

3. HEALTH CARE SETTINGS: A GLOBAL PERSPECTIVE

Because they define health and illness and grant or deny access to life-saving treatments, the health professionals have a tremendous influence on the physical and emotional welfare of people with HIV or who are vulnerable to infection. It is not surprising, therefore, that people with HIV/AIDS are highly sensitive to the attitudes and behavior of health workers. In a study developed in 1990s in the United Kingdom, 96% of HIV/AIDS patients interviewed reported that the attitudes of health personnel were more important to them than their competency or the effectiveness of the treatment. (Beedham & Wilson-Barnett 1995)

Unfortunately, individuals living with HIV/AIDS have frequently described feelings of stigmatization, social rejection and discriminatory behavior from health personnel. This reality crosses frontiers and continents. In Zambia, “the most extreme forms of stigmatization towards people known or suspected to have HIV were reported in health care settings. This included denial of drugs and treatment, being left in the corridor waiting, being dealt with last, being labeled or called names; being subjected to degrading treatment and breaches of confidentiality.” Similar attitudes were reported from Burkina Faso, India and Ukraine. (Panos / UNICEF 2001)

This chapter focuses on those areas which have been most studied – health workers’ knowledge and attitudes and experiences of people living with HIV/AIDS in health care settings. It discusses findings and conclusions and areas that have yet to be resolved. The perspective is global; Chapter 4 reviews the issue in Latin America and the Caribbean.

3.1. Health workers

Many surveys of health workers’ knowledge and/or attitudes towards HIV/AIDS have been carried out since the disease was identified. These have been in isolation or as baseline or follow-up studies to training programs designed to improve knowledge and reduce discriminatory attitudes. Recent surveys include studies undertaken in China (Wu et al 2002), India (Tibdewel & Wadhva 2001), Israel (Ben-Ari 1996), Ivory Coast (Diarra et al 1996), Morocco (Laraqui Hossini et al 2000), Nigeria (Ezedinachi et al 2002), Pakistan (Najmi 1998), Singapore (Bishop et al 2000), South Africa (Chamane & Kortenaar 1997), Spain (González López 1996) and the United States (e.g. studies referred to in Bennett 1995, 1998 and Brown et al 2003).⁸

Among the different health professions, nurses have been the personnel most studied, followed by doctors, laboratory technicians and dentists. There appears to have been little research into the knowledge and attitudes of other professionals linked to the health services, such as psychologists, counselors, social workers, occupational therapists and administrative staff.

The problems that arise in comparing studies were identified in the previous chapter, in particular lack of consistency between papers in terms of methodology and content. Not only do studies use different mechanisms to elicit responses, but also interpretation of those responses may be open to question. Studies may emphasize the negative or draw conclusions that others might not share, for example confusing homophobia with fear of contagion. (Bennett 1995)

⁸ Dates refer to year of publication, not the study. For example, the research for Bishop et al was carried out in 1996-1997, although the results were only published in 2000. In some cases the year of research is not given.

However, enough information is available to provide a general overview. This is followed in Chapter 5 by examples of programs which have been shown to improve health workers' understanding of HIV/AIDS and which have led to some reduction in discrimination.

3.1.1. HIV transmission and fear of contagion/infection

Surveys of health workers' knowledge of HIV/AIDS are generally restricted to awareness of how the virus is and is not transmitted. Such surveys generally reveal moderately high (over 10%) or high (over 20%) ignorance of this topic⁹. Thus, among recent studies, 46% - 62% of health workers in China who had not received HIV/AIDS training were misinformed on transmission and non-transmission, compared to 0% - 11% who had received training (Wu et al 2002); 11% of Moroccan health workers were uncertain of means of transmission (Laraqui Hossini et al 2000) and 10% to 25% of health workers in Singapore believed that the virus could be transmitted by mosquitoes (Bishop et al 2000). Among older studies, 15.5% of Israeli health workers could not confirm that HIV cannot be transmitted through sharing food or eating utensils and 22.9% did not know that sterilization was required to ensure needles and syringes were HIV-free (Ben-Ari-1996).

There is a high correlation between ignorance of the means of HIV transmission and the fear of contagion / infection; in some cases the proportion of health workers expressing fear is much greater than the number who have misconceptions about transmission.¹⁰ For example, 56% of doctors and 62% of paramedics in Morocco admitted anxiety in taking care of a patient with HIV. (Laraqui Hossini et al 2000)

In fact there are two kinds of fear: the unfounded fear of casual contagion, which can be dispelled through accurate information in appropriate training, and fear of the real but low risk of infection from occupational exposure – needle stick injury or body fluids when treating an open wound. (Brown et al 2003)

Unlike the first, this second fear is rational. “When the possible consequence is immense or inevitable, even negligible risk is not so acceptable. Thus, it is not so unreasonable to find that despite the greater transmissibility of hepatitis, nurses appraise HIV risk as more serious, given the greater morbidity and mortality (virtually 100% risk) associated with its (albeit unlikely) transmission”. (Bennett 1998) While it may be reduced through adherence to appropriate control procedures, it may not be appropriate to seek to totally eliminate fear of this form of infection; a better approach may be to seek a clearer understanding of the different fears related to HIV/AIDS and to develop appropriate responses.

Fear of HIV may be exhibited in different ways. A study in the mid-1990s identified several different reactions among nurses that could be the result of fear, including support for policies intended to protect health workers from infection, fear of contact with blood and body fluids, rejection of people with HIV/ AIDS, restricting care to those who “deserve” to be helped and fear of being abandoned if the health worker him-/herself contracted HIV/AIDS. (Wang & Paterson 1996) Fear can lead to extreme reactions, such as support for measures to isolate all patients with HIV/AIDS and to ban children with HIV/AIDS from attending school. (Ben-Ari 1996)

3.1.2. Vulnerable groups

Surveys of health workers generally show that about 10% - 20% hold negative attitudes towards people living with HIV/AIDS. Such attitudes are associated with both fear of transmission and fear or disapproval of the actual or presumed lifestyles of people living with HIV/AIDS.

In 1992 16.6%-19.1% of nurses in Georgia, USA, expressed resentment at “having to risk [their] health

⁹ Ideally, comprehensive research into the HIV/AIDS-related stigma and discrimination would undertake comparative studies with other diseases. These were not identified, so it is not certain whether health workers are more, equally or less knowledgeable about HIV/AIDS than, for example, hepatitis, influenza or other viral or bacterial infections.

¹⁰ This fear was identified above (Section 2.2.1) as instrumental to AIDS stigma.

Fear of contagion may also represent a symbolic response to threats associated with the unknown, sexuality, punishment and mortality; in this analysis, fear is rooted less in the reality of risk than in the deep social and cultural values which mold people's perceptions of the disease. (Meisenhelder and LaCharite 1989) As an example of this phenomenon, anecdotal reports from Latin America suggest that in that region, and possibly elsewhere, fear of occupational exposure and homophobia may combine. Some heterosexual male health workers report being afraid of contracting HIV at work, not so much because the disease is fatal, but because when HIV-positive, they may be identified as homosexual.

to treat persons who became infected with HIV from multiple sex partners / intravenous drug use". (Dimick et al 1996) Similar attitudes were expressed in an Israeli survey of health workers, when 46.3% of health workers agreed with the statement that "The high cost of treating AIDS is unfair to other people in the hospital", and 71.3% agreed with the statement "There is more talk than actual discrimination against people with AIDS". (Ben-Ari 1996)

Homophobia is a significant element in health workers' negative attitudes. In the United States, where HIV transmission between men has fallen from over 75% of all cases in the early years of the epidemic to 40% of all cases in recent years, homophobia continues to be a significant element in health workers' negative attitudes. In 1993, one study reported that student nurses were more "afraid" of homosexuality than of HIV/AIDS (Eliason 1993) and several other studies in the early 1990s found antipathy towards homosexual men (Glad et al 1995).

Such a response may not be universal; a later study of student nurses in the United Kingdom found more prejudice towards HIV/AIDS than towards homosexual men (Stewart 1999) while it has been suggested that in some studies where health workers' reactions were interpreted as homophobia, the

response could actually reflect fear of casual contagion. (Bennett 1995) Nevertheless, in Latin America and elsewhere, there is sufficient anecdotal evidence to suggest that homophobia is an important, or even over-riding, element in HIV/AIDS related stigma, but there is little statistical information to confirm this.

Meanwhile, little research has been undertaken into the extent to which negative attitudes towards injecting drug users and women sex workers are a component in HIV/AIDS-related stigma and discrimination.

3.1.3. Personal contact

It is generally agreed that personal contact, combined with accurate knowledge of the disease, is a significant element in improving health workers' attitudes and behavior towards people with HIV/AIDS. (Brown et al 2003) As noted above, personal contact varies, with nurses spending more of their work time in contact with patients than any other health profession. However, little research has been undertaken into the substance or impact of the interactions between HIV-positive patients and health staff. One exception is a US study which noted that "the behavior of nurses greatly affect the nature of the behavioral response returned by the patients"¹¹, but the implicit correlation – nurses' reactions to patients – was not studied. (Kemppainen et al 1998)

Greater contact time means that nurses are both more able to develop personal relationships with patients, but also that they are more vulnerable to occupational exposure to HIV, particularly through syringes. It has been suggested that despite the higher risk of infection, nurses tend to stigmatize and discriminate less against people with the virus than physicians. This is attributed partly to greater familiarity, and therefore ease, with patients and partly to the fact that nurses, who are mostly women, are less hostile to than men to men who have sex with men. While that may be true in some communities, other studies have indicated, a large percentage of nurses feel threatened by or are antipathetic towards homosexual patients. (see Sections 3.1.4 and 4.4)

¹¹ A positive approach from nurses led to a positive response from patients, while a negative approach, such as anger or lack of respect, similarly led to a negative response from patients.

Furthermore, personal contact does not always lead to positive attitudes. While some nurses in resource-rich communities welcome the opportunity to develop close relations with such patients (Hayter 1999), others are anxious because patients often have greater knowledge of the disease and they (the nurses) fear to appear incompetent or ignorant (Taylor 2001). Meanwhile, health workers in communities with few resources may respond negatively, particularly if they feel overburdened. For example, some Zambian care providers claim that patients with HIV/AIDS are “more difficult because of their multiple infections, their ‘hysteria’, their ‘attention seeking’ and their ‘many thoughts’ (i.e. the need for psychological as well as medical support).” (Panos / UNICEF 2001)

It is widely agreed that interventions such as management of pain, malaise and fever, nutritional assessment and counseling, STI management, management of TB and other HIV related diseases should ideally be the responsibility of primary care (PAHO 2000). However, care is mostly provided in specialized centers, such as reference clinics and hospitals. This means that health workers in primary care have little experience with people with HIV and the result may be greater discrimination in the primary care services than in the secondary and tertiary levels.

3.1.4. Systemic failures

Both patients and health workers point out that failures in health systems may lead to discrimination even where no discrimination is intended. Such failures include:

- Limited human & financial resources, resulting in:
 - Inadequate HIV/AIDS-related training and skills
 - Overwork
- Lack of cure and/or lack of available treatment for HIV/AIDS
- Lack of protective equipment and/or other health supplies
- Lack of support for health workers with HIV/AIDS or at risk of infection
- Lack of an environment and infrastructure that

supports both patients’ and health workers’ needs

Any combination of these factors may result in inappropriate treatment as health workers adopt the attitude, “if the system does not care for me, why should I care?” (ICN 2003). And the lack of antiretroviral therapies can lead even the health staff that cares to be overcome by a sense of helplessness and/or to the opinion that the patient is less important than others who can be treated. Zambian health workers “admitted that HIV/AIDS patients were often not given the same services because doctors know they are going to die and, therefore, spent less time on them.” (Panos / UNICEF 2001)

3.1.5. Burnout

Health workers working with patients with chronic fatal conditions such as cancer and HIV/AIDS frequently suffer from burnout, also known as fatigue or compassion fatigue. Burnout may be defined as end-stage discouragement with one’s work that is comprised of three components: emotional exhaustion, depersonalization and a reduced sense of personal accomplishment. Health workers suffering from burnout develop more negative or cynical attitudes about their patients and burnout can affect organizational functioning by contributing to employees’ physical symptoms and reduced job performance. (Brown et al 2002)

Many different factors underlie burnout, including anxiety over safety practices and close identification with dying patients. “[M]ost individuals who have AIDS belong to the same age group as service providers; more than 60% of people with AIDS are under the age of 40. ... In addition, gay physicians are more likely than heterosexual physicians to report increased fear of death and higher levels of anxiety with AIDS patients [who are mostly gay]”. (Gueritault-Chalvin et al 2000) Paradoxically, burnout is sometimes the result of attempts to overcome stigma and discrimination. But it can also inadvertently become the cause of discrimination.

Research in the early 1990s in the United States suggested that burnout with HIV/AIDS occurred more intensely than with cancer. (Bennett et al 1991) The rate of change of health personnel in care centers

for hemophiliacs with HIV/AIDS may reach 35% (Brown et al 2002), and burnout may affect up to 66% of nurses caring for people with HIV/AIDS (Hayter, 1999). However, given that burnout is strongly associated with high rates of death among patients, rates of burnout may have begun to fall in settings where anti-retroviral drugs are widely available.

In Burkina Faso, India, Ukraine, Zambia, “[t]here was evidence in all sites of health workers feeling overwhelmed and powerless. Some service providers were forced to deal with situations beyond their means. In Zambia, for example, when women are denied treatment within clinics, the traditional birth attendants are left to provide the care to women in the villages. ... One nurse / midwife [in a rural health centre] recalls: ‘We are also at risk of HIV and are negligent, not using gloves... If a woman comes [to the health centre] in the second stage of labor and the baby has the cord around its neck, what can you do? You have to assist.’” (Panos / UNICEF 2001)

3.1.6. Stigma and discrimination experienced by health workers

It is not only patients who are subject to HIV/AIDS-related stigma. In the early years of the epidemic, infectologists – the physicians who worked mostly with people with AIDS – were themselves stigmatized and suffer discrimination and even threats from other physicians. Today, there is anecdotal evidence that physicians who specialize in HIV are applauded by colleagues who are grateful and relieved that they take this responsibility.

An increasingly important issue is the stigma and discrimination against HIV positive health workers, who may have contracted the virus sexually or, in rare instances, through occupational exposure. Health workers with HIV often are transferred to administra-

tive services, restrained to perform certain activities or to take safety measures that are not supported by the universal precaution guidelines.

3.2. Patients’ experiences

Although the majority of health workers report neutral or positive attitudes, the experiences of people with HIV/AIDS in health care settings suggest that discrimination is widespread. Discriminatory behavior is not only directed at people known to be HIV-positive, but also, in many cases, applies to individuals known or perceived to belong to vulnerable groups. Reported discriminatory actions and inaction in health care settings include:

- Treatment delayed
- Treatment withheld
- Inappropriate treatment provided
- Other forms of care (e.g. presentation of food, hygiene) delayed or withheld
- Premature discharge
- Refusal to admit patients to health care facility
- Non-attendance to patients in beds
- Non-attendance to individuals in outpatient clinics
- Testing without consent
- Breach of confidentiality within the health care system
- Breach of confidentiality outside the health care system
- Inability to diagnose the clinical manifestations of AIDS¹²
- Inability to give news of HIV-positive result
- Inappropriate comments
- Inappropriate behavior (e.g. shouting, rudeness, etc)
- Selective use of theoretically universal
- Use of excessive precautions

Any of these acts may have a significant physiological or psychological impact on the individual concerned and it is certain that the lives of at least thousands of people have been affected or even shortened by the actions or inaction of health work-

¹² For example, failure to diagnose AIDS in married women.

ers. Unfortunately, however, as noted earlier, studies of patients' experiences almost always failed to measure the extent of discrimination by including reports of positive or neutral experiences; nor do they attempt to measure the impact of discriminatory acts.

The only document studied for this report, which undertook a statistical analysis of HIV/AIDS patients' experiences identified more positive (participation, appreciation, respect, proximity: 42%) than negative experiences (anger, distance, disrespect: 26%). The authors concluded "Patient responses in this study

contrast with current literature which continues to place emphasis on the overall negative prevalence of nurses' attitudes and behaviors." (Kemppainen et al 1998) Another study of patients' experience, although focusing on the negative, also recognized that health workers occasionally displayed neutral and positive behavior. (Surlis & Hyde 2001) These studies were undertaken in the United States and Ireland; anecdotal reports suggest that positive experiences are not unusual in other Western countries and they may be more common than is reported elsewhere.

"They don't want to look after you because they say it's a waste of money, you are going to die after all." (Botswana: ICN 2003)

"The staff were looking after my husband well, but after they tested his blood for HIV their behavior changed." "My blood was tested and from that day they stopped giving me injections. They didn't tell me why." (India: UNAIDS, 2001)

"I used to say 'I'm in pain.' [The nurse] used to say 'Well, that's what you get for using drugs.'" (Ireland, Surlis & Hyde 2001)

"Some of [the nurses] used to [say]: 'We haven't got time for you, there's more sicker people than you.' ... It was because I was a criminal and drug user." (Ireland, Surlis & Hyde 2001)

"[Junsuda] learnt about her HIV-positive status, when her test results were publicly announced in front of other patients and their relatives. "I did not feel human anymore," she states, "My papers were taken from me by the nurses who passed them around the room to other nurses." ... She believes her HIV status became known around town due to lack of confidentiality by the hospital. The HIV-associated stigma was more than her family could bear. Her mother feared ... that the local community's prejudice would have a negative impact on the family's food-selling business. At 18, Junsuda was evicted from the family home." (Thailand: Sexual Health Exchange 2002)

"I went to the health centre with gastritis. I am not supposed to pay because I am HIV-positive. When I told the clerk this he was amazed and went to see the sister-in-charge. She came to me and told me 'There is no need for you to have medicine because you are going to die.'" (Zambia: Panos / UNICEF 2001)

"The nurses went over to the sick man and said 'if you want to go to the toilet get out of that wheelchair and help yourself on the ground outside. When your relatives come they are going to clean up the place and make sure you dress up before you climb back on the wheelchair.' The sick man pleaded with the two nurses that he didn't have the strength to get off the wheelchair and that made the nurses go mad and they started shouting at him. 'Were we there when you were enjoying yourself? And is that why your relatives are not taking care of you?' [... on the following day] I found the man outside on the same wheelchair asking for food from well wishers. One man attempted to give him some food. The nurses refused them and said whoever is going to give him food will be responsible for any mess that he was going to make on the bed, and that person is going to wash up the linen."¹³ (Zambia: Panos / UNICEF 2001)

3.2.1. Institutional issues

Some of the above acts and quotes are the result of discrimination by individuals and not the policy of the institutions where they work. Others, such as inability to diagnose the clinical manifestations of AIDS or some inappropriate comments may be the result of poor training. Where HIV/AIDS is rare and health workers are unfamiliar with appropriate management techniques, incidences of unintentional discrimination are likely to be high.

However, there are also instances of institutional discrimination. This may be active policy; for example private health services in several countries have been reported as refusing admittance of patients with the disease. It may also be the result of failure to respond to patients' specific needs. For example, "[m]ost services established to provide medical and other forms of assistance to people living with HIV/AIDS have been designed to meet the needs of people who acquired HIV infection sexually. They have generally not been specifically designed to meet the needs of HIV-positive injecting drug users." (Burrows 2003)

3.3. Unresolved issues

In this chapter several areas of uncertainty have been noted and they need to be resolved. Firstly, studies of health workers' knowledge are often restricted to uncontroversial facts such as the means of HIV transmission. No studies were identified which surveyed their knowledge of the background, context and lives of vulnerable groups. Such knowledge is likely to be influential in reducing discriminatory attitudes, but yet that relationship has to be proved.

Secondly, the term "health workers" covers a wide range of professions, each having different relationships with people living with HIV/AIDS. These range from those working in clinics who see individual clients only once or sporadically in such circumstances as testing for HIV or other infections,

to doctors who see patients more frequently, particularly when the patient is ill, and nurses in wards who have daily contact with patients. While most surveys of health workers specify the branch of the profession they work in, not all of them take account of these variations in their discussion.

Thirdly, surveys of the experiences of people living with HIV/AIDS often fail to take into consideration the different contexts in which discrimination occurs or the impact of discriminatory acts. For example, an offensive remark from a receptionist may be remembered (and therefore have psychological impact), while poor treatment from a doctor is forgotten, despite the fact it may have lasting physiological impact.

Finally, there is the apparent anomaly, while surveys of health workers consistently indicate that the majority has accurate knowledge and neutral or positive attitudes towards people with HIV, surveys of patients indicate high levels of discriminatory behavior. Future studies should, wherever possible, compare attitudes and perceived behaviors within the same health care settings.

There are three possible explanations for this. First, discriminatory behavior may be widespread. What people say and what they do may be very different and neutral and positive attitudes may not translate into neutral or positive behavior (see box below). Yet the opposite may also be true – discriminatory attitudes may not become discriminatory behavior: health workers who claim they have the right to refuse treatment may not in fact do so. (Bennett 1995) At least one study has found that nurses who held negative attitudes regarding patients who had contracted HIV sexually or through injecting drugs were, nevertheless, willing to offer those patients the same care as patients who had contracted the virus through blood transfusions. (Cole & Slocumb 1993, 1994)

Second, discriminatory behavior may not be widespread, and reports of experiences described by people living with HIV/AIDS give a misleading

¹³ It is arguable that this case reflects both discrimination and institutional failing. In a society where much hospital care is provided by relatives, part of the nurses' reluctance to clean up after the patient may be based on concern that other patients would expect the same treatment.

impression by focusing on the negative and omitting positive or neutral experiences. Reports of positive experience may be rare because they are not seen to illuminate a problem that needs to be resolved. (An alternative explanation, not researched, is that negative experiences are the norm, but health workers do not discriminate because they are equally abusive to people suffering from diseases other than HIV/AIDS.)

Third, experience may vary considerably within a society, even within a locality. Studies that demonstrate that most health workers have neutral or positive knowledge and attitudes may be undertaken in different health care settings from surveys that emphasize patients' negative experiences. Both may be equally valid for the circumstances they describe.

3.4. Grounds for optimism

However, despite many negative reports of discrimination in the health services, there are grounds for optimism. From the perspective of health workers, consistently high levels of knowledge (75% and over) and low levels of discriminatory attitudes (under 25%) are reported. And while surveys of the experiences of people living with HIV/AIDS highlight the negative, the little statistical data available suggests that in at least some communities neutral or positive experiences are the norm.

The true extent of discrimination remains unknown, but there is some evidence that the situation is improving. Statistical surveys are rare, but a 1994 survey in Oklahoma, US, showed significant improvement in health workers' attitudes compared with 1986 (Latman et al 1996). Meanwhile anecdotal reports suggest that in a number of countries people living with HIV/AIDS have, in recent years, perceived a reduction in discrimination in the health services.

Better training and greater access to accurate information have undoubtedly helped. Furthermore, stigma and discrimination may diminish once "saturation point" has been reached. In Zambia, "although stigma is prevalent ...", there is also evidence of changing values, together with increased pragmatism, care and compassion. Media images of the epidemic are now more positive and informative, and a gradual shift in the attitudes of health workers was noted. (Panos / UNICEF 2001) In Uganda many health workers are reported as taking active steps to challenge stigma and in one community health workers have a socio-medical committee specifically aimed at addressing the social aspects of people living with HIV/AIDS. (UNAIDS 2001).

Nevertheless, if left unchallenged, stigma and discrimination in the health services are likely to persist for many years to come. It is therefore essential to identify mechanisms for reducing stigma and discrimination in the health services and to promote these mechanisms widely. Such mechanisms are discussed in Chapters 5 and 6.

Behavior that may be perceived as discriminatory by people living with HIV/AIDS or observers may be motivated by good intentions. Two examples come from India: "When a young woman who is first-time pregnant is found to be HIV positive, we call her mother-in-law. We explain the report to the mother-in-law and ask her to get the son also tested. These patients who come in here are from low-income groups, and if the girls are newly married they are really dumb and don't understand anything, so mother-in-law is called." "The patient, as it is, is half-dead. If he were told of the test results, he might commit suicide." (UNAIDS 2001)

Furthermore, health professionals may unwittingly encourage patients with the virus to feel stigma by emphasizing potential negative reactions from others or by giving unwanted or over-cautionary advice. (Taylor 2001) Training can help health professionals carry on their duties in a more appropriate manner.