

“I will come again with my partner”

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Abstract

Many things come to our minds when we think about HIV/AIDS. Among these are the two words “resistance” and “stigma”. The resistance comes from our patients who find it difficult to share their burden with a partner/significant other. The stigma attached to the HIV/AIDS condition comes from the community as a whole.

While traditionally the extended African family has provided a

support and safety net for its members in time of need, it appears as if the HIV epidemic has affected even this effective system.

This review explores the above aspects so as to help us to be more open with our patients and to, perhaps, find together with them the way to overcome the ‘premature death’ caused by their HIV+ status.

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Introduction

Proper consultation, in general, means to enter into the patient’s privacy, into his/her family life, to uncover his/her wishes, expectations, fears, worries, joys, and feelings. It becomes even more demanding if one tries to involve the family in the management of the illness.

This sometimes long, obscure, uneasy road becomes longer and more obscure, in the case of HIV related issues. With HIV, the whole counselling process and the involvement of the family in the management of the patient has become much more complex and, at times, very difficult to deal with because of practical and ethical implications. We all experience the resistance of the HIV+ patient in sharing his/her status with close relatives or partners. What is behind that resistance?

A vanished dream?

Years ago I received a booklet on the AIDS Prevention and Control program in Swaziland¹, which spoke about the role of the family and of the Community in supporting HIV+ patients. Two

statements in particular gave me hope that things were being placed in their proper perspective:

‘The role of the extended family, and the willingness to care for family members at home, points to home care as a valuable alternative to hospitalisation.’

‘The impact of HIV/AIDS is similar to that of other debilitating chronic illnesses.’

Unfortunately, over the years, that booklet has reflected more and more an idealistic program, because reality has shown us, so far, a different picture.

In fact, while on one side we know that disclosure of one’s HIV+ status with a significant other:

- increases both practical and emotional support, shares responsibility for sex and facilitates self-acceptance of one’s condition;²
- translates into better adjustment and it enhances the patient’s medical prognosis;³
- helps coping with AIDS and related

problems, since the confidante will be caring, supportive, and can help share the diagnosis with others who should be informed;⁴

on the other side we also see that the HIV-positive diagnosis has a profound impact on the individual’s psychosocial life, particularly on interactions with others. Most people infected by the virus are lonely, and are confronted with prolonged uncertainty about their lives; yet they are not always able to discuss these fears and anxieties openly with friends or family.^{5, 6}

This may be part of the patient’s own acceptance process, or it may be due to some other reasons.

Let us then explore some of the reasons that underlie this strong resistance.

“I cannot tell anyone!!”

The most commonly reported reason for not sharing the diagnosis is “fear”: fear of being blamed, rejected, discriminated against, isolated,

abandoned; fear of violence and of not being understood.^{7,8,9}

I have been trying to understand what could be at the root of all the above-mentioned, and I have found one short word, which is mentioned in almost all the articles I have read and which seems to be playing a key role. The word is "STIGMA": the stigma attached to the HIV diagnosis not only by people in general but also by Health Workers.¹⁰

The shocking part is that there are studies which show that this "fear" is not just a matter of perceptions of the HIV+ patients, as family members at times actually reject their sick relatives¹¹ or even assault them verbally and physically.

However, this issue is much more complex, because the presence of the HIV spectrum of illnesses stimulates a powerful emotional reaction from a patient's family and friends. Different aspects of this reaction have been reported.

Lippmann and others describe grief as the first reaction for family members and for the patient. Shock, disapproval, disappointment and anger or vindictive feelings concerning the infection are often present especially if it was transmitted through drugs or sexual contact. Sadness, anxiety and helplessness are also common due to the disabling progression and fatal outcome of the disease. Fear, shame, dependency and hopelessness complicate bereavement. Another major stress factor is the fear of contagion (though this can be much reduced through health education).

There are studies that have also reported positive, supportive and understanding responses from the family members.^{12,13} Nevertheless, even in those cases, we mostly find the familial tendency of social retreat and of coping with the burdens without help from outside.¹⁴

What happens is that those fears that the patient experiences as an individual are also experienced by his family towards the society, due to the perceived **stigma** associated with AIDS.¹⁵

Again, the key word is "STIGMA".

"Don't forget: I am a woman!!"

The quality of responses is also influenced by pre-existing patterns of support and discord within the family (where trust is high and spousal conflict slight, for example, HIV and AIDS are reacted to more positively than where there is mistrust and inter-spousal conflict); nevertheless findings also show that men are responded to more positively than women.¹⁶

Particularly our female HIV+ patients don't want their husbands/ boyfriends to know the diagnosis as it often results in them being 'thrown out' of the house or relationship, or being accused of 'being unfaithful' even if it is the other way around. Women now constitute the fastest-growing population of persons with AIDS in the U.S. The psychosocial problems of women with AIDS and HIV infection are under-recognised, and economic, personal, and social resources to meet their needs are often inadequate. HIV-infected women often feel isolated and experience the **stigma** and shame. Their roles as caregivers and as wives and mothers are often changed or lost, and they experience anxiety and confusion about options for sexual activity. They sometimes fear transmitting HIV to family members through non-sexual contact. Other issues involve coping with being both ill and a mother, disclosing information to children about the illness, and loss of reproductive choice.¹⁷

Still in the United States, many HIV+ poor women of African American or Hispanic American descent have experienced many forms of oppression and discrimination and have been labelled as drug users, prostitutes, and carriers of acquired immune deficiency

syndrome (AIDS). They have been stigmatised for their gender, their sexuality, their minority status, and their poverty, as well as for their HIV-positive status.¹⁸

Stigma: an old word for a new disease

HIV/AIDS has generated panic, fear, anxiety, and negative attitudes among the general public. As an illness, it has become the new source of STIGMA and it has already resulted in the unnecessary loss of jobs, denial of insurance, exclusion from religious or other associations, school dismissal, and estrangement from family and friends.^{19,20}

The key word "STIGMA" emerges again. I therefore decided to explore the meaning of "STIGMA" and its role in the whole mechanism of social, family and patient's responses to HIV related issues.

The Concise Oxford English Dictionary defines Stigma as "a mark or sign of disgrace or discredit." The question is: where is the source of this disgrace and discredit?

At times, a negative evaluation may be attached to a certain ethnic group, or to members of certain groups displaying certain types of behaviour (e.g. drug addicts, homosexuals, prostitutes, etc.) who are perceived as undesirable, and therefore in turn serve to justify discrimination, avoidance and exclusion.

In those specific cases one can understand where the source of the STIGMA is. What about the common negative attitude towards HIV+ patients?

1. According to Sontag some diseases are regarded with special fear, dread, and repulsion because their causality is unclear and the treatment ineffectual. Since he wrote before HIV was known, the best example he could provide was that of cancer and TB before TB chemotherapy was introduced.²¹

2. Schaalma and others report that data from a sample of 1,018 Dutch secondary school students support the reasoning that emphasising in AIDS health education personal responsibility, and consequently personal controllability, increases negative reactions to people with AIDS.²²

3. Nichols states that Society itself has been disrupted by the new information about sexual behaviour that has been brought to light by AIDS, indicating that primitive sexual taboos still influence modern Society.²³

4. Some people perceive AIDS as deserved retribution for a 'life of sin'.²⁴

Africa: solidarity against constraints!

Having worked for many years in an African environment, I thought that all these reports were meaningful in places like America or Europe. The African family, in fact, in the nuclear or the extended form, though changing in size, structure and function, has persistently maintained its place as the central human social unit, providing a safety net for individuals in times of need. Therefore, I have been wondering why my patients are still reluctant to disclose their HIV+ status to their family members.

According to Seidel the issue of confidentiality as it is presented to the patients leads to social isolation, whether in the town or in the country. This, in turn, leads to a premature 'social death'. Patients with HIV are afraid of telling anyone about their HIV status because of the stigma. 'They have been advised never to tell anyone by their counsellors. And that adds to their fear. We see these people every day.' 'This confidentiality thing does not help us. It holds us back. We cannot care for our patients.' 'This secrecy is killing us.'²⁵

Ankrah reports on how the AIDS epidemic has strongly affected and thus

disturbed the capacity of the nuclear and extended African family to respond to the needs of members afflicted by HIV and AIDS.

In his review it is clear that severe family stress may be worse in HIV/AIDS than in other serious illnesses. This is because of the stigma attached to it as well as its mode of transmission, associated with promiscuity, and linked to the gradual physical weakening and loss of body weight, which may heighten isolation from the community.

Another point on which he reports is the financial burden that HIV/AIDS places on the family budget:

- expenses due to medical care (traditional and western);
- death of a breadwinner;
- going from one traditional healer to another in search of a cure;
- funeral expenditures (due to the way in which African funerals are often done);
- if a woman in the family has a job, she can be asked to leave it so as to care for the sick at home.

Another perspective on how AIDS has changed traditional patterns surrounds bereavement. A bereaved family was traditionally assisted by the community in organising the funeral, contributing to costs including food, as well as comforting and sharing in the bereavement, while agricultural and other work were suspended for a considerable period of time—depending on the rituals.

In a certain research area in Uganda, in 1990 people were already overwhelmed by the demands of agricultural work and by the neighbourly demands to spend three non-working days to mourn the death of the persons who had died in the village. Already at the time of the review, in some areas the practice was to keep the bereaved company on the night of death or until the arrival of the body, assisting with preparing the grave, feeding the mourners and attending the funeral.²⁶

Another study in a rural population in South West Uganda reports that for 17 patients who died during the study period, records of seven cases show that other relatives were asked to help with care but refused on the grounds of poverty or other commitments. However, in all but one of these cases, extended families did provide assistance for the funeral.²⁷

Conclusion

In this article I have referred to "STIGMA in HIV/AIDS" as if it is something that comes from 'nobody knows where'; as if it is something created by 'the Society'; as if we all aren't part of Society!!!

How many times, surely without realising it, do we differentially apply disease labels, with the diagnostic process being influenced by the characteristics of the patient (age, sex, social class, race, etc.) and by the particular circumstances in which the diagnosis is made?²⁸

How many times, by doing so, are we contributing to the increase of stigmatisation in our society?

In the history of mankind, literature has always had a role in helping people reflect about happenings. It is my wish that this article will help us to reflect about our daily lives with our people with HIV/AIDS, so that it can motivate us to encourage a greater culture of openness, of acceptance, of understanding, of love towards our patients affected by HIV/AIDS!!

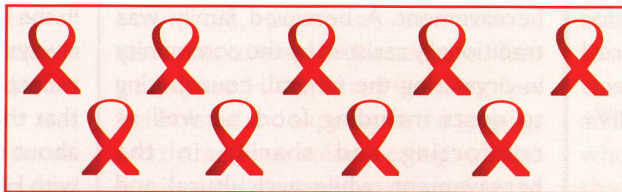
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The South African Academy of Family Practice / Primary Care Statement on AIDS

The SA Academy of Family Practice/ Primary Care (the Academy) represents family/general practitioners in South Africa with an interest in the academic development and support of the discipline of family medicine and primary health care. The Academy is gravely concerned about the devastating effects of the acquired immune deficiency syndrome (AIDS) on the wellbeing of our patients, communities and country. The Academy states categorically that AIDS is caused by the Human Immunodeficiency Virus (HIV); and accepts that poverty, malnutrition and stress could hasten the progression of the disease. Coming from a comprehensive primary health care perspective the Academy regards the prevention of HIV/AIDS of crucial importance. Change of behaviour and attitudes must receive attention. The impact of the disease on the incidence and progression of tuberculosis as health threat also needs to be taken into account.



Efforts to prevent the spread of the HIV infection/AIDS are materially frustrated by propagation of serious miscon-

ceptions that HIV does not cause AIDS. The Academy noted with concern the media debate about the effectiveness of medicines used to prevent infection by HIV. No drug is entirely without side effects, and when prescribing any medicine a doctor must weigh up the potential dangers against the manifest

benefits. Taking this into account, and remembering that the use of medicines needs to be part of a broad plan of treatment and management, The Academy wishes to draw attention to two specific points. Firstly, transmission of HIV from mother to child, or infection with HIV after being pricked with a contaminated needle, may be prevented by use of appropriate medicines. Secondly, The Academy supports the view that selected anti-HIV medication may reduce the likelihood of HIV transmission in surviving rape victims. We suggest that the appropriate, least expensive, medication be available, for

both prevention and treatment, to all patients.

The HIV/AIDS issue poses a challenge to medical practitioners in acquiring the appropriate knowledge and skills mix, to be of effective assistance to our patients.

We as family/general practitioners subscribe to a holistic approach towards our patients, which is particularly appropriate in HIV/AIDS, particularly concerning our role in disease prevention, health promotion, public health, commitment to patients that are dying, continuity of care, multidisciplinary team management, and discussing sexual issues. All of these must be prioritised in undergraduate education, postgraduate education and continuing professional development of general / family practitioners. We believe that general / family practitioners have an important role in patient advocacy, adequate counseling, compassion, ethical management and utmost respect for the human rights of our patients and greater society.

We support controlled research, aimed at behavioral change and prevention and treatment of AIDS.