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'Living positHIVely in Tanzania'.

The global dynamics of AIDS and the meaning of religion for international and local AIDS work[1]

AIDS as a phenomenon of globalisation

Having spread to all countries of the globe in the last 20 years, AIDS is, in the international community, discussed as a *global epidemic* (e.g., UNAIDS 2000). Even if the high concentration of the disease in the Southern hemisphere is a clear sign of the inequalities and local differences immediately connected with the ongoing epidemic, and although AIDS most drastically effects the economically weakest countries of the globe, it seems as if such differences have been dissolved in an international partnership, and as if the world is committed to a common solution for the containment of the epidemic on all societal and political levels – however diverse the intentions and motives. Thus, the former US Secretary of Treasury, Lawrence Summers, emphasised in July 2000 that combating the disease is a "moral and economic imperative" which has to be understood as an "investment in global prosperity" (U.S. Department of State 2000). At the same time, on the occasion of the World AIDS Conference in Durban, AIDS activists of all nations gathered for a *global march* and launched a *global manifest*. In their declaration, they demanded from both Western pharmaceutical manufacturers, and 'first world' governments, a reduction in prices for anti-retroviral drugs; moreover, they appealed to South African politicians for the immediate institution of a distribution program providing cheaper AIDS medications which had, until that time, been blocked by the South African government (see Act Up New York).

However, if one takes a closer and more critical look at the modalities of international AIDS work, and at the manifold AIDS policies which have been created in the fight against the epidemic, this oversimplified image of global concern and of world-wide co-operation becomes less convincing. Global

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inequalities are not only mirrored strongly in the powerful position of Western pharmaceutical concerns and in the heated debates which surround the distribution of expensive AIDS medications to the poorer nations. Moreover, as HIV/AIDS prevention programs and other measures of intervention are to a great extent funded by US or European donor organisations, they are strongly influenced and shaped by guidelines of these same institutions, and working models of international AIDS work are mostly based on cultural conceptions and assumptions stemming from the donors' countries of origin. The success of some of these models in the contexts in which they were developed has lead to their transferral to other parts of the world, without adequate consideration of the possible cultural differences between the original and the prospective target groups. With regard to Southern Africa, the director of a Tanzanian AIDS NGO describes this uncritical adoption of concepts in the following way:

> "Until now, the majority of prevention models implemented throughout this region have adopted and utilized European and North American models of health, education, and prevention with little or no accounting for African cultural differences. (...) Because this virus was initially identified in a specific group in the United States with its own cultural norms and practices, prevention efforts necessarily took into account this group's socio-cultural environment. As the virus continued to spread not only throughout North America and Europe, but Asia, Australia, Latin America, and Africa as well, most prevention efforts simply borrowed intervention tools that had been developed within the originally identified population group in North America." (Bauer 1997: 1)[2]

One example of these global dynamics of international AIDS work is the preventive model *safer sex*, which emphasises the use of condoms, and not abstinence from the sexual act *in itself*. Safer sex was first 'invented' in the gay communities of the United States and Europe, and has proven to be an effective means of prevention in these same contexts. Presently, it is being used in AIDS work in countries throughout the world and in the most diverse cultural settings. The *Red Ribbon* - a symbol of solidarity with HIV infected persons intended to create a broader consciousness of AIDS in the 'general population' – is another example of the same dynamic at work. The concept of the Red Ribbon began with a group of artists in New York at the beginning of the 1990s and was soon adopted by Hollywood, as well as by organisers and participants of international AIDS conferences. Today, while the meanings attached to the symbol have not changed over the years, the Red Ribbon is worn by people all over the world (Pwha-Net: message 453).

While the typical scenario has become the application of concepts developed in richer Northern countries to the poorer countries of the Southern hemisphere, such a transfer is often less one-sided than it appears and has become increasingly ambivalent. The use of condoms, for instance, has become a contested issue in many African countries, and is often rejected in favour of pre- and extra-marital abstinence not only by the older generation or by conservative, religious

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[2] The application of a concept like *safer sex* for different target groups is, however, not only problematic in the international context. *Within* North America and Europe, for example, it is necessary to question whether the safe sex model, which is based on certain assumptions and values of the gay community, is, for instance, in accord with the needs and wishes of heterosexual women (Giffin 1998). Furthermore, there is - in Germany and most European countries - an increased need for prevention programs that take into account the cultural backgrounds of the growing number of HIV infected migrants.

organisations, but also by many young people (see for Tanzania: Dilger 2001). Such ambivalence was also evident in the controversial discussions that preceded the World AIDS Conference in Durban. Sparking this controversy, the South African President, Thabo Mbeki, publicly questioned the dominant paradigms of medical AIDS research and defended - against massive critique from the national and international communities - the theories of the so-called ‘AIDS dissidents’ who doubt the causal connection between HIV and AIDS, and the existence of the virus in general. By defining ‘poverty’ - not HIV - as the actual cause of the massive spread of the epidemic in Africa, Mbeki supported the thesis of the dissidents that AIDS is a conglomerate of poverty diseases which had plagued the continent even before the official outbreak of the epidemic. When a South African opposition leader accused Mbeki of being ignorant of scientific facts and of searching the solution to AIDS in "quackery", the President responded that "for African problems African solutions are needed", and that just because these solutions were African, does not mean they are synonymous with "superstition" (Media-AIDS: message 58).[3]

The different positions and attitudes towards AIDS, as outlined thus far, make it clear that the ways in which different states and institutions cope with the epidemic mirror exactly those mutually contradicting, yet inseparable, aspects which are characteristic for the tensions of a globalising world, and which were named by Meyer/Geschiere (1999) the "dialectics of flow and closure". AIDS has led to an increased demand for the *strengthening of borders* (cf., Wolf 2000) - *because* it is perceived as a global and translocal threat. This could result in special immigration laws for HIV-infected persons[4], in calls for obligatory HIV tests for so-called ‘risk groups’, as well as in stigmatisation or the wish for ‘African solutions’. On the other hand, AIDS has brought about a *flow* between continents, states and institutions, and it has - at least in some contexts - created a ‘global identity’ which connects people with HIV/AIDS around the globe, and which can even transcend more ‘traditional’ categories of identity formation. Schwartzberg, in his book on US-American gay men in the times of AIDS, has put it in the following way:

> " (...) some men find in their HIV infection a feeling of universal belonging - a sense of participating in an universal community, beyond the confines of any particular subgroup or ethnic identity. Their connection moves beyond family and friends, beyond the HIV community and gay community, beyond the limited membership of their own particular religious sect. They derive from their own infection a sense of kinship with humanity, of inseparably belonging to a chain of humanity linked across the globe, through the ages. With this aspect of HIV as belonging, the

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[3] It is interesting to note that Mbeki, while calling for "African solutions", saw no contradiction in the fact that most of the dissidents - the most prominent among them the molecular biologist Duesberg from Berkeley - are scientists from the US and European countries. The international community’s rejection of the theories of Mbeki and the dissidents can be understood in a more differentiated manner if considered from the background of mutual blaming which has shaped the transnational and transcontinental discourses on the epidemic from the beginning (with referral to Africa see Dilger 2000: 169ff.).

[4] In the United States of America which hosted the UN special session on HIV/AIDS there exist harsh restrictions for the visits and immigration of HIV infected individuals to the country. With the right to deny entrance to people with HIV/AIDS, the United States find themselves in line with countries as Armenia, Iraq or Turkmenistan (PWHA-Net: messages 701, 704).

> community is that of humanity, the kinship is to the people of the world." (Schwartzberg 1996: p. 44)

In the following, I want to take a closer look at another, central concept of international AIDS work and explore it with regard to its global and local dynamics and meanings. *Living positHIVely* represented, since it came into use, a paradox in the field of AIDS work. The diagnosis 'HIV', on the one hand, is immediately associated with death, stigma and social isolation, and thus with the strong physical and emotional suffering of the affected persons. *Living positHIVely*, on the other hand, stands for a self-conscious and self-determined life with HIV/AIDS, and it tries, as it sees in this suffering the potential for a transformation of the self (cf., Schwartzberg 1996: 71ff.), to give a 'positive turn' to the lives of people with HIV/AIDS (PWHAs). The concept not only includes the medical treatment of opportunistic infections that are caused by HIV, it also applies to other areas of life, like sexuality, partnership, social life, etc. It has been integrated into AIDS work in countries like the United States and Germany, but also of South Africa, Zimbabwe, Uganda, Tanzania, and India. Yet, the cultural meanings that shape the concept, as well as the social frameworks, which determine its realisation in the respective settings, are not the same everywhere.

In the next section, I will specify the local settings in which *living positHIVely* first came into use, as well as some of the guidelines which are most relevant for the application of the model in practical AIDS work. I will then illustrate how the concept has been appropriated by several AIDS NGOs in Tanzania and how *living positHIVely* has been integrated into the lives of PWHAs in the country's major town, Dar es Salaam. By drawing on case studies from Tanzania, as well as on literature from other contexts, I want to argue that religion plays an important role not only in the self-perceptions of PWHAs in Tanzania, but also in many other parts of the world. Considering the fact that, in Uganda, it was the reduction of sexual partners rather than the 'Western-model' of condom use which has led to a decrease in the infection rates of specific population groups, such 'local' ways of coping with the disease are, to my mind, particularly meaningful.

Origins and meanings of *Living positHIVely*

In the United States, the origins of 'living positively' can be traced back to the 1970s, that is, even to the time 'before AIDS'. As the two books *Positively black* (Abrahams 1970) and *Positively gay* (Berzon/Leighton 1979) illustrate, 'living positively' was a prominent concept in the emergence of the black and the gay communities. Both groups fought for the dissolution of common stereotypes of blacks and homosexuals predominant at that time in the society in which they lived. Essentially, the aim of these two parallel emancipation movements was the creation of a unique 'positively shaped' collective and individual identity on the basis of individualistic-psychological theories.

In the 1980s, the idea of positive living and thinking was taken up in the context of AIDS. Similarly to the black and homosexual communities of the 1970s, HIV infected persons - at the beginning of the epidemic, predominantly gay men - were confronted with the strong stigma attached to their disease, as well as with their threatening isolation and marginalisation. As the US government under President Reagan did not, in the first years of the epidemic, show much interest in HIV infected persons (Crimp/Colson 1990), PWHAs depended mainly on the activities and solidarity of their own communities. They put pressure on the government and on medical institutions to intensify medical research into AIDS and to make available AIDS medications to HIV infected persons although they were still in their testing phase. AIDS activists also contributed to the dissolution of the stereotypical perceptions of PWHAs as ‘doomed victims’ and called for their more positive representation in the media. In 1983, several AIDS activists formulated the Denver Principles in which the terms ‘victim’ and ‘AIDS patient’ were rejected. According to their view, these terms implied, and over-emphasised, characteristics like ‘passivity’, ‘helplessness’ and ‘dependency on others’ (Act Up New York, Denver Principles). Another important step towards the improvement of the status of PWHAs was made ten years later when, in 1993, the heads of 42 governments demonstrated their solidarity with HIV infected persons, guaranteed their basic rights and signed a document for the greater involvement of PWHAs in national and international AIDS work (UNAIDS 1999).[5]

Looking backward, it is difficult to say for certain when the term *living positHIVely* was applied in the United States for the first time. However, today the concept is - especially because of the anti-retroviral combination therapies which have been in use since 1996 and which strongly increase the life expectancy of PWHAs - central for the AIDS work in the US, as well as in many countries of Europe.[6] Brochures and journals give tips on how HIV infected persons can lead a ‘positive life’ despite their deadly disease (cf., Deutsche AIDS-Hilfe 1995; Public Health, Seattle & King County 2000). On the Internet, the columnist Danny Gayle, himself a person living with HIV, gives "advice from a positive perspective" (The AIDS Channel). On the same channel, one can, via webcam, take part in the life of an HIV infected family father and observe how he has integrated the deadly and stigmatised disease into his and his family’s everyday life. Some insurance companies, via Internet, offer their clients - who can prove to be ill with a deadly disease – to buy their life insurance "so that they can gain control over their lives and enjoy their final days" (Finances for Positive Living).

Yet, although the model for *living positHIVely* seems obviously to be rooted in Western culture and has become an important tool for AIDS work in this context, the origins of the concept are less clear than they seem to be. When I questioned the origins of the concept in an Internet forum on HIV/AIDS, the first two responses - from the US and Denmark - agreed that the term was, in connection with AIDS, first applied in Uganda in 1987. There, the concept was made prominent by an HIV-infected couple, Noerine and Chris Kaleeba, who had been living in England at the time the husband fell ill because of HIV. When the illness of Chris Kaleeba

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[5] In the United States, and finally in Europe, the social status of PWHAs was further improved by the ‘outings’ of prominent persons like Rock Hudson and Magic Johnson. These outings contributed very much to the fact that the public perception of HIV infected persons was normalised and that stereotyped images were modified.

[6] In the meantime, the concept ‘living positively’ has also been applied to other diseases, for example, Parkinson disease (cf., Ochsner 1997).

reached a critical stage, the couple returned to Kampala. Faced with the minimal available support from Ugandan institutions, as well as the strong social stigma attached to HIV, the Kaleebas organised a group of infected persons who visited each other at their respective homes, exchanged information on the new disease, prayed together and supported each other.

After the death of her husband, Noerine Kaleeba continued to meet with the group and in 1987 they formally founded TASO (*The AIDS Support Organisation*). As TASO was the first organised group of PWHAs in Africa, there was no organisation on the continent that could have served as a model for their work. For this reason, the TASO group drew mainly on the experiences which Noerine Kaleeba and her husband had collected in English hospitals, as well as with an AIDS NGO in Britain. Looking backward, the cofounder of TASO, who is today working for UNAIDS in Geneva, had the following to offer:

> "The idea of TASO originated from the example of the doctors and nurses who looked after Chris in Britain - the kindness and care they showed him, despite the fact that he was a foreigner and had AIDS. We were also impressed by what we had seen in Britain of the Terence Higgins Trust and the 'buddy' system of counselling." (Cited in Hampton 1992: 4)

The TASO members chose as a slogan for their work, which consists mainly in the support and care for PWHAs and their families, "Living positively with AIDS". The concept was defined for the first time in a booklet from 1990 which was intended as a working tool for other AIDS NGOs in Africa. The first recommendation offered for a 'positive life with HIV/AIDS', is to maintain a positive attitude towards oneself, as well as towards others, and not to blame anyone for one's infection with HIV. Medical advice should be followed and opportunistic infections should be treated quickly. A healthy diet is recommended and the abstinence from alcohol and cigarettes. Furthermore, social activities should be maintained and it is advised to talk with others (for instance, in the support groups of AIDS NGOs) about one's fears and hopes. It is only at the end of the booklet that advice is given for the use of condoms with sexual partners and the issue of sexuality generally does not play an essential role in the TASO booklet. With regard to this last point, *living positHIVely* in Uganda differs widely from the equivalent working concepts in the US and Europe where an infection with HIV is not thought of as sufficient cause to restrict engagement in sexual activity in itself. In these contexts, it is advised to satisfy one's sexual needs and desires, however, by practising 'safer sex' in *every* sexual encounter - even if neither partner is infected with HIV. With regard to the TASO booklet, it is also interesting to note that the possible role of religion for *living positHIVely* is not mentioned at all although all of the founding members were practising Christians who met regularly for common prayers (Hampton 1992: 5).[7]

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[7] The limited presence of religious elements in TASO's programs may have several reasons. According to their own statement, the founders wanted to give a signal that the organisation was open to people with the most diverse cultural and religious backgrounds (Hampton 1992: 5). Yet, as, at the beginning of its work, TASO was financed by two British organisations it may be supposed that the donors would have refused to pay for a program with a highly religious orientation.

In recent years, the TASO experience has served as a model for the work of several other AIDS organisations in Africa, and the concept *living positHIVely* has been applied by NGOs in Zimbabwe (Kaleeba/Ray/Willmore 1991), but also in Tanzania.

Kuishi kwa Matumaini - 'Living positHIVely' in Dar es Salaam

In Tanzania, organised work for PWHAs started several years later than in Uganda, and until today it differs widely from the example of its neighbouring country. One reason for this difference is of course that the Tanzanian government became active in the fight against AIDS much later than Uganda and, to a great extent, under pressure from international donors, for instance, the World Bank. And although the Tanzanian government has in the meantime increased its efforts towards HIV/AIDS prevention there has still been no outspoken governmental engagement for HIV infected individuals and their families.[8] For this reason, most of the work for PWHAs is done by non-governmental organisations - mainly in Dar es Salaam and only partially in rural regions or other major towns of Tanzania.

Following the example of Uganda, an organisation of HIV infected people, SHDEPHA+ (*Service Health and Development for People living with HIV/AIDS*), was founded in Dar es Salaam in 1994. This branch of SHDEPHA has about 100 members[9] and has as its main objective to enable PWHAs throughout Tanzania to 'live positively with HIV/AIDS' (Swahili: *kuishi kwa matumaini* = living with hope). Similarly to TASO, SHDEPHA rejects the stereotypical image of PWHAs as emaciated, helpless and doomed persons – an image propagated for many years by governmental prevention campaigns in order to underline the deadliness of HIV. SHDEPHA offer counselling and care to their clients, and they demand from their members 'openness' about their *own* infection - not only with each other, but also with their families and their communities. In this way, the organisation wants to set an example for the population so that others are encouraged to reflect on their own health. On the other hand, by talking openly about their own infection the members of SHDEPHA hope to reduce the stigma and prejudices against PWHAs within the society. Yet, it was only in 1998 that two of the founding members made their positive serostatus publicly known in two newspaper interviews - of which one had the sensationalistic title "Full-blown confessions of an HIV victim" (The Express, Dar es Salaam: 26/11 - 2/12/1998).[10]

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[8] The Tanzanian government has recently demonstrated its will to make up its neglect of the past years. One step in this direction was the creation of a 'National Advisory Board on AIDS' which is chaired by the former President Ali Hassan Mwinyi and which includes a representative from the national organisation of PWHAs. But even if some actions by the government which are intended to cope with the increasing number of infected persons and AIDS patients seem spectacular they are less convincing if more critically examined. For instance, according to official law, medical treatment for HIV infected persons is free in governmental hospitals. Yet, those who want to profit from this regulation are confronted with widespread corruption practices in these institutions and are only treated 'for free' after they have paid an appropriate amount of money.

[9] In the last two years, the organisation established more branches in seven rural and urban regions of Tanzania, including in Arusha, Bukoba and Iringa.

[10] Compared with countries like the United States, most of the 'outings' of prominent persons occurred in Africa at a much later stage of the epidemic - with the exception of Uganda where, at the end of the 1980s,

SHDEPHA's approach to being open about the disease is not easily accepted by Tanzanian society. There are not only doubtful voices and rumours from the general public if the members of SHDEPHA, most of whom are in good health, are 'really' infected with HIV, or if they use AIDS as a way of profiting from the money of international donors. The organisation is also criticised by many PWHAs themselves, who fear making their infection publicly known and the negative consequences that this step might have for them. For this reason, the majority of PWHAs in Dar es Salaam prefer to join one of four other AIDS NGOs, some of which have been in existence even longer than SHDEPHA. These organisations offer their clients, in contrast to SHDEPHA, material aid - making them even more attractive to many PWHAs.[11]

The support groups for people with HIV/AIDS, which were established in the last ten years by these four NGOs, are regularly attended by about 600 persons. Although the number of new clients has increased in recent years it still represents only a small percentage of the overall HIV cases in Dar es Salaam: with about two million inhabitants, the city's infection rate is 9 %, and HIV has become the major cause of death among adults between 15 and 59 years of age (The United Republic of Tanzania 1999: 6ff.). In addition to high infection rates, the worsening family situation of many PWHAs, with regard to the ways care and support are given to sick family members, could lead to the assumption that more people turn to the NGOs for assistance. Most families are willing to care for ailing relatives, and to support them in the search for medical treatment, either in the hospital or through 'traditional' healers. However, if it becomes publicly known that a family member is infected with HIV, the deadliness of AIDS and the strong stigma attached to the disease result in many PWHAs being abandoned by their families and left to themselves. In such situations, the NGOs replace the families in providing support and care, especially for those people without enough money to pay for their medical treatment. Unfortunately, frequenting one of the NGOs brings with it the risk that the family, or the wider social network, learns of the HIV-infection - which is particularly feared as it can lead to the loss of home and work.

As well as medical and psychological counselling through individual counsellors, and within the support groups, two of the NGOs offer free medical treatment to their clients - if necessary in the form of home based care. One of the NGOs concentrates on legal counselling and support (e.g., in the case of property and inheritance disputes), and helps PWHAs with the preparation of a will. Furthermore, most of the organisations give material assistance to the poorest of their clients which may include not only food or small amounts of money, but also

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the singer Philly Lutaaya made his serostatus publicly known. The text of his song "Alone" - which became famous among PWHAs in Africa, and even world-wide - is reprinted in Kaleeba/Ray/Willmore (1991: 101). However, the most prominent person on the African continent to make his HIV infection public was Nkosi Johnson. The eleven year old boy who talked openly about his illness at the World AIDS Conference in Durban (2000) died in June 2001.

[11] SHDEPHA, on the other hand, is proud of the fact that the organisation is chosen by PWHAS 'for the cause itself'. They claim that most of the HIV infected people in Dar es Salaam attend the other NGOs because of the material profit they get there, and that they do not want to be open with their illness. One of the (unofficial) demands of SHDEPHA is that the lives of PWHAs should not be 'controlled' by NGOs that are run by non-infected persons.

the payment of school fees for their children. Finally, it should not to be forgotten that for those PWHAs who are voluntarily engaged in the care and prevention programs of their NGOs there exists the possibility of taking part in national and international AIDS conferences. This can mean gaining experiences in contexts which have been foreign to them.

Although the support and assistance offered by the NGOs does not differ widely most of the PWHAs use their offers complimentarily and attend the support groups alternately. In this way, they create a new social network for themselves as they may have, each month, up to four meetings - one in each of the support groups - and in this way, start to build closer relationships with other HIV infected persons. One of the NGO clients is Ernesta[12]:

> Ernesta (48) was born in a village in Western Tanzania, not far from the shores of Lake Victoria. Just after having finished her primary education she got pregnant and gave birth to her daughter who has remained, until today, her only child. At the age of 24, Ernesta moved to Dar es Salaam where she went to live with her brother and where she found work as a traffic warden. When, in 1985, Ernesta became seriously ill, she was taken to several hospitals and was, after a series of ineffective treatments, found to be HIV positive. Fortunately, a counsellor in the hospital told her about an AIDS organisation, WAMATA, which had been founded in 1989 and which had established a support group for people with HIV.[13] In this group, Ernesta learned, through many talks and discussions with the counsellors and other group members, to ‘live positively with HIV’. Part of this ‘positHIVe life’ was for Ernesta the separation from her former partner because, as she told me, she "wanted to take care of herself and couldn’t have found peace if she had stayed with him". Ernesta had also given up her job and was living with her family, mainly through the financial support of another NGO (PASADA) which had been opened several years after WAMATA by a Catholic missionary from France. With the help of the missionary, Ernesta got a job at this same NGO so that she was able to take care of the basic needs of her growing family - her daughter, who is also infected with HIV, had, at that time, eight children.
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> Then, in 1996, Ernesta heard of Bishop Kakobe, the leader of a Pentecostal Church in Dar es Salaam who purportedly healed HIV, as well as other chronic illnesses, through the laying on of hands and prayers. Ernesta was ‘born again’[14], and today she plans to become a preacher in Kakobe’s church and to preach the gospel in rural regions of Tanzania. Since her salvation in 1996, Ernesta hasn’t had any contact with her parents or with the people of her home village. During her last visit, her father who regularly consumed strong alcohol had chased her away from his house so that she had to sleep outside in the fields. This incident, together with similar experiences which her sisters - who both died of HIV - had with her father, are the reason that Ernesta doesn’t want to return to her parents’ home.
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> Today, Ernesta relies, in the case that she becomes seriously ill, much more on her church and (to a lesser extent) on the NGOs, than on her extended family. Yet, she remains somehow ambiguous about these issues, and while she speaks about the solidarity and the helpfulness of other believers from her church she admits that she hasn’t informed them about the (medical) cause for her illness, namely the HIV infection. And although Ernesta firmly believes in being cured of HIV as a result of her ‘salvation’ she nonetheless does not deny the possibility that she could fall ill and die because of AIDS. Ernesta concludes that she has found in her church rather than in the NGOs (which she attends mainly because of their material aid), a community which takes care of her and which would, as she told me, even wash and cook for her if she should become bedridden.

Ernesta represents the general profile of HIV positive clients in the NGOs of Dar es Salaam. She is, like 90% of all clients attending the HIV/AIDS support groups in

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[12] Fictitious name.

[13] The counsellors of WAMATA (Swahili: *Walio katika Mapambano na AIDS Tanzania* = Those who fight against AIDS in Tanzania) were, in the founding phase of the NGO, trained by TASO (Madsen, K., e-mail: 16 Aug 2000). WAMATA’s work is described in Mulindwa (1994) and - in more detail - in Bujra/Mokake (2000).

[14] ‘Born again’/‘saved’: terms for members of Pentecostal churches which have a strongly apocalyptic character and expect from their adherents high moral integrity, particularly with regard to sexuality.

Dar es Salaam, a woman, and like most of the other women she has only completed primary school. In the male group, on the other hand, the percentage of men with a higher education (secondary school / college) prevails. Furthermore, like 70% of the NGO’s clients, Ernesta was born in a rural area. This means that the greater part of the extended clan family lives in the home village and that there are only a few members of the family who live permanently in Dar es Salaam. As is the case with Ernesta, most of the clients are no longer adequately supported by their rural or urban families once they have learned of their HIV status. As most of the PWHAs live from small-scale trade, and have therefore no regular income, they depend to a great extent on the help of the NGOs, particularly with regard to medical treatment, but also for material assistance for their children.

Another feature common to the lives of most PWHAs in the NGOs, is the high significance of religion in their lives. Many of my interview partners told me that their belief in God, as well as the support of their religious community, which mostly takes place outside of the NGOs, helps them very much to live with hope, i.e., to *live positHIVely*.

Religion and the moral perception of illness: perspectives for a ‘localised’ AIDS work

Drawing on the examples of Ernesta and the work of AIDS NGOs in Dar es Salaam, I want to define several issues which could improve the living situations of people with HIV/AIDS in Tanzania.

"The most important condition for ‘living positHIVely’ is to know that one is infected with HIV" (Kaleeba/Ray/Willmore 1991: 81). In Tanzania, as well as in most African countries, the access to this knowledge cannot be taken for granted. On the one hand, there are not sufficient testing and counselling facilities, especially in rural areas. Even more important, however, is that positive test results are only in the rarest cases given directly to the HIV patients themselves - even if this should be the case according to the official medical law of Tanzania. In my rural research area, in 90% of all cases it was the relatives who were first informed by the hospital about the illness of their family member. The families, for their part, were mostly inclined not to tell their relatives about the diagnosis. Firstly, they are afraid that to know about one’s infection could intensify the course of the illness, and secondly, HIV bears a strong social stigma and the relatives fear that their social contacts could find out that there is AIDS in their family.

Since there is no ‘open’ discussion of AIDS within most of families, a ‘positive life with HIV/AIDS’ depends on the context of NGOs, and many families are not even aware that their relatives attend these organisations. Even if the work of NGOs for PWHAs has been successful in many respects, it has not really been internationally acknowledged or adequately reflected upon. Some of the PWHAs have been living with the virus for up to ten years, although their medical treatment consists ‘only’ of the treatment of opportunistic infections with non-aidsspecific drugs. There is more to the success of the NGOs than just the medical aspect however. Through individual counselling, as well as in support groups, PWHAs learn to come to terms with their illness and to integrate it into their everyday lives.

In group discussions, information is exchanged on possible medical treatments, as well as on common problems in families and partnerships. Moreover, preventive behaviour is a central issue in these group discussions. The groups may therefore contribute considerably to sexual behaviour change of PWHAs and their partners and to the spread of general information on AIDS prevention among families and the community at large. Finally, the support groups play an important role with regard to the care for PWHAs in case of serious illness: most clients have no telephones and contact with NGO counsellors and doctors is mainly maintained through other group members and, if necessary, medical treatment can be arranged via home based care.

Despite its success, there are also difficulties in the work of AIDS NGOs. The organisations suffer particularly from the fact that they can only offer insufficient medical treatment to their clients and that they are still waiting for anti-retroviral drugs. Additionally, the financial resources for material aids which are given to PWHAs are becoming increasingly scarce because payments from international donors have been reduced in recent years as a means of putting pressure on the Tanzanian government to take care of the growing AIDS problem. Yet, these reductions effect primarily the infected themselves and create an atmosphere of competition among the NGOs that has resulted in mutual accusations of corruption, or even embezzlement of donor funds.

For the further planning of programs for PWHAs in Tanzania, these deficiencies mean that, on the one hand, structural improvements have to be made in the areas of HIV testing and counselling, as well as of medical treatment - whereby, in a first step, medical treatment can even be effective in the absence of anti-retroviral drugs. Yet, as a comprehensive, and countrywide AIDS work cannot be provided through the rather isolated efforts of NGOs the Tanzanian government has to intensify its engagement for the growing number of people with HIV/AIDS: as the example of the neighbouring Uganda showed, an effective AIDS work, which finally leads to the reduction of infection rates, is only possible with the backing of an offensive governmental AIDS policy.

However, there is still another critique with regard to the work of AIDS NGOs, whereby this critique comes from PWHAs themselves and concerns particularly their own behaviour. My HIV positive interview partners complained often that there was not much solidarity among PWHAs in Tanzania. As they told me, this becomes especially evident if one of the group members falls seriously ill, as there emerges only seldom a functioning network of mutual support and care. The reason for this is, according to my interview partners, mainly the fear that the families could find out about the nature of their relatives' illness because of the visits by members from the support groups. However, this scepticism becomes also clear in the case study of Ernesta who has been longer infected with HIV than most of the other NGO clients and who had, for this reason, the opportunity to compare the work of different AIDS organisations. Ernesta said that she relied only to a small extent on the help of NGOs, and that she rather counted, for the worst case, on the solidarity and the concrete support from her church community.

The attitude of Ernesta can only be understood if one does not simply dismiss it as a sign for the 'low level of solidarity' among Tanzanians, nor should it be exclusively attributed to the fear of social discrimination. It is not to be forgotten that in Southern and Eastern Africa religion plays an important role in the perception of illness and healing, and that discourses on illness are often shaped by moral or spiritual categories: especially in the case of chronic or deadly illness the individual suffering is associated with spiritual forces, with witchcraft or malevolent ancestors. This strong dominance of discourses on spiritual dimensions of illness does not mean that there is no comprehensive biomedical knowledge, or that there is no 'scientific' understanding of disease - in fact, the research on HIV/AIDS showed that the biomedical knowledge on HIV and on its ways of transmission is widespread in societies of the sub-Saharan Africa. Yet, as in these local contexts the discourses on moral and spiritual causes of disease are often as real as the biomedical explanations themselves, there may be a very fluent relationship between different concepts of disease, which is also why it is often impossible to draw a clear line between different discourses on the same disease or to classify them within a closed *medical system* (Pool 1994a).[15]

The fluidity of the relation between different discourses on disease may be the cause that someone who is medically treated by an NGO and who has accepted the biomedical conception of 'HIV' does, in addition to this, not exclude a moral or spiritual cause for his illness. These last causes are then rather seen as reinforcing the course of illness, and the spiritual healing can become the necessary condition for the success of the biomedical treatment. On the other hand, someone who is strongly integrated into his or her religious community will not necessarily consider the discourse on spiritual causes for illness as the only relevant, or simply deny the presence of HIV. The example of Ernesta made it clear that her church, or her spiritual beliefs, do not prevent her from being medically treated within the NGOs. Yet, she receives her strength for a 'life with hope' - for a 'positHIVe life' - not so much from the community of people living with HIV, but rather from the spiritual universe of her church.

If one leaves the African context and takes a comparing look at other continents, it becomes obvious that even there the relation between religious-spiritual discourses and biomedically-oriented discourses on AIDS may be fluent.[16] In Northern Thailand, the Buddhist religion and its conception of a predetermined

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[15] The conception of *medical systems*, which has to a great extent been developed by the Anglo-American Medical Anthropology, was criticised for several reasons. On the one hand, the question was put to what extent this search for systematic approaches to illness and healing was bound to the hierarchical ordering of different medical models, and what consequences such an hierarchy could have for financial policies (Last 1992). On the other hand, it was stated that medical systems are neither closed entities, nor that it is only the biomedical model which has an influence on non-biomedical, 'traditional' perceptions of illness - such processes have proven to work in both directions (Pool 1994a: 259f.). Drawing on these different strains of critique, there was the call for the "dissolution of ethnomedical systems" (Pool 1994b).

[16] The following examples have intentionally excluded the North American and the European setting. However, this does not mean that PWHAs deny a spiritual dimension of their illness in these local contexts, as, for instance, spirituality contributes strongly to the self-perceptions and experiences of HIV infected gay men in the United States (Hardy 1998). Yet, as Hardy writes, the dimension of organised religion is less meaningful for most gay men than it is for PWHAs in other parts of the world. This difference may be due to the fact that the relationship between homosexual men - who represented, in Europe and the US, the most affected group at the beginning of the epidemic - and most religious denominations has been conflictive even before the outbreak of AIDS.

life which is based on the *karma* from a previous incarnation shapes the self-perceptions and self-acceptance of HIV positive women to a great extent: as the illness is, in their eyes, part of one's destiny, the women do not see much sense in blaming anyone, including themselves, for their infection with HIV (Akaike 1998: 70). This positive influence of religion, together with the successful work of Buddhist monks with HIV infected people, contributes to a "positive understanding" of AIDS in such a decisive way that religious elements have already been integrated into the counselling work of several hospitals (ibid.: 81).

In Australia, religious and spiritual elements were reflected in the regional AIDS work when, in September 2000, a "Hindu and Buddhist AIDS Memoriam" (which was also documented in the Internet) was organised for those who had died of the illness. This memorial event was, on the one hand, thought as a "ceremony of hope and healing"; on the other hand, it resulted from the wish to pay more attention to the religious background of PWHAs and, by doing so, to give expression to the multicultural composition of the Australian society. Thus, the organisers wrote:

> "Despite the very multicultural and multi-faith nature of Australian society, which is reflected in the communities affected by HIV/AIDS, to date no options have been developed for those who came from faith traditions other than Christian. (...) There were stories about being excluded from the funerals of partners, and similar issues. Some people spoke of their feeling of alienation in the rituals they had been able to participate in, because the nature of their relationships were not to be acknowledged." (Hindu and Buddhist AIDS Memoriam 2000)

These examples from different local contexts could give rise to the assumption that even in Tanzania more attention should be paid to the integration of religious-spiritual elements into the organised AIDS work. Yet, the rather negative aspects of religion in the context of AIDS were mentioned several times, and with regard to different local contexts. In Thailand itself, the Buddhist religion has influenced HIV/AIDS prevention programs in a negative way: the belief in a predetermined *karma*, and the acceptance of an unchangeable destiny resulting thereof, are the cause for an ambivalent attitude which is expressed in the local saying *'Siang duang'* ("Take your destiny as it is") and which may decrease the acceptance of individualistic health promotion programs in the society (Akaike 1998: 70). In Africa, Christian religions have, with their discourse on AIDS as a punishment from God, led to a conceptual dichotomy between 'good'/'pure', and 'bad'/'impure' Christians which is why HIV positive persons are in some cases excluded from their communities (Gruénais 1999). A probable result of this discourse on punishment is also the refusal of several clergymen to carry out funerals for those who have died from AIDS: according to their view, PWHAs are, because of their supposed sexual promiscuity, no real Christians, and such a funeral could reinforce the 'immoral behaviour' within the communities (Foster 1996: 197).

Despite this critique several religious organisations have also been successful with their contributions to the prevention of HIV/AIDS. In South Africa, it is particularly the Pentecostal churches that could, through their approach of social control and their threats to exclude those members who act against the morals of their church, influence the sexual behaviour of their adherents. Other religious denominations, on the other hand, were not able to bring about a change in the sexuality of their members - even if they represent, in their principles, no other moral values than the Pentecostal churches which are flourishing on the whole continent (Garner 2000). In Uganda, the ‘salvation’ has become a strategy for young girls - which is even accepted by men and boys - to reject sexual offers and to protect themselves in this way from an infection with HIV (Wimberley 1995). However, not only the Pentecostal churches were successful with regard to the prevention of HIV. In Uganda, an Islamic medical association established, amongst others, an HIV/AIDS education program in mosques and in the *madarasa* for adolescents (Islamic Medical Association of Uganda 1998). In Zimbabwe, the Catholic church became active in the fight against the epidemic several years ago when it declared that it had, as a charitable organisation, the responsibility to take care of the growing number of HIV infected people (personal communication, Ute Luig, 2000). In Tanzania itself, the Catholic church founded an NGO that has, until today, been very successful with its preventive work and its programs for PWHAs. These last examples show that by integrating spiritual elements into AIDS work the more positive, and non-confessional aspects of religion - namely mutual responsibility and the willingness to help and care - can be emphasised. By referring to a religious belief system, which is *not* bound to a certain confession and which is filled with ‘positive meanings’, the calls for solidarity and behaviour change could be made more motivating and more effective.

However, religion fulfils yet another, essential aspect of ‘positHIVe living’ in Tanzania. In the European and North-American contexts, the positive living model is based primarily on psychological and political conceptions of socially marginalised groups and persons struggling to transform the negative experience of living with a stigmatised illness into a more positive attitude towards life and the future. In Tanzania, in contrast, people with HIV/AIDS draw their strength to develop a positive life perspective – which may, as Klaits (1998) has intriguingly argued for Botswana, also extend to death itself – essentially from their beliefs and their religious denomination. In this regard, the discourse on AIDS as a disease created by God has an important implication: most people I interviewed felt that if AIDS was brought about by God it can also be healed by God. This perception is strongly reinforced by the fact that biomedicine - which was accepted by most as the strongest instrument of *human* healing power - hasn’t succeeded in finding a cure for AIDS. This rarely discussed aspect of a spiritual cause of AIDS is not only expressed in uncountable stories and rumours of miraculous AIDS healings in rural and urban areas. It is also substantiated by the fact that spiritual-religious conceptions contribute, often on the same scale as medical treatment, to a ‘life with hope’ for PWHAs. Thus, ‘living with hope’ refers to the physical aspects of living with a deadly disease, but equally as importantly, to spiritual healing and bearing life with an illness which is, in Tanzanian society, widely associated with ‘shame’ and ‘sin’ – conceptions which are shaped significantly by religious ideas and discourse themselves.

Conclusion: religion and AIDS work in global context

An integrated approach to AIDS programs which combines western and local perspectives should not be understood as a standardisation of AIDS programs, nor as a reduction of AIDS work to a ‘local element’. It is, without a doubt, impossible to repeat the success of charismatic Pentecostal churches on another level, as for instance the HIV prevention programs (Garner 2000: 65f.). And perhaps more importantly, the religious-spiritual discourses on illness cannot lead to a ‘positive’ life with HIV/AIDS as long as they do not accept the existence of the disease and do not give room to the medical dimensions of AIDS in public discourse. The ‘public’ aspect of AIDS, the call for public recognition of a stigmatised and tabooed disease, is on the other hand a very Western concept, which - together with other aspects of Western AIDS work - has proven fruitful and stabilising for PWHAs in Africa. Publicity has opened new social spaces, for instance in the NGOs, which help to compensate for the lack of support on the part of one’s family, or one’s religious community.

As the example of the "Hindu and Buddhist AIDS Memoriam" shows, the combination of these different approaches can succeed. The memorial was, despite its obvious religious orientation, not a purely Hindu nor Buddhist ceremony. While the event gave expression to elements and ideas of these two religions, it also referred to Western discourses on AIDS. This integrating approach was appropriately expressed in the emblem designed for the ceremony. The Red Ribbon, which is a symbol of strength, unity and hope, was placed in the centre of the Asiatic *Yantra* which, for its part, represents the diversity of the universe and the coexistence of forms and beings. The importance of this Australian example lies in the fact that the diversity of approaches and concepts has become the most important factor for the success of HIV/AIDS programs, particularly with regard to their popular acceptance. It has become clear that AIDS programs have to consider the respective cultural contexts in which they are applied, but that this does not mean that a ‘global’ model like *living positHIVely* is rendered useless. *Living positHIVely* itself is *not* a model with exclusively ‘local’ meanings, as is the case with other working concepts of HIV/AIDS. On the contrary, *living positHIVely* has, from the beginning, been ambiguous in its meanings and open for varying interpretations, and it is exactly this openness which offers the possibilities for its success.

However, the prominent role of religion in the context of a global epidemic raises still another issue. Religion is a domain of society that is - often as an institutionalised defender of local moral values – particularly confronted by the influences of globalisation. The popularity of religious movements is to a great extent measured by their flexibility and their ability to navigate their *own* position in the context of social change. For example, Luig (1999) has shown that among possession cults in Zambia, the most popular cults are those which make, through modification and appropriation, translocal innovations accessible and understandable to the local population – while adhering to their own local values and morals. In Tanzania, as in other African settings (cf. Marshall-Fratani 1998), it is the fast-growing Pentecostal churches - rather than the ‘mainstream’ religious organisations and institutions - that manage to provide moral guidance in the face of globalisation, and to incorporate - often ambivalently - the social tensions and challenges created by the ongoing AIDS epidemic.

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Abstract:

AIDS work in Africa is to a great extent based on models which originated in North America or Europe and may be, for this reason, culturally inappropriate for the international setting. The global dynamics of AIDS work are explored in the paper with regard to a neglected topic of research: the care and support for people living with HIV/AIDS in sub-Saharan Africa. Referring to the concept of *living positHIVely*, the author describes where and how the model came into use, how it has later been appropriated by Tanzanian NGOs and how it shapes today the lives of PWHAs in the country’s major town, Dar es Salaam. It is argued that, as religion plays an important role for the conceptions of illness and healing in Tanzania, religious-spiritual elements have contributed strongly to the understanding of a ‘positive’ life with HIV (Swahili: *kuishi kwa matumaini* = living with hope). The paper concludes by calling for an integrating approach in international and local AIDS work which takes into account both the working experiences from the North, as well as the cultural conceptions and circumstances that shape the respective contexts in which AIDS work takes place.

Zusammenfassung:

AIDS-Programme in Afrika basieren zu einem großen Teil auf Arbeitsmodellen, die in Nordamerika oder Europa entstanden sind und daher für die Anwendung in anderen internationalen Kontexten ungeeignet sein können. Diese globale Dynamik der AIDS-Arbeit wird hinsichtlich eines bisher vernachlässigten Forschungsthemas untersucht: der Versorgung und sozialen Einbindung von Menschen mit HIV/AIDS im sub-saharischen Afrika. Ausgehend vom Konzept ‘PositHIV leben’ zeigt der Autor, wo und wie dieses Arbeitsmodell zuerst zur Anwendung kam, wie es später von tanzanischen Nicht-Regierungs-Organisationen übernommen wurde und wie es heute von HIV-Infizierten in Dar es Salaam, der größten Stadt des Landes, in ihr Leben integriert wird. Insofern Religion eine wichtige Rolle für Vorstellungen von Krankheit und Heilung in Tanzania spielt, wird ein ‘positives’ Leben mit HIV/AIDS (Swahili: *kuishi kwa matumaini* = Leben mit Hoffnung) stark von religiös-spirituellen Konzepten bestimmt. Abschließend plädiert der Autor für einen integrierenden Ansatz in der AIDS-Arbeit, der sowohl Arbeitserfahrungen aus dem Norden, als auch kulturelle Konzepte und Bedingungen, die den jeweiligen Kontext der AIDS-Arbeit prägen, mit einbezieht.

Résumé

Les programmes contre le SIDA en Afrique reposent en grande partie sur des modèles de travail conçus en Amérique du Nord ou en Europe et qui, donc, peuvent ne pas être appropriés à d´autres contextes internationaux. Cette dynamique globale de l´action contre le SIDA est ici examinée à partir d´un thème de recherche jusqu´ici négligé: les soins et l´intégration sociale de personnes positives ou malades du SIDA en Afrique subsaharienne. A partir du concept «vivre positif», l´auteur montre où et comment ce modèle de travail a d´abord été mis en pratique, comment il a été adopté par des ONG tanzaniennes et comment il est intégré aujourd´hui dans la vie de personnes positives à Dar es-Salaam, la plus grande ville du pays. Dans la mesure où la religion joue en Tanzanie un grand rôle dans l´idée de maladie et de guérison, une vie «positive» avec le VIH ou le SIDA (souahéli: *kuishi kwa matumaini* = vivre avec espoir) est fortement déterminée par les concepts religieux et spirituels. En conclusion, l´auteur plaide pour une approche intégrative dans l´action contre le SIDA, qui prenne en compte aussi bien les expériences du Nord que les concepts culturels et les conditions respectives caractérisant l´action contre le SIDA.