

## STIGMA AND DISCRIMINATION – AN INTEGRATIVE PERSPECTIVE

Spatial disparities and their impact on the introduction of an antiretroviral therapy scheme for HIV and AIDS treatment in Botswana

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With 4 figures

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**Summary:** The article outlines the empirical finding that there are spatial differences in HIV and AIDS-related stigma in Botswana. Most common theories on stigma and discrimination disregard such disparities. It was necessary to develop an integrative perspective in order to explain these findings and this required a broad interdisciplinary review of the literature in the fields of sociology, education, psychology, social psychology and applied sciences. The article explains how stigma and discrimination developed dependent on the local condition of the research sites. The relevance of the topic is apparent from the fact that stigma and discrimination in an urban community hindered the introduction of a medication scheme with antiretroviral drugs.

**Zusammenfassung:** Der Artikel beschreibt den empirischen Befund von regionalen Unterschieden im HIV und AIDS bezogenen Stigma in Botswana. Da gängige Theorien von Stigma und Diskriminierung derartige Unterschiede nicht vorsehen, war es nötig, eine integrative Sichtweise auf das Thema zu entwickeln, die es ermöglicht, dieses Ergebnis zu erklären. Diese Arbeit entstand auf Grundlage einer interdisziplinären Theoriearbeit, die soziologische, pädagogische, psychologische und sozialpsychologische Literatur sowie Arbeiten der angewandten Wissenschaften betrachtete. Der Artikel beschreibt, wie sich Stigmatisierung und Diskriminierung unter den lokalen Bedingungen der Untersuchungsorte ausprägten. Die Relevanz des Themas zeigt sich insbesondere in der Beobachtung, dass Stigma und Diskriminierung die Einführung der Therapie von HIV und AIDS mit antiretroviralen Medikamenten in einer städtischen Gemeinschaft besonders beeinträchtigten.

**Keywords:** Stigma, discrimination, rejection, integration, HIV, AIDS, identity, social identity

### 1 Introduction: ARVs in Botswana

Southern Africa is particularly strongly affected by the HIV/AIDS pandemic, and Botswana, where about 34 percent of the 14 to 49-year-olds are affected, has one of the highest HIV seroprevalence rates in the world (MOH 2006). Life expectancy has dropped to 36 years (UNAIDS 2006; UNDP 2005) and people were confronted with death on a daily basis.

A treatment exists in the form of antiretroviral therapy (ARV therapy)<sup>1)</sup>, but at the end of the 1990s, the affordability and efficiency of ARV programmes in developing countries were debated. Experts calculated costs and benefits (cf. FORSYTHE 1998) and sometimes advised against implementa-

tion (FLOYD and GILKS 1998). Even for middle-income countries, ARV treatment did not seem to be affordable (cf. PRESCOTT 1997).

Ultimately it was a worldwide movement that brought about a change in this appraisal. Since 2000, the UN and some pharmaceutical companies have declared their intention to provide ARVs worldwide. The “Global Fund to Fight AIDS, Tuberculosis and Malaria” (The Global Fund) was established in 2001, and in 2003 the WHO launched the “3 by 5” initiative, which aimed at providing ARV treatment to 3 million patients by the end of 2005 (cf. HARDON et al. 2006, 26). Botswana was the first HIV high-prevalence country where antiretroviral therapy was provided nationwide and free of charge.

In 2002 the ARV programme “Masa” was initiated. “Masa” is a Setswana word meaning a new dawn. The rollout was officially completed in 2006 with 32 ARV-referral sites (GEISELHART and KRÜGER 2007), and since then only so called “satel-

<sup>1)</sup> Antiretroviral therapy is still the only way to treat AIDS, but it does not cure an HIV Infection. It only limits the ability of the virus to reproduce. The medication needs to be taken lifelong.

lite clinics” are being established in order to provide a more decentralised supply of the medication. In 2007 an estimated antiretroviral therapy coverage of 79% was reached with about 93,000 patients on treatment (UNAIDS 2008).

Since the ARV therapy effectively delays or avoids the outbreak of AIDS, HIV-positive people can live an almost normal life. People living with HIV and AIDS (PLWHA) and self-help initiatives say that now stigma and discrimination have become two of the most important factors in the lives of those who are infected. This article shows that these factors vary spatially and explains how they form specific local conditions in different places. In individual cases they may even determine the success or failure of treatment.

## 2 Methodology

This article relies on a qualitative research design. During three field campaigns in Botswana (2004, 2005 and 2006) I held open qualitative interviews with about 85 members of HIV support groups, of which 73 (52 women and 21 men, ranging in age from 20 to 84 years) could be identified as PLWHA. Some of those interviewed I visited more than once. Some interviews were translated by a local interpreter but if possible the interviews were held in English. All interviews were recorded and transcribed. Because the topic required a special sensitivity, I was dependent on the members of self-help initiatives to refer me to persons I could interview. I thus used a snowball sampling technique. In a later stage of the survey, as my partners gained more trust in me, I was able to ask for certain interviewees, who, I hoped, would be able to provide me with additional, in-depth information. This approach corresponds to “theoretical sampling” as a concept of empirical field work, in which further interview partners are chosen deliberately according to analytical considerations (GLASER and STRAUSS 1967). All interviews were transcribed.

In addition, I interviewed 16 experts. These were mainly staff members of HIV and AIDS support services (e.g. nurses, youth counsellors), but also included individuals who were based in the community, representing either religious denominations, non-governmental organizations (NGOs), or the city council. Another important source of information was the presentations and discussions at a workshop that our research group organised in Gaborone in March 2006. This workshop fo-

cused on the social transformation processes following the introduction of the nationwide antiretroviral treatment schemes. Participants came from the government, from medical care services, from scientific institutions and from support organizations and self-help initiatives. All speeches and discussion were recorded and made available for transcription.

All transcriptions, field notes, and other material (e.g. flyers, advertisements) were coded and analysed with “atlas ti”, a computer program designed for qualitative data analysis. This program employs the principles of the *grounded theory*, which was invented by GLASER and STRAUSS (1967). On the basis of the empirical data a rough framework was developed to describe how processes of stigmatisation and discrimination develop depending on local conditions. A broad review of literature from the fields of geography, sociology, education, psychology, social psychology and the applied sciences served to generalise this framework. Various lines of theory on the subject matter were disentangled and finally integrated into a concept of stigma and discrimination, which will be outlined below.

## 3 Stigma and discrimination, the two sides of a coin

### 3.1 The front side: stigma

The most influential work on stigma is still that of ERVING GOFFMAN (1990 [1963]), even though his theory has frequently been contested because of its assumption of a normative order (WEISS and RAMAKRISHNA 2001; KUSOW 2004). GOFFMAN describes stigma as a discrediting attribute that is a deviation from the norm. He analyses many examples of stigmatised people, who relate their experiences in interviews, and concludes that the “stigmatised” ultimately have to take on the roles society provides for them. The biggest point of criticism is that the focus of GOFFMAN’s notion of stigma is too narrow and individual based and is not suitable for designing interventions to reduce stigmatisation (SAYCE 1998; JEWKES 2006). Nevertheless, GOFFMAN’s ontological deliberations have never been supplanted or even substantially enhanced.

Nowadays, most perspectives on stigma found in the literature can be characterised as “social approaches” (e.g. PARKER and AGGLETON 2002; BOND and MATHUR 2003; OGDEN and NYBLADE 2006). These works define stigmatisation as a “social

process” and emphasise that it is a product of social conduct. PARKER and AGGLETON, for example, show how stigma and discrimination can be utilised to legitimise social inequality and maintain social hierarchy. The causes and effects of processes of stigma and discrimination are considered on a broader social, cultural, political, and economic level. Some works, for example, develop tools to measure stigma (USAID 2006); others aim at identifying the public health implications of stigma (LINK 2001), and some are especially useful for public health issues because of the tools for interventions they design (KIDD and CLAY 2003). These works often categorise different forms of stigma, and the resulting categorisations depend on the purpose and method of research. For my work one idea was especially inspiring. It was the distinction between “identity stigma” and “treatment stigma” which indicates that there is a self-related and a community-related aspect of stigma (STUBER and SCHLESINGER 2006). This distinction ultimately led me to the point that stigma and discrimination itself should be divided as such.

Apart from the indisputable achievements of these social approaches to stigma, there is a great deal of confusion in their use of terminology. Each work defines different causes and also different forms of stigma, because ultimately these approaches treat stigma as a “black box”. They regard only the input and the output without asking about the internal processes, and they are not based on a common conception of stigma. I do not wish to minimise the yields of the “social approaches” but to suggest a consistent terminology that will enable me to integrate all works on stigma with which I am familiar. The concept outlined here extends from the individual to the societal level. Hence it is necessary to include another topic, and that is discrimination. While stigmatisation denotes the self-related processes of individuals who bear an extraordinary attribute, discrimination is the reaction of those who encounter a bearer of a stigma.

### 3.2 The reverse side: discrimination

A series of works exists that deal with discrimination related to single attributes, such as age, race or mental illness (LOTT and MALUSO 1995). Such works are especially important for gaining the insight that there are no fundamental differences in processes of discrimination based on the attribute that is the reason why a given person is discriminat-

ed against. Each attribute can create its own metaphors (SONTAG 1990 [1977/1988]) or specific consequences. It may be utilised for political purposes to different extents, but there is a similar core in these processes. Ultimately in all cases social distance is induced and individuals either use their agency to overcome this distance or not.

Many sociologists take a structuralist perspective. Authors such as ESSER (1986) or RYDGREN (2004) have focused on social and economic aspects and consequences of discrimination. They show how it is difficult to escape the structural consequences of social categories and provide the insight that social categories effectively stratify society. The psychologists TAJFEL (1978), who invented the social identity theory, and TURNER (1978), through his theory of self-categorisation, explain how socially divisive behaviour is rooted in individuals. With this paper I want to show that it is possible for individuals to counteract the structural ties of their communities. There is a way to bridge social distances even if discrediting social identities exist.

### 3.3 Further reasons for an integrative perspective

Since such authors as KILLIAN (1985), SAYCE (1998), and later also KUSOW (2004) contested existing concepts of stigma, the term has hardly been used any more with regard to e.g. race or religion. Currently social exclusion on the grounds of such affiliation is explained in terms of discrimination. But what exactly is the essence of the difference between those attributes of people that are best described in terms of discrimination and those that should better be referred to as “stigmata”? It is not possible to identify a fundamental difference between the attribute of being a member of a certain race, sex, or religion and that of having a life-threatening illness, a mental disorder, or being poor. The latter are mostly dealt with in terms of stigma.

In view of the obvious interdependencies between stigmatisation and discrimination it is not understandable why scholars often restrict their considerations to either stigma or discrimination. LINK (2001) already explained that labelling, stereotyping and discrimination are important factors in stigma. As a result I conclude that stigmatisation and discrimination should always be considered together, but at the same time clearly distinguished from each other.

#### 4 An integrative perspective on stigma and discrimination

For stigmatisation and discrimination to occur a person who bears an “extraordinary” attribute<sup>2)</sup> (represented in figure 1 by the figurine with red hair) must meet someone who does not bear this attribute. The attribute is “extraordinary” in a way that catches the attention of the non-bearer, and the bearer knows that it might be considered extraordinary by others.<sup>3)</sup> The concept outlined here thus assumes that attributes of individuals are perceived and interpreted. It is not the attribute itself but these processes of perception and interpretation that make an attribute cause social distance.<sup>4)</sup> An attribute thus becomes a stigma when the persons involved in a social encounter stop behaving in a relaxed manner and an uneasy situation results.

It is also important to see who perceives and interprets the attribute, the bearer of an attribute or another person. Accordingly, we can distinguish between *stigmatisation*, as the self-related process of the bearer, and *discrimination*, as the perception and interpretation of those who encounter a person bearing a stigma.

It is further possible to distinguish between a structural dimension (*category based processes*) and an individual dimension (*individuating processes*) of stigma and discrimination.

#### 5 Category-based processes

In society prejudices, stereotypes and social identities about certain groups exist. Social identities are complex notions that society provides for certain groups. These notions comprise not only the attribute that defines a person as a member of a certain group (such as a wheel chair, which reveals that a person is handicapped) and traits that are directly connected with this attribute (such as that a wheel chair-bound person cannot climb stairs).

<sup>2)</sup> In social psychology the term “salience” is used when an attribute evokes social categorisation.

<sup>3)</sup> GOFFMAN has explained that an attribute does not need to be visible; information about the attribute is sufficient (GOFFMAN 1990[1963]).

<sup>4)</sup> Social distance can also be induced by an emotional response to an attribute. Because of space limitations this special case cannot be discussed here. For an explanation see GEISELHART (2009, 86ff).

Social identities consist of a complex assortment of characteristics that affect many areas of everyday life. In this sense social identities are usually socially divisive (TAJFEL 1978; WAGNER and ZICK 1990; BLANZ 1997).

With his “minimal group experiments” TAJFEL (1978) found that a group affiliation, once stated, no matter how irrelevant it may be, leads to behaviour that discriminates against out-group members. The subjects of the experiments did not even know who belonged to one group or the other. The group itself also did not have any significance that could establish a meaningful identity. Nevertheless, the subjects were eager to minimise the benefit for the out-group, even if that meant that they failed to achieve the maximum for their own group. Humans seem to have a psychologically based tendency to discriminate. TAJFEL based his theory of social identities on these findings.

The tendency of individuals to search for signs that allow them to categorise other people is a basic condition of “labelling”. The readiness to do so is the reason why social identities can be easily utilised for political intentions (MONCRIEFFE and EYBEN 2007).

The bearers of a stigma also see themselves confronted with stereotypical ascriptions and thus may easily categorise themselves accordingly (TURNER, 1978). This might ultimately lead to the adoption of social identities in the manner described by GOFFMAN (1990 [1963]). Because all three alternatives open to the stigmatised to react to their stigma in a self-determined way lead to discrediting situations and an unsatisfying self-perception (GOFFMAN 1990 [1963], 154f. and 19ff.), GOFFMAN eventually proposes that stigmatised persons have no other choice than to behave as they are expected to do.

It is not only GOFFMAN’s normative theory that regards solely category-based processes. Even newer approaches that define stigma as a social process mostly remain on this level. Only few authors (e.g. KIDD and CLAY 2003; STUBER and SCHLESINGER 2006) broaden the discussion to include individual coping and the educational implications.

#### 6 Individuating processes

From a pedagogical point of view identity building is not only a casual construction made by a post-modern mentality of bricolage, as GROSS suggests (1999). Individuals find themselves con-



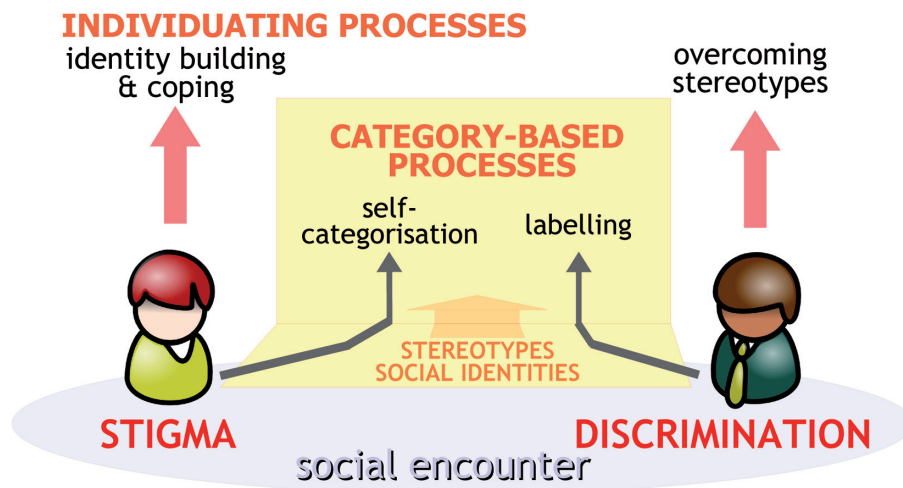


Fig. 1: Integrative concept of stigma and discrimination

fronted with prevailing social identities, but they also have their personal experiences from socialisation and acculturation that they have to include. Identity building is a process that challenges the individual emotionally. It is therefore more appropriate to speak of “identity work” (KEUPP and HÖFER 1997) than of casual play with exchangeable identity options (BHABHA 1996). The challenge for juveniles and young adults is to invent themselves within a social context and to define their roles. Of course, self-identities are not fixed, but they are also not absolutely volatile or arbitrary. Identity building has not become easier, as BAUMAN’S (1997) post-modern lifestyles suggest. Identity work remains a serious task for every individual within the omnipresent hybridism of social identities and the increasing demand for flexibility (SENNETT 1998).

It is obvious that especially for stigmatised persons identity building is not easy. It requires trust in one’s self-efficacy (BANDURA 1993) to question existing social identities. Within their process of identity building the bearers of a stigma can also consider other attributes and experiences of themselves and thus distance themselves from stereotypical ascriptions.

The process of coping with a stigma is not only an intellectual process of defining oneself. In cases of stigmata and their socially divisive effects, coping is not only coping with stressors (ANTONOVSKY 1980[1979]). Coping with a stigma also entails a social dimension. In the interviews the people affected spoke of “accepting oneself”.

Originally the self-help initiatives borrowed this term from KÜBLER-ROSS (1971). In her inter-

views with dying people she identified accepting as a final stage before death, as a kind of coming to terms with oneself. My interviewees, however, did not describe accepting oneself as a final process for preparing themselves for death. To be able to accept oneself, it is necessary to include one’s social environment in the process of coping. When the coping is successful, the respective person establishes relationships in which the respective attribute no longer causes social distance. This includes overcoming self-reproach and stopping blaming others (cf. GEISELHART 2009, 69ff).

It is important to see, that “coping with a stigma” refers only to the process of coming to terms with the socially divisive effects that cause an attribute to be a stigma. It does not refer to the fact that each attribute may bring other effects and consequences, which also need to be coped with. In the case of an HIV infection this might be side effects of the medication or psychological difficulties. These constraints may require coping in the sense of biomedical treatment or as described by ANTONOVSKY (1980[1979]). Not only the bearers of a stigma can overcome social categories. Those who encounter a person who bears a stigma also have the chance to revise the first impression that they derived from social categories (FISKE and NEUBERG 1989). They can enter into a social interaction and perceive other characteristics of the bearer. The resulting individuating perceptions can lead the non-bearer to recognise stereotypes as prejudices. With repetitive interactions the social counterparts come to see each other more and more as distinctive individuals and social categories no longer play a major role.

## 7 Consequences

Because people are social entities, the processes described above influence each other. On the one hand people define themselves on the basis of how they are perceived by others and what others think of them. On the other hand, they have a certain agency with regard to their self-identity and their social role (BANDURA 1993). To a large extent one's social behaviour determines the outcome of social encounters, which are a major source of experiences of stigma and discrimination. The experience of social distance can only develop from social encounters. In further processes of perception and interpretation these impressions can be either fostered (category based processes) or reduced and even eliminated (individuating processes). In this fabric of influences openness plays a key role. People with open attitudes can become acquainted across the dividing borders of social categories. Rejective attitudes, in turn, can be assumed to strengthen social distances. Openness can thus be the key for reducing stigma and discrimination.

From this insight we can derive some ideas for intervention against stigma. Openness towards a stigma must exist on the part of the bearers of a stigma and on the part of the non-bearers. Openness can in principle be encouraged by intervention. Openness does not mean publicness. It should not be confused with a call for stigmatised people to talk about their experiences in public, although activists who do so are very important for the general awareness of a stigma.

What is meant here with openness is first of all the readiness of non-bearers to question their stereotypical ways of assessment and to not simply reject bearers in social encounters. Furthermore, readiness is also needed on the part of the bearers. They should talk about their stigma to close acquaintances and probably also to people with whom they are less familiar. In this sense openness can be targeted by family counselling, self-help initiatives and public events dealing with a stigma.

Of course it is essential to seriously ponder the question whether this can also be harmful to the respective persons. This certainly is dependent on the kind of stigma at issue. It should be born in mind that in highly discriminative environments openness might also have negative effects.

The concept of stigma and discrimination outlined here also opens a bottom-up perspective on social chance. Stigma and discrimination are linked to social encounters and thus take place at the lo-

cal level, in concrete places. The individuals involved have leeway to react to the social dynamism of stigma and discrimination. By organising they may be able to change the conditions for social encounters in their local communities. In this respect, social change means that two things need to change. One is the expectations of the bearers of a stigma regarding the interpretations or images applied to them and the other the expectations of the non-bearers about which images should appropriately be applied to the bearers of a stigma. In the wake of such change ideas about what actions are socially acceptable would also change.

In local places the influences of different actors can be identified. Even actors from higher levels of society have an influence. Unfortunately, such change is not only induced for the benefit of those who bear a stigma. Category based influences, which tend to cause social distance, can be utilised in order to achieve social segregation and political advantage. Individuating influences, in turn, which tend to help overcome social distance, can be utilised for the purpose of social integration. For a list of measures that can be taken see GEISELHART (2009, 219).

From this perspective we see how local differences in stigma and discrimination can evolve. In the following this will be explained in relation to HIV- and AIDS-related stigma in Botswana.

## 8 Spatial differences in HIV-related stigma

The study was conducted as a comparison of rural and urban living conditions. Intuitively one would tend to assume that urban neighbourhoods would be more progressive and open-minded than rural communities. Therefore one would expect stigma to be higher in rural sites. Surprisingly, the fieldwork carried out among members of HIV and AIDS support groups, showed that the opposite was the case. As these findings stem from a qualitative study, they cannot be generalised. Nevertheless, the principles derived from an analysis of how stigma and discrimination developed locally can be regarded to be valid in a broader context.

The interviews were conducted in a deprived urban neighbourhood, Old Naledi, and in the two villages of Tshane and Letlhakeng (Fig. 2). Old Naledi is a township of Botswana's capital city Gaborone and is thus situated in an urban environment. The official population figure is 21,693 (CSO 2001), but Old Naledi has a somewhat semi-official character. Initially established as a temporary workmen's

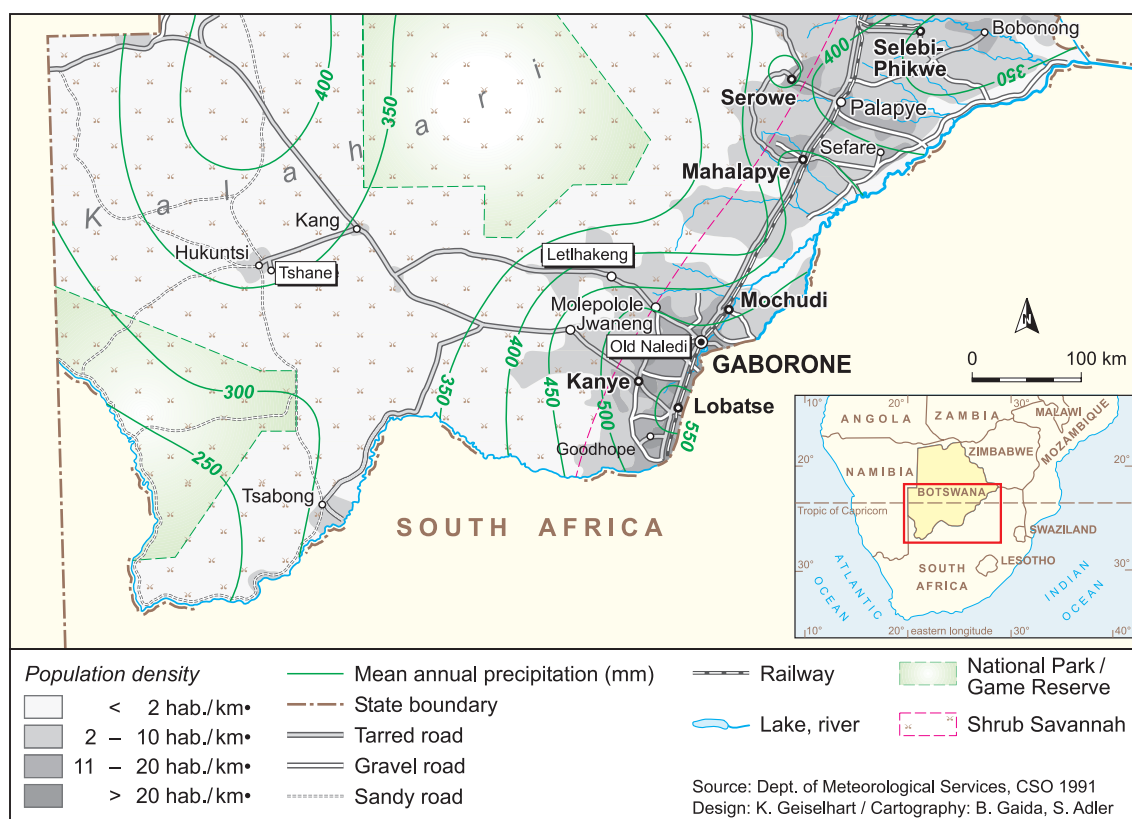


Fig. 2: The research sites Tshane, Letlhakeng and Old Naledi in Southern Botswana

camp for the labourers who built the capital city, Old Naledi developed into a stable informal settlement. Several upgrading programmes only partially remedied the illegal character. Today Old Naledi is the gathering place where rural-urban migrants find their first shelter. The building restrictions on residential plots that allow only two structures on a compound are obviously disregarded. Furthermore, the houses are overcrowded with up to 5 or 6 persons living in a small room. Some estimates are thus as high as 50,000 inhabitants for Old Naledi.

The villages are situated in a relatively homogeneous natural area, the Kalahari basin. This area provides rather poor conditions for agriculture as it is dry and drought prone. The villages differ in size and in their distance from Gaborone. Whereas Letlhakeng with its 6,000 inhabitants is only 111 km from Gaborone, Tshane with its 858 inhabitants 532 km from Gaborone is situated extremely peripherally (Fig. 2) (CSO 2001).

The research sites were chosen in order to get a sample as homogeneous as possible. Therefore, the research sites were chosen in an area where the cultural characteristics of their population do not differ

much. There are some cultural differences between different social groups in Botswana, most of which derive from their origin in different ethnic groups or Tswana tribes. The major fault lines lie in the East of Botswana, between the Kalanga and the Tswana but not in the area of research. Furthermore, the national culture has levelled many differences. Old Naledi, being the place where people from the western hinterlands migrate, also accommodates people from the groups interviewed in the villages. In the villages the survey addressed marginalised groups, which cannot rely on a job in a governmental organisation. In the rural areas the government is the major source of formal employment. Its workers live in privileged housing conditions and could thus easily be excluded from the survey.

## 9 How the findings were derived

These findings are based on a triangulation of three methods. These consist first in a categorisation of members of the local support group according to their attitude towards their HIV-positive status,

second, on observations made during the fieldwork and third, a presentation of preliminary results at a workshop in Gaborone. These sources of information will be described in the following.

### 9.1 Attitudes towards HIV infection

It was surprising to establish that the attitudes of PLWHA differed in the different living locations (cf. Fig. 3). About 85 interviews were conducted with members of support groups. They were interviewed about their situation and their living conditions.

73 of the interviewed members of the local support groups were identified as being HIV-positive. 8 of them were not living in one of the three research sites and thus were not considered in the following analysis. The remaining 65 were categorised according to their attitude towards their HIV-positive status. 6 could not be categorised because of inconsistencies in their statements or because they had only been tested recently. PLWHA who learned about their HIV-positive status less than 6 months ago were not included, because it was assumed that they had not had enough time to develop an open attitude. In the end 27 persons in Old Naledi, 25 in Letlhakeng and 7 in Tshane were included in this evaluation.

All of the interviewees were members of the local HIV and AIDS support groups. It was assumed that members of the support group have the tendency to try to develop a *positive* and open attitude towards their HIV-positive status and, as a result, we interpret the data as marking the tip of the iceberg. It was therefore all the more interesting to find differences between the places of residence.

The PLWHA were classified to in five categories:

- A total of 8 of our interview partners were public about their status, which means that they had spoken at public events where they declared their status, told their personal stories, and talked about their experiences with the illness.
- A large number of our interview partners (23) were identified as being open about their HIV-positive status. These people would not raise the subject of their HIV positivity by themselves but, if asked, would admit to being HIV-positive. They talked about their status with friends, neighbours and even with people less familiar to them if the topic was raised. They also assumed that others knew about their status.
- 21 further persons were secretive about their status, which means that they had disclosed their

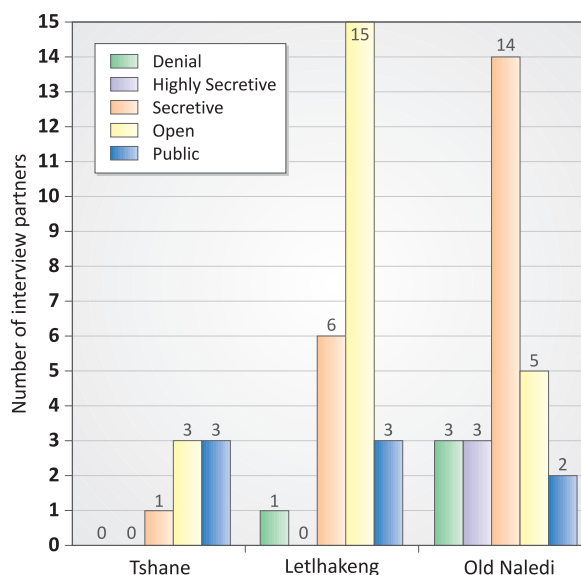


Fig. 3: Attitudes of support group members towards their HIV-positive status (n=65, missing 6)

status to one or more members of their families, but outside the household their status was kept secret.

- 3 interview partners were highly secretive, which means that even close relatives did not know about their status. However, these people may have had a confidant in the self-help group.
- We also had the opportunity to talk to 4 people who lived in denial. Living in denial means to reject the biomedical explanation of HIV and AIDS and to pretend not to be HIV-positive. Persons living in denial may still actually know about their infection status, but they may also refuse to go for a test, in spite of obvious symptoms. People living in denial could only be identified because others disclosed their status. This was only possible by gaining the trust of the interpreters, who were also members of the support groups, but the researcher did not encourage such disregard of confidentiality. These interviews gave interesting insights into further dimensions of HIV and AIDS but do not contribute to the findings here.

The category “public” is also of less interest in this context. Each support group has a limited need for activists. Only few people are needed to speak at public events. The number of activists thus is limited and is the same in all the sites assessed. For this article it is most interesting to compare the category “open” with the categories “secretive” and “highly secretive”. In these categories people can actively develop their attitudes. Furthermore, the data can be regarded as reliable.



In the urban neighbourhood of Old Naledi the majority of the interviewees were secretive or highly secretive. In the rural communities most support group members were open about their HIV-positive status and there were no highly secretive persons among the interview partners.

## 9.2 Openness and the fear of disclosure

The findings can be reinforced by some observations. In contrast to the rural sites, in Old Naledi the interviews took place inside the houses. There were only two exceptions. One was an interview with a person who was public about his status, who accordingly did not mind the open scene. In the second case the dialogue partner had also attended the aforementioned interview with the interviewee who was public and thus also accepted the scene. A few other interviews were begun outside but were soon moved inside the houses. In one case, a group of people had clustered around the corner close by the house just as we settled down to begin the interview. Our interview partner immediately felt that the interview was being listened to and asked if we could go inside the house. In many cases, it was obvious that from the beginning interviewees tried to hide us<sup>5)</sup>. While we were doing the interviews inside the houses, there was sometimes a knock at the door. In these cases, the interviewed parties usually opened the door just a crack to make sure that the visitors would not see us.

In the rural sites it was completely different. Often when we were walking through the village to find the next interview partner, people asked us what we were doing. When we provided information the person who had asked often said that he or she was HIV-positive as well and offered an interview. In the villages people sometimes even exchanged jokes about their HIV positivity over the fences of their compounds. In contrast, in the urban sites it was much more difficult to establish contact with the interview partners. In Old Naledi, it was necessary to emphasise the point that HIV-negative interview partners were also of interest. It turned out that there was no consensus within the group about the need for all members to be open about their status. There were frequent

discussions about this point and many members demanded that all members should know about each other's respective status, but a decision could not be reached. When asked about this fact, some members replied that they were afraid people who are just inquisitive could come to see who attends the meetings of the support group.

## 9.3 Presentation of the findings

In 2006 our research team held a workshop on the social implications of the antiretroviral drug scheme in Gaborone, Botswana. There we presented our preliminary findings about the spatiality of stigma. The findings were confirmed and the presentation led to a lively discussion about the effects of stigma in different social groups.

## 10 Explanation of the urban-rural divide

It is possible to regard the large numbers of support group members who are secretive as an indicator that stigmatisation is comparatively high in the urban site of Old Naledi. If stigma depended on a norm, as described by GOFFMAN, it would not vary between different locations but would be more or less homogeneous throughout a given society with shared values and beliefs as in Botswana. With the help of the framework outlined above it was possible to explain the findings of this study.

### 10.1 In the villages

In the villages assessed, a high degree of social control and lack of discretion led to a situation in which it is virtually impossible to conceal an HIV infection. Though the official organisations propagate confidentiality, it is almost impossible to enforce. The call for confidentiality is the result of a westernised view of illness in which illness is a matter of the individual alone. In traditional Botswana society such an abstract commitment to confidentiality concerning private information is unknown. In a formerly oral culture information is supposed to be shared rather than hidden. In Setswana there is not even a word for confidentiality.

On the one hand, from an international perspective this violates the sphere of personal privacy of PLWHA. On the other hand, as a result in

<sup>5)</sup> The research team consisted of the author and one member of the respective local support group, who acted as translator when needed.

the villages virtually everybody knows everybody. In such environments, category-based discrimination is not that prevalent because stereotypical images are easily recognised as such. This leads to individuating perceptions of HIV-positive people, because more is known about them than only that they are infected.

With the introduction of ARV therapy people saw how other people who were expected to die soon came back to life. Their recovery became visible, just as previously it was impossible to conceal the illness and people saw the person suffering. As the ARV therapy proved its efficacy, HIV and AIDS lost much of their horror and it became more and more usual to talk about HIV and AIDS openly. The ARV scheme gained broad acceptance.

PLWHA in turn saw that they were no longer being judged over-hastily. The fact that they saw that others did not simply perceive them in stereotypical ways helped them with their personal process of coping with the stigma.

## 10.2 In the city

The urban environment, however, was characterised by a high degree of individualisation and the values associated with it, such as flexibility, personal productivity and means-end orientation. When individuals who are confronted with such values receive a diagnosis of HIV their process of identity building is disrupted. To a large extent the affected individuals see themselves as being dependent on the perceptions of others, which in turn are dependent on prevailing stereotypes and prejudices. For example, PLWHA knew that it was often assumed that they could not do certain jobs, especially exhaustive ones, any more. They therefore tended to hide their HIV-positive diagnosis.

Many PLWHA expected it to be possible to conceal their infection in the anonymity of an urban setting. To some extent they succeeded, but the result was that the illness did not become visible until, for example, side effects occurred and the illness could no longer be concealed. Even after the introduction of the ARV scheme, HIV and AIDS-related issues are not dealt with openly in Old Naledi. Many patients failed to seek treatment at the right time and fell sick or even died.

The socio-economically deprived situation of Old Naledi also led to a dominance of category-based interpretations of HIV. The interviews showed that other old stereotypes also easily per-

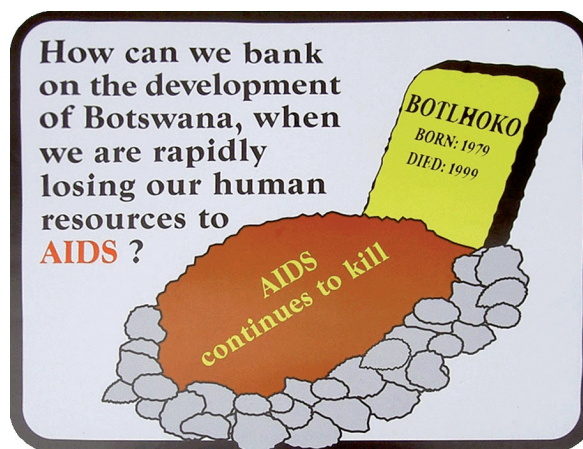


Fig. 4: An appeal by the Members of Parliament to the youth (1999)

sist in such an environment. In early prevention campaigns HIV often was linked to promiscuity. In a poor environment where many women can only survive by offering sexual services, HIV positive women are often viewed as prostitutes (cf. ZULU et al. 2004). STILLWAGGON (2006) analysed the complex interdependencies between poverty and HIV and AIDS. These are also reflected in the notions of the inhabitants, and the stigma of HIV and AIDS thus becomes associated with the stigma of urban destitution.

Early prevention campaigns helped to establish another common prejudice about PLWHA (Fig. 4). They stated that a person who is HIV positive is inescapably doomed to die. These pronouncements were frequently interpreted such that the respective individuals are no longer worthy of being dealt with as persons. Such prejudices were affirmed by the conditions in Old Naledi.

In the urban context stigmatisation and discrimination formed a self-reinforcing fabric of prejudices, denial, concealment and shame. Some individual persons tried to break the cycle but they did not succeed in altering the situation for the community at large.

It is interesting to see that to a large extent the affected people perceive the local conditions as unshakeable realities. Some people from Old Naledi spoke of their fear of returning to their home villages. They assumed that they could not hide their infections because the people in the villages would recognise HIV induced changes in their bodies. Of course these worries were justified, but they did not consider the possibility that this could have a positive effect on their situation.

### 10.3 Impact of stigma and discrimination on the ARV scheme

In Old Naledi the socially divisive effects of an HIV infection were aggravated by a lack of openness. The high degree of secretiveness led to a situation in which the communities lacked experience with people who deal with the illness in a *positive* way. "Living positively" is the usual term among PLWHA for such a positive attitude to life despite an HIV infection. In contrast, the high degree of openness among PLWHA in the rural communities led to comprehensive knowledge about HIV and successful handling of the consequences.

The local situation had an effect on the implementation of the ARV programme. In the villages the effectiveness of the drugs was visible and the programme thus quickly gained acceptance. In Old Naledi by contrast, the implementation of the programme was more difficult. Although this neighbourhood was closest to the innovation centre of the therapy, the programme met with only sluggish acceptance. Even three years after its introduction, some people did not seek treatment until they were in very poor condition. Between 31 May 2004 and 21 April 2005, Miss Leabaneng Masedi, the director of Old Naledi's support group, referred 12 patients to the Holy Cross Hospice, which is situated in an adjacent neighbourhood called New Stands, Gaborone. The Holy Cross Hospice is not a hospice in the usual sense, because it serves more as a day care centre for seriously or terminally ill patients. The patients are referred to the support group by neighbours or relatives because of their poor physical condition. In most of the cases, they refused to be HIV tested and did not seek treatment in time. The Holy Cross Hospice establishes contact to doctors so that the people can be treated. When patients are in poor health, treatment with antiretroviral drugs is more difficult. The danger of treatment failure rises, as does that of permanent damage to health.

Leabaneng Masedi gives a reason why people go for therapy too late:

"Here in Old Naledi, my brother, we are dying. [...] The most people they don't die because of HIV. They die because of that frustration, that loneliness." (39 Interview PLWHA OldNa)

In Old Naledi the many cases of successful treatment remained invisible because of the high degree of anonymity. On the contrary, cases of treatment failure were tangible, when for example bedridden people could no longer be helped. HIV and AIDS did not lose their horror to the same degree as in the rural villages.

## 11 Conclusion

This article explained how stigma and discrimination occur in local contexts. It is always necessary to regard both phenomena together because they are like the two sides of a coin. Merely regarding stigma implies the danger of "blaming the victims" (SAYCE 1998) because it delegates the responsibility entirely to those who are already suffering. To consider a case merely in terms of discrimination, in turn, would disregard the fact that affected people also have agency. They are not simply victims who are at the mercy of societal expectations and existing roles, as in GOFFMAN's (1990 [1963]) analysis.

Newer approaches to stigma often neglect the pedagogical aspects of coping with a stigma and lay the stress on measuring or analysing structural constraints. The concept outlined here offers an integrative perspective that also does justice to the efforts of the self-help initiatives and allows a bottom-up perspective on social change.

For geographers it is especially interesting to see how stigmatisation and discrimination vary locally. It is not enough to analyse the societal conditions, the discourse about a given stigma or the relevant legislation. To see the local peculiarities a micro-perspective is needed.

In the case of HIV in Botswana it would be possible to conclude that conducting the ARV programme requires extra endeavours in some areas. First, there is a need for further awareness campaigns directly in the neighbourhood that address therapeutic issues and the needs of people who are on therapy. Second, initiatives to reduce old stereotypes and prejudices are necessary in order to reduce stigma and discrimination. Much could be achieved by supporting the local self-help initiatives more effectively.

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