brittoe Alves (2002) explored quality of care issues in focus groups at an HIV/AIDS health clinic in Brazil. Patients as well as doctors identified client-provider communication as a priority in determining quality of care. The authors wrote: 'Open lines of communication improve adherence to treatment and facilitate patients' acceptance of the disease as well as coping skills with the stigma of being HIV-positive'.

For persons living with HIV/AIDS, stigma is one of the most insidious barriers affecting access to and provision of health services, particularly in southern Africa and India (AIDS Alert, 2002). According to Aggleton and Parker (2002, p. 9), '[t]he real battle against AIDS in Africa is being played out in the families and villages of Africa, where the authority of government rarely extends. This sort of discrimination is intensely personal and it takes many forms'. Personal testimonies (Integrated Regional Information Networks [IRIN] 2002), support this: 'Even doctors and nurses don't know about AIDS and treat us badly,' said Paula (22), who learned she was HIV-positive when her baby died 6 months ago.

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Care for patients living with HIV/AIDS might be substandard because caregivers often fail to comply with universal precautions, perhaps due to perceived stigma (Horsman & Sheeran, 1995). Among health care workers in Kampala, Uganda, 29% indicated they had never talked with patients about how to prevent AIDS and 26% had not referred any patients for HIV counselling (Mungherera *et al.*, 1997). Other researchers have reported that health care personnel knew very little about the potential for HIV contamination in the workplace (Hossini *et al.*, 2000). In Kuwait, some family doctors knew less than they should have about HIV and looked upon AIDS patients negatively, even in the third decade of the AIDS pandemic (Fido & Kazemi, 2002). Similar to the findings of Adebajo, Bamgbala and Oyediran (2003) in Nigeria, the results in Kuwait showed that nurses and laboratory technicians also had negative attitudes toward AIDS patients. Health care workers' poor attitudes and inadequate care in these anecdotal reports could be related to stigma.

As with quality of care issues, few empirical studies explored stigma's relationship to quality of life, and most information about stigma's negative impact on quality of life as perceived by persons with HIV/AIDS is in the form of testimonials: 'It's so hard,' said a tearful Rita. 'The moment people learn I'm HIV-positive, they treat me differently. Neighbours shun me. Children avoid touching me. The landlord finds an excuse to kick me out of my room.' (IRIN, 2002).

Elsewhere in the world, Ayarza and Reyes (2002) described the traumatic effect that stigmatisation and lack of pretest counselling had on the quality of life of persons with HIV/AIDS in Ecuador. Studies by Castle *et al.* (2002) and Ortega, Gonzales and Liwanag (2002) found that such persons had both positive and negative experiences when they became involved in community-based programmes. According to these researchers, access to services that offer peer support ends self-isolation and reduces stigma, and thus enhances quality of life.

The International HIV/AIDS Alliance links HIV and tuberculosis (TB) care programmes in Cambodia, India, and east and southern Africa. Stigma and discrimination at community and institutional levels were significant barriers to quality of life for persons living with HIV/AIDS and to the Alliance's efforts to improve HIV and TB services (Cornu & Dhaliwal,

2002). In Italy, researchers found a significant correlation between lipodystrophy and lower quality of life among 175 AIDS patients (Orlando *et al.*, 2002). Although investigators did not measure stigma, they reported that lower role functioning, as measured by their quality of life scale, was attributable to perceived stigma. These studies illustrate the lack of empirical information about the relationship between stigma and quality of life. In summary, no empirical studies have been located that explore the impact of stigma on quality of care or quality of life for persons living with or affected by HIV/AIDS. In addition, no empirical studies have documented the impact of stigma on quality of work life for nurses and other health care workers.

Testimonials also support the contention that AIDS stigma gravely affects the quality of work life for nurses in southern Africa (South Africa Development Community AIDS Network of Nurses and Midwives, 2000), yet no studies have documented its impact.

How can health care workers address stigma in a way that helps clients manage their HIV in a stigmatising environment?

Understanding the attitudes of nurses and other health care workers toward AIDS patients is important in order to plan how to use health care workers to intervene against stigma. Health care workers themselves are the recipients of stigma because they care for people living with HIV/AIDS and are also often the source of stigma from the perspective of many people living with HIV/AIDS. Horsman and Sheeran (1995) found a lack of information when they conducted an extensive literature review of the impact of HIV/AIDS on such workers in relation to three major themes — their fear of becoming infected, their perceived rights in refusing to care for patients with HIV/AIDS, and the stresses they experienced in providing HIV care. The researchers offered these suggestions: (i) in order to compare results from various studies about the attitudes and knowledge of health care workers, investigators should consistently use instruments that have been validated; and (ii) investigators should study effects at the cultural level rather than focus exclusively on individuals.

Some health care workers feel reluctance or discomfort about having direct contact with AIDS patients (Adebajo *et al.*, 2003; Adelekan *et al.*, 1995; Hossini *et al.*, 2000; Mungherera *et al.*, 1997; Wiley,

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Heath, Acklin, Earl & Barnard, 1990). According to a study at the University of Ilorin Teaching Hospital in Nigeria, about one-third of nurses hesitated to care for AIDS patients and half refused to help with births (Adelekan *et al.* 1995). In another study, which looked at health workers who cared for HIV-positive haemophiliac patients, the high stress associated with the workers' demanding jobs was significantly related to lower retention and job satisfaction (Brown *et al.*, 2002). Nurses in Argentina experienced high levels of symptoms, such as depression and burnout, related to working with AIDS patients (Martearena & Celentano, 2002).

Unger, Welz and Haran (2002) studied the workload and job satisfaction of 200 nurses working in a rural KwaZulu-Natal hospital in South Africa where the incidence of AIDS was very high. Between 1995 and 2000, nursing staff increased 10% (from 620 to 683) yet annual absenteeism shot up 310% (from 316 total days per year to 981 days per year). The number of nurses who died during any one year rose from 2 per year to 13 nurses per year. Working conditions, the authors concluded, caused high rates of sick leave and job dissatisfaction. HIV/AIDS had a major impact on nurses' capacity to respond to patient care needs in that setting.

Although nurses and social workers in Canada were concerned about becoming infected by HIV, Olivier and Dykeman (2003, p. 649) found that 'they demonstrated shared professional values such as the importance of self-awareness and professional knowledge, positive and non-judgmental attitudes, and non-discriminatory treatment of client groups'.

Far less research has been done to assess the impact of AIDS stigma on HIV-positive nurses. Published data on the HIV status of various levels of nursing personnel are almost nonexistent. One exception is a study that focused on 26 HIV-positive health care providers in Cameroon, including physicians ($N = 4$, 15.4%), nurses ($N = 6$, 23.1%), nurse aides ($N = 7$, 26.9%), and 'other' ($N = 9$, 34.6%) (Mbanya, Pollaa & Kaptue, 2002). O'Keeffe and Frankham (2002) followed 15 HIV-positive health care providers (type not specified) in Uganda, noting that these providers needed support for their fear of disclosure and stigma.

There is little empirical information about the effect that stigma and discrimination might have on the

quality of work life for nurses and other health care workers in southern Africa. Testimonials by nurses support the perception that their families and community members stigmatise them. Testimonial data also suggest that patients with HIV/AIDS report that nurses and other health care workers stigmatise them. Educational interventions are needed to address this duality and might include role-playing, case studies, and visits with persons who have HIV/AIDS. There are numerous reports about nursing curricula and continuing education programmes that build nurses' capacity to respond effectively to the HIV/AIDS pandemic. Laloo *et al.* (2002) cited a continuing education programme for 912 health care workers in KwaZulu-Natal, which emphasises the continuum of care. The Baylor College of Medicine in Houston and the South African Development Community AIDS Network for Nurses and Midwives (SANNAM) have co-developed an HIV/AIDS Nursing Curriculum for use in southern Africa (Kline *et al.*, 2002). Zengwa, Msiska and Anderson (2002) described how SANNAM seeks to 'make a significant impact on HIV/AIDS care and prevention by strengthening the role of nurses and midwives in the region. The network shares information, promotes best practices, and builds capacity', by linking nurse leaders so they can work and consult with each other. In Uganda, nurses and midwives need broad education about HIV/AIDS prevention and care (Walusimibi, Okonsky, Colagreco, Kirton & Fitzpatrick, 2002).

Although some curricula address the basics of AIDS care, the attitudes and behaviours related to stigma receive little attention. Three training guides are currently available to address HIV/AIDS stigma:

- *Combating HIV/AIDS stigma, A manual for nurses.* (Uys, 2003). This is a guide consisting of seven units, aimed at health workers, mainly nurses. It was developed and tested for the SADC AIDS Network of Nurses and Midwives (SANNAM).
- *Understanding and challenging HIV stigma. Toolkit for action.* (Kidd & Clay, 2003). This is also a seven-unit guide, and has a unit specifically dealing with stigma faced by children.
- *Reducing stigma and discrimination related to HIV and AIDS. Training for health care workers.* (EngenderHealth, 2004). This guide is organised into 16 sessions, and deals very thoroughly with risk of infection faced by health workers, using an infection control approach to reducing provider stigma. They tested the impact of the package in

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Nigeria, and initial results indicate that the training greatly reduced stigmatising by providers (Nwando & Enuga, 2004).

All three guides are available on the web.

Various authors have tried, through community support, to reduce stigma by improving quality of care and adherence to medication, and by enhancing quality of life. One of the more creative efforts in the Dominican Republic used a national song contest focused on the stigma and discrimination associated with HIV/AIDS (Brito, 2004). While such efforts seem to have lowered the perception of stigma, actual changes in stigma have not been measured. Brown, Trujillo and Macintyre (2001) reviewed 21 studies of interventions explicitly designed to decrease AIDS stigma in developed and developing countries.

Overall, they concluded that there was agreement that stigma could be reduced. When any two interventions were compared, both were usually somewhat successful. Interventions in developing countries tended to be at the community level, while those in developed countries tended to be at the individual level. According to the authors, most intervention studies in developing countries were not rigorously evaluated and usually lacked validated measures of stigma. Furthermore, few of the studies explored changes in stigma scores over time.

In Thailand, villagers reported less stigma toward persons with AIDS if health volunteers in the villages had undergone training (Mashimo *et al.*, 2001). Buhendwa, Zachariah and Labana (2002) examined the role of communities in caring for and supporting persons with AIDS in Malawi. Two nurses and a doctor there supervised 160 volunteers working with nearly 1 000 AIDS patients who received home-based care. As a result, the morbidity rate fell from 50% to 15%, and the mortality rate dropped from 35% to 8%. 'The stigma begins to disappear and the much-needed solidarity for [persons living with AIDS] begin[s] to emerge,' the authors reported. However, they did not present any data measuring change in stigma. Lack of measurement is common in other studies of stigma interventions (Carneiro-da-Cunha *et al.* 2002; Garda, Rao, Bopardekar & Rout, 2002; Green, Chum, Moth, Suon & Ma, 2002; Kiguli, Batusa, Mayanja & Ssebikije, 2002; Mutissa & Lingani, 2002; Omondi, Auka, Kimanzi & Mangira, 2002; Schimmer, 2002).

A small number of empirical studies have looked at the impact of stigma on the quality of health care for persons with HIV/AIDS. But most published research lacks rigorous qualitative or quantitative methods and relies instead on testimonials. Thus, to better understand how stigma truly affects patients and their families, there is a need for rigorous qualitative studies. Also needed is empirical outcomes research on the quality of care that AIDS patients receive when health care workers highly fearful HIV will infect them on the job, are reluctant to treat such patients. Other studies should explore the effect on patients of nurses' stigma — including nurses' care-giving behaviours — and the extent to which nurses contribute to the stigma perceived by patients and their families. Psychometric studies to develop valid and reliable scales for measuring stigma are necessary for a better understanding of the extent of stigma, its correlates (e.g. gender and class), how stigma changes over time, the impact of interventions, and stigma's impact on quality of care and patient outcomes.

Based on this review of the work related to stigma, Table 1 suggests some strategies that nurses and other health care workers could use to assist people living with HIV/AIDS to manage the stigma associated with their illness. They are offered as a beginning point for discussion about using a decision-making process, such as the nursing process, to assess, diagnose, manage and evaluate the impact of perceived stigma on the lives of people living with and affected by AIDS stigma.

Conclusion

This paper reviewed the literature on stigma and AIDS care, with a particular focus on understanding different definitions and conceptual models of stigma, the impact stigma has on quality of care for, and quality of life of persons living with AIDS, and intervention strategies related to the management of stigma. Nearly all of the research on this subject has lacked rigorous scientific analysis, relying instead on testimonials. Few studies have actually measured stigma or documented how stigma changes over time or its impact on quality of care or quality of life for people living with HIV/AIDS. Few authors have discussed the implications of AIDS stigma for health care workers, including nurses. Nurses and health care workers worldwide are committed to providing quality patient care in a supportive environment. If health care workers are themselves a reservoir of

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TABLE I. SUGGESTED STRATEGIES FOR REDUCING AIDS STIGMA

Assessing	Diagnosing	Managing	Evaluating
Determine family, partner and friends' support	Determine psychosocial strength of client	Link client with social support services, including PWA groups if appropriate	Assess adherence to medications, explore for stigma-related non-adherence behaviour
Assess community support, legal issues	Determine need and readiness for ART	Establish ongoing care relationship with client	Assess engagement with care, keeping appointments, etc.
Determine strength of the person to cope with negative attitudes from others	Diagnose client's knowledge, attitudes, and behaviours related to stigma and HIV/AIDS	Assist with medication and illness management	Assess adequacy of social support and environment for managing stigma
Assess for mental health, including depression, fear and suicidal ideation			
Assess readiness for participation in HIV care, including ART			

perceived stigma from the patient's perspective, research strategies are necessary to better understand the phenomenon, and intervention strategies are necessary to eliminate it from practice. Anecdotal evidence, particularly from southern Africa, suggests that perceived stigma has a significant negative impact on the quality of life of persons living with HIV/AIDS and on the quality of work life of nurses and other workers who care for them. Part of the challenge of AIDS stigma is to recognise its impact on patients and caregivers alike and to develop strategies for mitigating its effects.

References

- Adebajo, S.B., Bamgbala, A.O. & Oyediran, M.A. (2003). Attitudes of health care providers to persons living with HIV/AIDS in Lagos State, Nigeria. *African Journal of Reproductive Health*, 7(1), 103-112.
- Adelekan, M.L., Jolayemi, S.O., Ndom, R.J. et al. (1995). Caring for people with AIDS in a Nigerian teaching hospital: staff attitudes and knowledge. *AIDS Care*, 7 (Suppl. 1), S63-S72.
- African Development Forum (2000). *AIDS in Africa country by country*. Geneva: Joint United Nations Programme on HIV/AIDS.
- Aggleton, P. (2000). *Comparative analysis: research studies from India and Uganda*. Geneva: Joint United Nations Programme on HIV/AIDS.
- Aggleton, P. & Parker, R. (2002). *A conceptual framework and basis for action: HIV/AIDS stigma and discrimination*. Geneva: Joint United Nations Programme on HIV/AIDS.
- AIDS Alert (2002). *AIDS stigma forms an insidious barrier to prevention/care. HIV experts describe problem in India*. Sept, 17(9), 111-113.
- 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.
- Ayarza, R. & Reyes, B. (2002). *Changes in quality of life of people living with HIV/AIDS in Ecuador*. Abstract, XIV International AIDS Conference, July 7-12, Barcelona, Spain. Abstract Number: WePeE6460.
- Bauman, L.J., Silver, E.J. & Camacho, S. (2000). *Stigma among mothers with HIV/AIDS*. Abstract, XIII International AIDS Conference, July 9-14, Durban, South Africa. Abstract Number: MoPeD2578.
- Berger, B.E., Ferrans, C.E. & Lashley, F.R. (2001). Measuring stigma in people with HIV: psychometric assessment of the HIV stigma scale. *Research in Nursing and Health*, 24(6), 518-529.
- Brito, C. (2004). *National songs contest: A channel to target stigma and discrimination*. Abstract, XV International AIDS Conference, July 11-15, Bangkok, Thailand. Abstract Number: MoPeD3931.
- Brown, K.L., Schultz, J.R., Forsberg, A.D. et al. (2002). Predictors of retention among HIV/hemophilia health care professionals. *General Hospital Psychiatry*, 24(1), 48-54.
- Brown, L., Trujillo, L. & Macintyre, K. (2001). *Interventions to reduce HIV/AIDS stigma: What have we learned?* Washington, D.C.: Population Council.
- Buhendwa, L.M., Zachariah, R. & Labana, S. (2002). *Role of communities in care and support to people living with AIDS in Thyolo, Malawi*. Abstract, XIV International AIDS Conference, July 7-12, Barcelona, Spain. Abstract Number: TuOrF1254.
- Bunting, S.M. (1996). Sources of stigma association with women with HIV. *Advances in Nursing Science*, 19(2), 64-73.
- Canadian HIV/AIDS Legal Network (1998). *HIV/AIDS and Discrimination: A Discussion Paper*. Ottawa: Canadian HIV/AIDS Legal Network and the Canadian AIDS Society.
- Carneiro-da-Cunha, C., Kerrigan, D., Malta, M., Fortuna, M., Strathdee, S. & Bastos, F. (2002). *Assessing and improving adherence to highly active anti-retroviral therapy among socially disadvantaged persons living with HIV/AIDS in Rio de Janeiro, Brazil*. Abstract, XIV International AIDS Conference, July 7-12, Barcelona, Spain. Abstract Number: WeOr1367.
- Castle, C.J., Cornu, C., Dua, R., Herrera, D., Nadkarni, V., Ouédraogo, A., & Velasco, N. (2002). *Meaningful involvement of people living with HIV/AIDS: positive and negative effects of involvement in community-based programs*. Abstract, XIV International AIDS Conference, July 7-12, Barcelona, Spain. Abstract Number: WeOrG1292.
- Chakrapani, V., Govindan, J., Joseph, M. & Balasubramaniam, S. (2002). *Establishing an STD clinic for men who have sex with men (MSM): experiences of an Indian community-managed organization*. Abstract, XIV International AIDS Conference, July 7-12, Barcelona, Spain. Abstract Number: F11847.
- Cornu, C. & Dhaliwal, M. (2002). *Linking HIV and TB services — a strategy for improving the quality of life of PLHA*. Abstract, XIV International AIDS Conference, July 7-12, Barcelona, Spain. Abstract Number: TuPeG5646.
- Corrigan, P.W., Bodenhausen, G., Markowitz, F. et al. (2003). Demonstrating translational research for mental health services: an example from stigma research. *Mental Health Services Research*, 5(2), 79-88.
- De Bruyn, M. (1999). Intersecting health risks: adolescent unwanted pregnancy, unsafe abortion, and AIDS. *Initiatives in Reproductive Health Policy*, 3(1), 4-5.
- Donini, A.A., Tunala, L.G., Castanheira, E.R.L., Melchior, R., Basso, C.R. & Britto e Alves, M.T.S. (2002). *Quality of care in HIV/AIDS health services in Brazil: a focus group approach*. Abstract, XIV International AIDS Conference, July 7-12, Barcelona, Spain. Abstract Number: B10642.

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- EngenderHealth (2004). *Reducing stigma and discrimination related to HIV and AIDS. Training for health care workers*. Retrieved September 17, 2004, from <http://www.engenderhealth.org/res/offc/hiv/stigma/index.html#stigma>
- Fido, A. & Kazemi, R.A. (2002). Survey of HIV/AIDS knowledge and attitudes of Kuwaiti family physicians. *Family Practice*, 19(6), 682-684.
- 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 Social Behavior*, 41(1), 50-67.
- Garda, L.F., Rao, V.N., Bopardekar, A. & Rout, P.B. (2002). *A self-help group of HIV-infected or affected women-a care and support initiative in rural India*. Abstract, XIV International AIDS Conference, July 7-12, Barcelona, Spain. Abstract Number: WePeF6639.
- Goffman, E. (1963). *Stigma: notes on the management of spoiled identity*. Englewood Cliffs, N.J.: Prentice Hall.
- Green, K.E., Chum, C., Moth, S.K., Suon, B.H. & Ma, S.S. (2002). *Home care along the Cambodian-Thai border: challenges and successes in delivering quality care to mobile people living with HIV and AIDS*. Abstract, XIV International AIDS Conference, July 7-12, Barcelona, Spain.
- Harvey, R.D. (2001). Individual differences in the phenomenological impact of social stigma. *Journal of Social Psychology*, 141(2), 174-189.
- 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. & 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., Mitnick, L., Burris, S., Chesney, M., Devine, P., Fullilove, M.T., et al. (1998). Workshop report: AIDS and stigma: A conceptual framework and research agenda. *AIDS & Public Policy Journal*, 13(1), 36-47.
- Horsman, J.M. & Sheeran, P. (1995). Health care workers and HIV/AIDS: a critical review of the literature. *Social Sciences and Medicine*, 41(11), 1535-1567.
- Hossini, C.H., Tripodi, D., Rahhali, A.E. et al. (2000). Knowledge and attitudes of health care professionals with respect to AIDS and the risk of occupational transmission of HIV in 2 Moroccan hospitals. *Sante*, 10(5), 315-321.
- Insideout Research (2003). *Siyam'kele: A report of the fieldwork leading to the development of HIV/AIDS stigma indicators and guidelines. A research report*. Retrieved November 10, 2004, from www.policyproject.com/pubs/countryreports/SA_Siyam_fieldwork.pdf
- Integrated Regional Information Networks (IRIN) (2002). *Angola: AIDS stigma pervasive. Luanda, 3 July 2002 (IRIN). UN Office for the Coordination of Humanitarian Affairs*. Retrieved November 10, 2004, from www.irinnews.org/report.asp?ReportID=28626&SelectRegion=Southern_Africa&SelectCountry=ANGOLA
- Jillings, C. & Alexus, L. (1991). The concept of stigma: timely, relevant, and possibly uncomfortable. *Critical Care Nurse*, 11(1), 62-64.
- Kaiser Family Foundation (2004). *HIV/AIDS Policy Fact Sheet: HIV Testing in the United States*. Retrieved November 10, 2004, from www.kff.org/hiv/aids/loader.cfm?url=/commonspot/security/getfile.cfm&PageID=37467
- Kidd, R. & Clay, S. (2003). *Understanding and challenging HIV stigma. Toolkit for action*. New York: CHANGE project (AED) International Center for Research on Women. Retrieved September 17, 2004, from <http://www.changeproject.org/technical/hiv/aids/stigma.html>
- Kiguli, K.A.R., Batusa, R.J., Mayanja, J. & Ssebikije, R. (2002). *Religious NGOs involvement to enhance HIV prevention and AIDS care*. Abstract, XIV International AIDS Conference, July 7-12, Barcelona, Spain. Abstract Number: MoPeE3765.
- Kline, N.E., Ferris, M.G., Zengwa, S. et al. (2002). *Implementation of a comprehensive HIV/AIDS nursing curriculum in Southern Africa*. Abstract, XIV International AIDS Conference, July 7-12, Barcelona, Spain. Abstract Number: MoPeF4121.
- Kumbi, S., Bedri, A., Abashawl, A., Isehak, A., Coberly, J.S. & Ruff, A.J. (2002). *Reasons for refusal of HIV testing in two Ethiopian antenatal clinics*. Abstract, XIV International AIDS Conference, July 7-12, Barcelona, Spain. Abstract Number: TuPeD4970.
- Laloo, U.G., Pawinski, R.A., Bobat, R. et al. (2002). *A comprehensive HIV/AIDS training course to meet the needs of public sector health care workers in the province of KwaZulu Natal (KZN), South Africa*. Abstract, XIV International AIDS Conference, July 7-12, Barcelona, Spain. Abstract Number: MoPeB3234.
- Link, B.G. & Phelan, J.C. (2001). *On stigma and its public health implications*. Retrieved February 21, 2003, from www.stigmaconference.nih.gov/LinkPaper.htm
- Madru, N. (2003). Stigma and HIV: Does the social response affect the natural course of the epidemic? *Journal of the Association of Nurses in AIDS Care*, 14(5), 39-48.
- Martareana, C.R. & Celentano, A. (2002). *Burnout and AIDS: a dilemma in mental health*. Abstract, XIV International AIDS Conference, July 7-12, Barcelona, Spain. Abstract Number: MoPeE3764.
- Mashimo, A., Miura, H., Sakano, S. et al. (2001). The role of AIDS volunteers in developing community-based care for people with AIDS in Thailand. *Asian Pacific Journal of Public Health*, 13(1), 3-8.
- Mbanya, D.N.S., Pollaa, E.D. & Kaptue, L.N. (2002). *Prevalence of HIV-1 among health personnel in semi-urban and urban populations of Yaounde, Cameroon*. Abstract, XIV International AIDS Conference, July 7-12, Barcelona, Spain. Abstract Number: MoPeC3518.
- Monico, S.M., Tanga, E.O. & Nuwagaba, A. (2001). *Uganda: HIV and AIDS-related discrimination, stigmatisation and denial*. Geneva: Joint United Nations Programme on HIV/AIDS.
- Mungherera, M., van der Straten, A., Hall, T.L., et al. (1997). HIV/AIDS-related attitudes and practices of hospital-based health workers in Kampala, Uganda. *AIDS*, 11(Suppl. 1), S79-S85.
- Munhenga, A., Chiwara, S., Jena, S. et al. (2002). *Challenges encountered during a clinical trial to prevent mother to child transmission (MTCT) of HIV in urban Zimbabwe: a nurse's perspective*. Abstract, XIV International AIDS Conference, July 7-12, Barcelona, Spain. Abstract Number: F11961.
- Mutissa, T. & Lingani, T.V. (2002). *A home based care strategy to take care of people living with HIV/AIDS in the community*. Abstract, XIV International AIDS Conference, July 7-12, Barcelona, Spain. Abstract Number: MoPeF4139.
- Newman, P.A., Grusky, O., Roberts, S.J. & Rivkin, I. (2002). *Organizational factors in the early detection of HIV*. Abstract, XIV International AIDS Conference, July 7-12, Barcelona, Spain. Abstract Number: TuPeE5146.
- Nwando, O. & Enuga, O. (2004). *Reducing stigma and preventing HIV transmission in Nigerian health facilities*. Abstract, XV International AIDS Conference, July 11-15, Bangkok, Thailand. Abstract Number: MoOrE1077.
- Nyblade, L. (2003). *Disentangling HIV and AIDS Stigma. Overview of findings from a two year study in Ethiopia, Tanzania, and Zambia*. Retrieved November 10, 2004, from www.icrw.org/docs/stigmaintro.pdf
- O'Keefe, C.M. & Frankham, J. (2002). *HIV positive health care professionals in Uganda: an examination of contributions made to HIV/AIDS and the needs of positive workers for support*. Abstract, XIV International AIDS Conference, July 7-12, Barcelona, Spain. Abstract Number: ThPeG8299.
- Olivier, C. & Dykeman, M. (2003). Challenges to HIV service provision: the commonalities for nurses and social workers. *AIDS Care*, 15(5), 649-663.
- Omondi, A.L., Auka, E.G., Kimanzi, J.K. & Mangira, C.O. (2002). *The impact on community-based HIV/AIDS counselors in HIV/AIDS prevention programs*. Abstract, XIV International AIDS Conference, July 7-12, Barcelona, Spain. Abstract Number: WePeD6290.
- Orlando, G., Guaraldi, G., Murri, R. et al. (2002). *Does lipodystrophy affect quality of life?* Abstract, XIV International AIDS Conference, July 7-12, Barcelona, Spain. Abstract Number: ThPeB7340.
- Ortega, N.L., Gonzales, G. & Liwanag, M. (2002). *Greater involvement of people living with HIV and AIDS: key to successful AIDS program*. Abstract, XIV International AIDS Conference, July 7-12, Barcelona, Spain. Abstract Number: WeOrG1296.
- Parker, R. & Aggleton, P. (2002). *HIV/AIDS-related stigma and discrimination: a conceptual framework and an agenda for action*. Washington, D.C.: Population Council.
- Sandelowski, M., Lambe, C., & Barroso, J. (2004). *Sigma in HIV-positive women*. *Journal of Nursing Scholarship*, 36(2), 122-128.
- Schimmer, B. (2002). *HIV/AIDS and human rights: youth in action*. Abstract, XIV International AIDS Conference, July 7-12, Barcelona, Spain. Abstract Number: C10796.
- South Africa Development Community AIDS Network of Nurses and Midwives (August 2000). *Minutes from planning meetings*. Pretoria, South Africa.
- Sowell, R.L., Lowenstein, A., Moneyham, L., Demi, A., Mizuno, Y. & Seals, B.F. (1997). Resources, stigma, and patterns of disclosure in rural women with HIV infection. *Public Health Nursing*, 14(5), 302-312.
- Unger, A., Welz, T. & Haran, D. (2002). *The impact of HIV/AIDS on health care staff at a rural South African Hospital, 1995-2000*. Abstract, XIV International AIDS Conference, July 7-12, Barcelona, Spain. Abstract Number: MoPeE3762.
- Uys, L.R. (2000). Confidentiality and HIV/AIDS in South Africa. *Nursing Ethics*, 7(2), 158-166.
- Uys, L.R. (2003). *Combating HIV/AIDS stigma, A manual for nurses*. Pretoria: SANNAM. <http://www.go2tech.com>
- Vlassoff, C., Weiss, M., Ovuga, E.B. et al. (2000). Gender and the stigma of onchocercal skin disease in Africa. *Social Sciences and Medicine*, 50(10), 1353-1368.
- Walusimbi, M., Okonsky, J., Colagreco, J.P., Kirton, C. & Fitzpatrick, J.J. (2002). Nursing in Uganda in the realm of HIV/AIDS. *Applied Nursing Research*, 15(3), 194-195.
- Weiss, M.G., Doongaji, D.R., Siddhartha, S. et al. (1992). The Explanatory Model Interview Catalogue (EMIC). Contribution to cross-cultural research methods from a study of leprosy and mental health. *British Journal of Psychiatry*, 160, 819-830.
- Weiss, M.G. & Ramakrishna, J. (2001). *Stigma interventions and research for international health*. Retrieved February 21, 2003, from <http://www.stigmaconference.nih.gov>
- Wiley, K., Heath, L., Acklin, M., Earl, A. & Barnard, B. (1990). Care of HIV-infected patients: nurses' concerns, opinions, and precautions. *Applied Nursing Research*, 3(1), 27-33.
- Zengwa, S., Msiska, G.M. & Anderson, S. (2002). *Networking for the advancement of nursing and midwifery in HIV/AIDS prevention, care, and support*. Abstract, XIV International AIDS Conference, July 7-12, Barcelona, Spain. Abstract Number: WePeF6782.