

Stigma, support initiatives and the "directors' dilemma": is anyone mitigating the socio-economic impact of HIV and AIDS related stigma in Botswana?

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Stigma, support initiatives and the “directors’ dilemma”

Is anyone mitigating the socio-economic impact of HIV and AIDS related stigma in Botswana?

Working Paper

This is a revised version of the presentation given at the workshop:

“Changing HIV and AIDS impact patterns in the wake of the ARV therapy”

(Gaborone, 30.03.2006).

This paper was presented under the title:

“Preliminary findings: Stigma and discrimination.

A new focus for socio-economic HIV and AIDS research”.

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Abstract

This paper outlines some results of an ongoing research project currently being carried out in Botswana and is compiled to specifically address topics that are relevant for policy making in Botswana. It was first presented at a workshop in Gaborone where the respective authorities and policy makers were present.

The title of the research project is „Current rural and urban livelihood transformation at selected sites in Botswana“¹. The project is not only about HIV and AIDS, but these form our major points of interest because we regard them as the most severe current influence on the society of Botswana. A further aim is to identify other ongoing processes like individualisation or modernisation that interfere with HIV and AIDS. There are a variety of methods used during the fieldwork: Semi-structured Interviews, interviews with experts, qualitative interviews, observation, and focus group discussions.

It was the aim to select research sites that are comparable with regard to the socio-economic status of their inhabitants in rural and urban environments. We mainly targeted mainly poorer and deprived people. The chosen sites were Tshane, a small village in the Kalahari near Hukunsti, and Letlhakeng, a village with a somewhat central function at the edge of the Kalahari. We also chose an urban site in Gaborone (Old Naledi) where mainly poorer people live.

Botswana is the first country and currently the only country in southern Africa that provides ARV (Anti Retroviral Treatment) countrywide, free of charge and within the public health system. Everyone who is in need of the medication (CD-4 count below 200 or HIV related illnesses) can receive the medication. This has changed the impact patterns of HIV and AIDS tremendously. Until now illness and death

have been regarded as the main socio-economic impact of HIV and AIDS but due to the ARV-medication this is now restricted to a very small group of patients who experience treatment failure. Most of PLWHA (People Living With HIV and AIDS) have the chance to continue with their lives and their personal life plans.

Firstly this article will give an insight into what PLWHA report about the ARV-medication. Then I will explain stigma as a new focus for socio-economic HIV and AIDS research. Further I will depict how stigma and discrimination influences the lives of PLWHA. This paper also draws on coping strategies at different levels and then names some key players in this repercussion against stigma. This leads to the concept that I call the “directors' dilemma”. It is the description of the difficulties within the sphere of HIV support initiatives. It's about misunderstandings, quarrels and unyielding barriers between activists and donors in the HIV and AIDS response. Finally, I will end with conclusions and recommendations. However, this presentation still remains preliminary as our field work has not yet been completed. Therefore, please consider this text as work-in-progress report.

Introduction

“Illness is the night-side of life, a more onerous citizenship. Everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick. Although we all prefer to use only the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place.” (Sontag, 1990 [1977 / 1988], S. 3) It's not the physical landscape of a country that Susan Sontag is referring to in the preface of her book “Illness as Metaphors”. What she is trying to depict is that forming kingdoms or, say, different groups is a social process. It implies that there is someone who gives out the passports and someone who accepts the rules of the respective country. She continues: “[This is] not real geography, but stereotypes of national character.

¹ The project is funded by the DFG (German Research Foundation)

My subject is not physical illness itself but the uses of illness as a figure or metaphor." Whatever side you currently belong to, you don't know the other side perfectly well but you have a notion of it. Certainly, you have been ill at some time, but the pain has gone and with it the illness and you only have a fleeting glimpse how other diseases might feel. And if you bear the passport of the kingdom of the sick you may only have hindsight into of how you regarded that same illness once you haven't been ill. Combined with fears, prejudices and a lack of knowledge this is the scope stigma derives from. And it leads to a disunion between two social groups, probably with clearly established borders and strict border control.

ARVs: A visible benefit to rural communities

It is self-evident, but it should be mentioned that people greatly appreciate the medication. Figure 1 shows a woman presenting her ARV medicines in a very open manner and one can see that she is very thankful. The next quotation about a woman from Tshane who has been living with HIV for 16 years also shows the benefit of the ARV-medication. She had severe health problems until she got ARV treatment. The people of her home village refer to her as a "living example". They mean that everybody in the village was able to observe how she recovered. Thus she is a public proof that one can get better if he or she follows the advices of the doctors.



Fig. 1: Lady presenting her ARVs

Interpreter: „She likes them [ARVs], she get them on time every day on eight o'clock in the morning and eight o'clock in the evening. [...] When she is out and the time for the ARVs is coming she just feels in her heart: 'My time is near. I must go and get my pills.'"¹

The benefits of the ARVs do obviously exist and they are visible within the communities, especially in the rural area. In the two rural communities we assessed, people have had the experience of seeing relatives, friends or neighbours recovering. As an effect of this, cases of severe exclusion, ostracism, maltreatment or abuse have been almost eradicated. Members of the 'VDC² home based care'

¹ Interview 31 PLWHA

² Village Development Committee

and support group members report that the patients are treated with much more care these days. In a broader sense we can state that open rejection and hostility are widely mitigated.

And this is followed by other effects. People are somehow more open about HIV. But this is not a generic situation. The following examples should be taken as individual cases but with the emphasis that they would have been impossible a few years ago.

- Sometimes we were asked what our interviews were all about. When we answered, that we ask PLWHA about their experiences. We often got a very open response and an invitation to interview the person who had just made the enquiry, who notified us of his or her positive HIV status as well.
- We saw people exchanging jokes across the fences of their compounds, containing the information that they were HIV positive. This is quite an open attitude towards HIV and AIDS compared to some years ago. Also, if someone has died of AIDS it is no longer impossible to mention that.

This can be valued as a reduction of stigma and discrimination. But it is important to state that it is restricted to rural communities and to a small group of people living openly with their HIV positive status. Stigma is still severe and it is not the same everywhere as I will show later.

ARVs: General constraints

But there are some constraints that the patients have to face if they enter ARV-therapy. They can be divided into three main categories:

- Biomedical factors
- factors deriving from distribution and organisation
- and factors influenced by macroeconomic changes

Under the biomedical factors are side effects, the requirement that the medication should be taken regularly, the weakening of the body through the ARVs, the need for high quality food, the need for rest, and to avoid exhausting oneself too much when on ARV therapy. These things make the lives of PLWHA more difficult. This could probably lead to the assessment that PLWHA are not as capable or strong as those not infected.

The following constraints derive from the way the distribution of the medication is organised. First, it takes time for PLWHA to travel to the clinics, and for some, the travel costs are a severe constraint. Second, PLWHA have to wait for a long time at the clinics to get a repeat of their medication or to see a doctor. Some PLWHA report having to wait up to two days to be assisted. The clinic opens at 8:00 a.m. but some arrive at 5:00 a.m. to secure a good place. Especially for those who are employed, this is a severe constraint because they have to explain

their regular absence to their employer. PLWHA report an aggressive atmosphere among the waiting patients and between patients and the overburdened clinic staff.

The tremendous expenditures for the provision of the ARV treatment challenge the macro-economics of Botswana. This compounds the already problematic current fiscal situation. A retrenchment of other social welfare programs is likely and in 2005 the cutback in their food-baskets was a development that concerned PLWHA.

Apart from psychological issues, these factors cause PLWHA on ARV-therapy to have to carry a heavier burden than those not affected. In particular the biomedical factors and the factors of organisation and distribution are directly interfered and aggravated by HIV and AIDS related stigma.

What is stigma?

Stigma can be attached to all illnesses but it is probably not so important in cases of ordinary illnesses, such as, a cold or flu. But there are some illnesses that clearly divide those who suffer from it from those who do not, in terms of social interaction.

Sometimes the effect is so severe, that people with an illness regard themselves as inferior to the rest of the community who are supposedly healthy. They adjust the way they view themselves in accordance with the view of the healthy group. They adopt the opinion of that majority and act as they think they are expected to act according to this group. This is what Erving Goffman (Goffman, 1963) calls "Stigma". According to Goffman there are no divided kingdoms like Susan Sontag suggested, but rather a lower or inferior rank or class of the "stigmatised" subsumed under a ruling party called the "normals". But we should not follow Goffman too closely. His theory gives an insight into how those he called "stigmatised" exclude themselves, anticipating rejections or discrimination. These mechanisms are very common and widespread and represent the most severe impact of stigma. But we should not adopt the terminology of Goffman. His disjuncture between "normals" and "stigmatised" claims that these social groups are entities that can not come close.

But stigmatisation is not necessarily as determining as Goffman predicts. Susan Sontag (Sontag, 1990) has not written directly about stigma, but she emphasises that the way we talk about HIV and AIDS influences peoples attitudes. This is in line with most recent research about stigma. According to USAID (USAID, 2005) stigma should be regarded as a social process. It can be fear-based, values-based, or caused by prejudices toward certain behaviours or groups.

A USAID working group identifies the following factors as important for the genesis of stigma.

- lack of knowledge, which directly implicates a fear of casual contacts
- values, that cause blame, shame and

judgement

- disclosure and
- discrimination which USAID calls "enacted stigma".

Furthermore, the USIAD working group comes to the conclusion that it is possible to mitigate stigma and discrimination. It can be impacted at the workplace, through health care institutions and in the communities

Finally, stigma is not clearly defined, and there is much confusion in the use of the term. This is not helpful for scientific approaches and this project will soon come up with a suggestion to redress this shortfall.

In summary, it can be stated that stigmatisation is an ongoing process which reproduces itself permanently within interactions between people or between people and institutions.

The socio-economic impact of stigma

While stigma is largely an issue of mental attitude, we have to regard the consequences of denial and secrecy as products caused within the social reproduction of stigma. The effects of denial and secrecy are mostly unrealised, people refrain from doing things they otherwise would do. Stigma results in unpractised action rather than positive manifestations. Figure 2 lists the socio-economic impact of HIV and AIDS related stigma.

	individual	community
human capital		
contagion	not knowing status risky behaviour	not talking about
recovery	too late for ARV	↓
adherence	fear of disclosure	
anxiety / depression	not seeking support	
financial capital		
employment	resign	being dismissed
agriculture outcome	physical weakening	
expenditures	dubious health services	
social capital		
families / networks	retreat	exclude
denial / secrecy		

Fig. 2: Socio-economic impact of stigma

In the first place, stigma tremendously diminishes human capital. Not knowing one's status is a prime threat for partners being infected because it leads to risky behaviour. But stigma can also lead to inferior recovery regarding ARV treatment because patients only come for treatment when they are very ill. Then the body may permanently be harmed by opportunistic infections. We even found a man who didn't go for medication at all although he was obviously suffering from AIDS. Eventually he died without being tested for HIV. Adherence to ARV medication can also be influenced when people fear

someone could watch them taking the pills. Or they fear to ask for some water to take the tablets. This was mentioned very often within our interviews. People could also fear seeking support. They could possibly be watched while waiting for Tebelopele (the Botswana voluntary counselling and testing centre), at the clinics or visiting support initiatives. They may also fear that confidentiality is not practised in those institutions and this fear is often well-founded because there are many stories about unwanted disclosure.

On the part of the community these factors are intensified because HIV and AIDS is a thing one does not readily discuss. One may not talk to a person about the sickness even if he/she is obviously ill. So the person might not be given proper advice or appropriate care.

The financial capital is affected in the following ways. Some PLWHA reported that they have voluntarily resigned from their jobs after they have tested HIV positive. This is interesting because dismissal is often mentioned as an act of discrimination against PLWHA. In our survey we found more people having resigned than being dismissed. But this may be restricted to the social strata our sample targeted. We mainly asked deprived people who mostly are untrained and within the research population the unemployment rate was high.

PLWHA seldom complain about adverse effects. But many PLWHA do not engage in agricultural activities, even if they have a plot of land. All of the support groups we assessed try to establish income-generating activities for PLWHA. In spite of this, no support group actually succeeded in doing so at a larger scale. Considering the variety of governmental programs available we asked why every single person could not make his own living. They argue that PLWHA have to follow special rules like resting or not exhausting themselves too much. Also they report about some times feeling weak and they emphasise that a conjointly conducted project could assist members in their phases of weakness.

People who deny that they may be HIV infected are obviously more likely to pay a lot of money to people promising to help. There are many suspicious offers which try to capitalise on that fact. There is an association of traditional doctors and most of the healers stick to their agreements but there are nonetheless some who claim that they can heal HIV and AIDS. There are also herbalists, healing priests and private doctors taking advantage of the stigma that is related to HIV and AIDS.

Finally, the social capital is influenced by stigma through the tendency of people to retreat from families and communities or through being excluded from these.

All these factors together cause a decline in productivity. The most direct influence is at the household level but the productivity of communities and of society are also diminished.

Some differences between rural and urban communities

Stigma is more “real” geography than Sontag claims. We found differences in the way support group members live with HIV and AIDS depending on their places of residence in Botswana.

We expect members of the support group to seek to develop a positive and open attitude towards their HIV positive status. We interviewed PLWHA about the way they handled their HIV infection and we found significant differences between the living locations. All assessed PLWHA were members of the respective local support group.

We divided these attitudes into the following categories:

- To be in **denial** means not to accept the biomedical explanation of HIV at all.
- To be **highly secretive** means not to disclose the status to relatives.
- To be **secretive** means not to disclose the status to friends or well known people.
- To be **open** means not to talk deliberately about ones HIV status but to talk about it if asked. This attitude assumes that the respective person supposes that others know his or her HIV status.
- And to be **public** means to speak in front of a larger community about ones HIV status and being known as a PLWHA.

First, it is clear that people who deny their HIV status could not appear in the survey because they will not join a support group for HIV and AIDS.

We found that, in Old Naledi, the group of those who are “open” is very small. In contrast, this category is dominant in Letlhakeng and also in Tshane where the majority of support group members are open about their status.

There are some observations that strengthen these findings. I'll mention some of those who illustrate the more open manner in the rural areas. In contrast to the rural sites, in Old Naledi, all the interviews took place inside the houses. Sometimes it happened that someone knocked at the door, in which case the interviewed parties would open the door just a slit to make sure that the visitors would not see us.

PLWHA who are willing to be open about their HIV positive status find better conditions in those rural communities we assessed than in the urban site of Old Naledi. There is obviously a better chance to develop a positive attitude towards HIV and AIDS in rural communities. But as we know from the support group members who also do outreach activities in remote villages, there are still rural communities that are still very unwilling to deal with HIV and AIDS issues. We also have to restrict our conclusion to those people we have assessed and, without exception, those have been poorer people. As observations and the discussions at our 2006

workshop in Gaborone have shown, openness among more affluent PLWHA is a very rare thing. It seems that there is something like a socio-economical ceiling for being open about one's status, but at the moment it is not possible to identify it properly. We can also state that we met some more or less affluent people being open about their status but then they had normally gone through a serious illness or had other events during their lives that have led to a disclosure of their status.

Coping strategies and how to effect a behavioural change

Several agents in Botswana are trying to effect a change in HIV- and AIDS-relevant behaviour. Figure 3 shows the efforts to reduce Stigma and Discrimination.

At national level a change in behaviour can only be addressed by information, education and communication programmes (IECs). But the governmental approach, Susan Sontag would state, is evidently using the "war metaphor". President Mogae gave out the slogan "Ntwa e Bolotse" which means "the fight has begun". The "national catastrophe" needs to be "addressed radically" as the "National Strategic Framework for HIV/AIDS" (NACA, 2003) says.

Looking at the recent media approach we found that most billboards in public sphere have disappeared. In 2005 there were a few PMTCT (Prevention of Mother To Child Transmission) advertisements and some smaller posters reminding people to be responsible. Even in newspapers the people who are primarily featured are those who have deservedly won a battle in the war against HIV, e.g. an employer who has introduced a HIV programme in his company or someone who has fund-raised a lot of money for a HIV activity. One can seldom find a report about crowded hospitals and weaknesses of the support systems.

This media approach is consistent with a particular point of view regarding prevention issues but it reduces the PLWHA to victims or lost soldiers.

It further seems that the public do not like PLWHA to be more than victims. Rarely one can find a report about a very successful person living with HIV and AIDS. "The face of HIV is poor" is a saying that in the first place names that all HIV activist derive from poorer origin. But it also reflects that everything that is in the public awareness about HIV refers to an inferior social status. There are virtually no affluent PLWHA in Botswana who are public about their status.

Silvio Waisbord (2003) from "The CHANGE Project" reflects some main misconceptions about IEC programmes in general. Contrary to the common belief, information is not enough to change behaviour. Furthermore, information has to be interpreted and activated from time to time. Communication is not only necessary for a short period of time.

This also emphasises the role of face-to-face communication and the importance of PLWHA talking open about their status. A personalised speech about HIV and AIDS should be encouraged, which means that HIV and AIDS should not always be referred to as the disease of others. If nobody ever confesses to being HIV positive then care and advice from an experienced angle cannot be given.

At the other end of the spectrum, there is the individual who has to cope with his or her respective living conditions and the sheer fact of being HIV positive. What the PLWHA describe as their main challenge is to accept themselves which is crucial for living positively with HIV. Mostly the self-confidence is most severely eroded by the news of being HIV positive so they have to overcome self-reproach, fear and, of course, the metaphors. And often there is no-one to talk to about HIV.

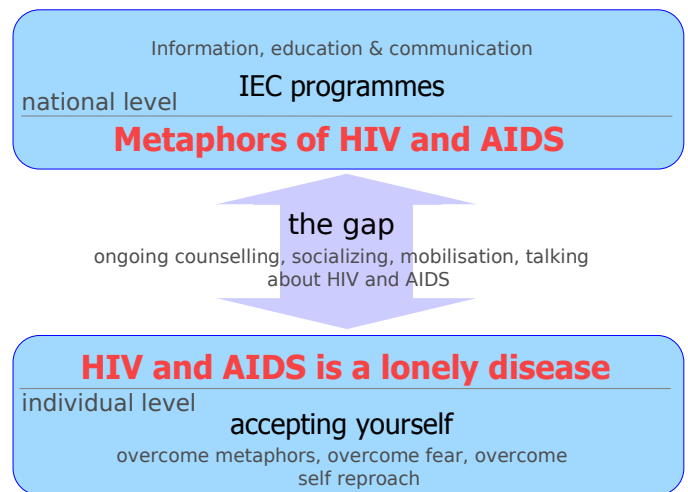


Fig. 3: The gap

In summary we can say that at the national level we have an approach dominated by metaphors of HIV and AIDS and at the individual level we find PLWHA, in an environment of stigma, experiencing HIV and AIDS as a lonely disease.

Identifying the gap we find that PLWHA have to talk about their HIV infection. They need ongoing counselling. They need to socialise without hiding their infection. And the community itself needs mobilisation for a change of behaviour, particularly regarding face to face contact with PLWHA being open about their status.

But is anyone meeting the gap? Probably the local community? Certainly not, otherwise stigma would not exist. Is it the civic society? NGOs or other associations are caught up in the national response and act more as a donor to the victims. The church in most cases adheres to the opinion that HIV is given by God as a punishment for sins. In the end we could only identify HIV initiatives as meeting the gap. They are prepared to speak openly about HIV. Most of the activists do not mind talking about their experiences and can effectively support other PLWHA. Within the other support group the members can develop an atmosphere whereby they

can feel free and discuss how to meet the daily challenges.

Care which is crumbling: Support groups and the "directors' dilemma"

But there are severe constraints for support initiatives. We found most of the support initiatives lacked appropriate funding. The only exception is BONEPWA the "Botswana Network for People living with HIV and AIDS" founded by David Ngele. But this organisation mainly provides workshops and training for activists. They call themselves an "umbrella body" for support initiatives and they are more a distributor of funds and knowledge. BONEPWA itself does not provide main services like counselling nor do they provide places where PLWHA can meet and talk.

The policy gap is glaringly obvious when looking at Spew Segwagwa from the support group of Letlhakeng. After nearly three years of activism it was not possible to get significant funding for the support group. We found him very frustrated and figure 4 shows him presenting all his certificates he has earned. He wants to demonstrate how ineffective these capacity building projects are when there is no possibility for HIV-educated people to convert their knowledge into action. For about the last three years the support group was without a place to meet. They met in the foyer of the clinic, where people were continuously passing through until they recently got permission to meet in a room of the clinic. But the room is used by the clinic as well so they still don't have a place to store some files, stationery or other materials nor do they have a telephone.

The process is very slow because responsibilities are not clear. For example when support groups attempt to getting a plot of land for income-generating activities they have to address the governmental "Land Board". Here they are rejected because it is not within the scheme to allocate land to groups unless they are registered societies. Despite the registration being just a formal process many support groups struggle with these requirements and do not manage to register. Support groups can apply for funds from BONEPWA or from the Global Fund through BONEPWA. They have to write a plan outlining the respective activity, objectives and cost effectiveness.

These demands contrast the situation of the support group. As explained, most members do not have the capacity and the fundamental resources for proper secretarial work. As a result the necessity of fund-raising without appropriate knowledge and endowment ties the workforce up in activities which are not the core task, namely mitigating the impact of HIV and AIDS. This is aggravated by the initial requirement for 500 Pula in order to register a support group at the "Registrar of Society", and 75 Pula per year is being charged for affiliation with BONEPWA, a sizeable amount especially for smaller support groups in less monetarised rural environments.

Also the needs of the support groups may be of a different kind as compared to what the application procedures allow. While we were in Letlhakeng the local support group attempted to build a house for a very active and public member. This woman lived in an old, crumbling mud hut with three children. This activity would never meet the requirements of any donor like such as BONEPWA or the Global Fund.

The question is: Why do those who are willing to mitigate the social impact of HIV and AIDS have fewer means to do so?

On the one hand there are the external reasons. There is no adequate policy to sustain support groups. But there is also an inner constraint, a reason caused by the support groups themselves. This is what I call the "directors' dilemma". It occurred in three of the four support initiatives I was in close contact with and I know of two further initiatives that were terminated due to the



Fig. 4: Spew Segwagwa

"directors' dilemma". Here "director" stands for the main persons of the various support initiatives founded by PLWHA. The leaders, founders, directors or however they refer to themselves.

The following observation is an analysis of the cases I assessed and, to begin with, I want to identify some attitudes that could characterise the majority of the directors.

Most of them are HIV positive. That means that they have gone through all those HIV-related experiences and mostly they are driven by the experience of being marginalised and rejected. They are primarily people who did not have access to higher education and they normally cannot fall back on managerial experience nor do they have the required financial skills to run an organisation. Normally they are public about their status within their communities and they are usually those who first went public in their respective communities. These early activists risk a great deal when they go public within a hitherto HIV-denying environment because at the outset they do not know how they will be treated. By their activism they mobilise other PLWHA to be more open or to go public as well. They see how others follow them without facing the

same obstacles and they somehow think that this pioneering act on their part should be honoured. This is also why later activists may act more rationally in conducting a support group because their public disclosure might not be that severe an experience of "one against all odds." Most directors mostly also see that many people benefit from their activism but only a few are willing to take responsibility for the concerns of the support group. So they begin to see themselves more and more as the driving force of the respective groups.

Secondly, the reaction of the communities towards the directors have several attributes in common. This is how the directors are generally regarded, whether it is true or not?

Initially their activism is very much appreciated. They are highly honoured but after a while it becomes "business as usual" and the attention declines. Later, in most of the cases, it happens that the members become displeased with their directors. The members sometimes claim that the directors dominate the group. There are complaints about mismanagement and about how the directors use resources or property of the support group for their own concerns.

These complaints often result in supporting institutions (e.g. BONEPWA or the social workers) adopting this perception. In many cases they only regard the support group as eligible for future support if the director resigns. Apart from the interest of the directors in retaining their posts this would often mean that the support group would go under because there would be nobody else who would make the effort to maintain it.

This causes a cycle of divergence between directors, members and external parties. But regardless of whether there are complaints about the director or not, the directors go through difficult times.

The directors normally become somewhat tired or frustrated after a while. They realise that their influence is limited and they do not want to accept it. Inevitable they experience that others take their commitment for granted. Also they still have to cope with their own HIV positive status and the very fact that they have gone public. Most of the directors also have to cope with very limited living conditions. As explained above, they are usually not well-to-do. As a result of frustration they begin to emphasise their caring role and start to present themselves more and more as martyrs for the concerns of PLWHA. Most of them become very uncomfortable partners for stakeholders and donors because they might begin to behave in a way others perceive as somewhat aggressive. Nevertheless, they never lose their caring heart for their fellows.

In summary it can be stated that an external policy gap and the internal "directors' dilemma" lead to an unclear situation for many of the support groups.

The need for fund-raising under unclear circumstances keeps the support groups from their main task. The unique expertise of the support

group members is their personal HIV and AIDS related experience that could effectively be used to encourage others. But instead their energy is expended on tasks for which they are not trained or qualified.

When the "directors' dilemma" occurs, it leads to an impasse in which funds are stopped and nobody knows how to proceed further. The "directors' dilemma" is caused by multiple factors. Firstly there is the restraint of a somewhat numb or inflexible political environment which the directors have to address with their concerns and there are the personal constraints and restrictions of the directors themselves. The coexistence and interdependencies between the professional and the private facets of the directors' role formidably challenge HIV and AIDS activists. To separate these two facets is an ability only few of them can maintain for an extended period. The directors are highly exposed to the public, not only through their post or role, but also in their most private concerns.

Finally, in a small minority of cases, support groups are sustainable without supervision. In Letlhakeng the support group is run by a committee that is elected every 2 years. Spew was most recently elected as the vice chairperson and he now only occasionally joins the support group meetings. He has taken the role of a mobiliser apart from the support group. The support group itself is evidentially sustained by the HIV/AIDS counsellor of the Letlhakeng clinic who currently chairs the committee and a social worker who also advises the group in strategic planning.

Nevertheless, support initiatives, run or self-determined by PLWHA, are a necessity of PLWHA because these could effectively meet the demand for support in the ongoing coping process of every individual living with HIV or AIDS.

Conclusion and recommendations

The PLWHA (People Living with HIV and AIDS) in Botswana are currently experiencing a lack of support in the sphere of their socio-economic needs. As the major threats of an impending illness and an early death are largely eliminated by the ARV-programme, their lives are now mainly impacted by stigma. HIV-related stigma is not only an issue of psychological concern, but it also has direct effects on the ARV-therapy and the productivity of households, communities and society.

The key actors who could effectively mitigate stigma are the HIV and AIDS support initiatives but many of them face difficult conditions caused by an external policy gap and what I have explained as the "directors' dilemma". The potential of the support groups is under-utilised because of a shortage in their basic requirements and their workforce being trapped in the need to fund-raise, for which they are not qualified. External partners, potential donors and the responsible governmental organisations respond to resulting internal problems with a suspension of funding. That freezes formal processes e.g. the registration as a society as well

as hampering the operation of the support group.

The directors need to improve their skills and their readiness for collaboration. But their partners should also understand and react to the special circumstances of PLWHA. HIV and AIDS related stigma and discrimination cannot be addressed without the commitment of PLWHA themselves. There is a need for PLWHA being open about their status and sharing their experiences with others. Also, there is a need for activists who are willing to initiate a process of creating an ready awareness about the challenges of living with HIV and AIDS through going public about their status. There is the need for establishing an efficient support system for support groups that also addresses the "directors' dilemma". There is a need to find a way for collaboration as well as a policy to evaluate, monitor and fund support groups effectively.

As this study shows, stigma in the urban site of Old Naledi is very high. This suggests, that deprived

urban communities in general probably may be critical areas and should be a major focus for the response against HIV- and AIDS-related stigma.

Further, one might ask if it may be a special capacity of rural communities effectively to integrate PLWHA who are open about their HIV positive status. That raises the question of whether there is something special in the rural communities that is probably endemic in Botswana.

Finally, I want to close with one quotation of Susan Sontag emphasising that illnesses should be regarded with as few emotions as possible: "My points is that illness is not a metaphor and that the most truthful way of regarding illness – and the healthiest way of being ill – is one most purified of, most resistant to, metaphoric thinking." (Sontag, 1990 [1977 / 1988], S. 3) This means, that generally it would be very helpful to establish an open atmosphere throughout Botswana's society concerning issues of HIV and AIDS.

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