FAITH MATTERS

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RELIGION AND BIOMEDICAL TREATMENT FOR HIV/AIDS IN SUB-SAHARAN AFRICA

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LIST OF ABBREVIATIONS:

ART	– anti-retroviral treatment
CAFOD	– Catholic Agency for Overseas Development
CHAG	– Christian Health Association of Ghana
CHAZ	– Christian Health Association of Zambia
CRS	– Catholic Relief Services
EHAIA	– Ecumenical HIV and AIDS Initiative in Africa
FBO	– Faith-based Organization
GAC	– Ghana AIDS Committee
PEPFAR	– President's Emergency Plan for AIDS Relief
PLWA	– people living with AIDS
PMTCT	– prevention of mother to child transmission
RAPAC	– Redeemers AIDS Programme Action Committee
RCCG	– Redeemers Christian Church of God
SACBC	– South African Catholic Bishop's Conference
VCT	– voluntary counselling and testing

PREFACE

This document is an outcome of a symposium entitled '**PROLONGING LIVES, CHALLENGING RELIGION: ARV'S, NEW MORALITIES AND THE POLITICS OF SOCIAL JUSTICE**'. The main organizers were:

- Hansjörg Dilger, *Free University of Berlin, Department of Anthropology*
- Marian Burchardt, *University of Bayreuth, Department of Development Sociology*
- Rijk van Dijk, *African Studies Centre Leiden*
- Thera Rasing, *University of Northern Zambia, Department of Gender Studies*
- Josien de Klerk, *University of Amsterdam, Department of Anthropology and Sociology*

The symposium was held in Lusaka/Zambia in April 2009 and organized by the '*International Research Network Religion and AIDS in Africa*'. The main objective of this network is to stimulate social science research on issues surrounding religion and AIDS in Africa and to facilitate dialogue between researchers, faith-based organizations and development practitioners. The symposium was generously funded by the Volkswagen Foundation.

A roundtable involving religious leaders, AIDS activists and faith-based organizations from Zambia was held in conjunction with the symposium. The roundtable was funded by Cordaid, the IS-Academy HIV/AIDS and the University of Amsterdam.

For more information on the 'International Research Network Religion and AIDS in Africa', please contact the chairman Dr. Rijk van Dijk (mail to: dijkr@ascleiden.nl).

SUMMARY

The importance of faith-based organizations (FBOs), religious communities and religious faith for HIV/AIDS prevention, care and support in Sub-Saharan Africa has long been recognized. With the enrolment of millions of HIV-positive people on anti-retroviral treatment (ART) the multiple links between religion and HIV/AIDS have taken a new shape: As a result of their involvement in ART provision and surrounding services such as VCT, care and treatment counselling, the role of FBOs as recipients of international funds and as healthcare providers has been greatly enhanced. Thus the expansion of ART has reshaped relations between FBOs and donors but also those between FBOs, public administrations and healthcare users. As religious faith shapes people's perceptions of medicine, these processes have also affected how patients negotiate available therapeutic options.

This document provides ethnographic evidence of these changes and points to emerging conflicts. We argue that while ART has undeniably saved and improved the lives of millions of people, it has also introduced new challenges that need to be addressed to safeguard sustained treatment success. We discuss these challenges from the perspectives of FBOs, the public administrations they interact with, and ART users. Meeting these challenges is critical not only for achieving universal access to ART but also for improving service quality and empowering users. The finding can be summarized as follows:

- Biomedical treatment for AIDS has been firmly embraced by most religious communities and leaders and included in their service structures. However, there are exceptions. Donors need to establish the unequivocal support for treatment programmes amongst their partners if they decide to cooperate with FBOs on ART.
- Information and knowledge about ART is contradictory, uneven and received from multiple sources. In order to enable patients to make autonomous treatment choices public information campaigns need to be strengthened.
- Churches, FBOs, and religious communities provide valuable structures and resources for implementing ART projects. The wish to attract funds, however, may also lead them to overburden their capacities. Donors should carefully assess existing capacities when making funding decisions.
- Levels of FBO involvement in ART programmes depend on church type, infection rates, the political environment and pre-existing institutional structures. The advantages and challenges arising from involving FBOs in ART programmes thus differ from country to country. Every choice of partners for ART programmes should be based on an analysis of the strength of FBO structures in particular countries or provinces.
- There are tendencies towards prioritizing co-religionists in FBO or church programmes, possibly leaving segments of the population unserviced. Donors can play an important role in strengthening coordinating mechanisms thereby ensuring equal access.

SUMMARY

- ART users rarely see biomedicine and religious forms of healing and recovery as mutually exclusive. Even with ART, religion is important in providing for the psychological, spiritual and social needs of HIV-positive people. It is pivotal to ensure that these resources do not 'dry up' as a result of the emphasis on treatment.
- Churches[1] and FBOs are important social actors in African societies and their involvement in development processes is appreciated. Nevertheless, working with them involves ideological messages. Donors need to decide whether they support the missionary tendencies that might come as a corollary of collaborating with religious organizations.

1. The majority of research projects on which this document draws have been carried out in Christian contexts. As a result, the document is characterized by an overall focus on Christian involvement in ART programmes.

1. AIDS, RELIGION AND ART IN AFRICA

According to UNAIDS estimates, 2.1 million people were receiving antiretroviral drugs in Sub-Saharan Africa by the end of 2007. In only six years the number of ART users has increased 10-fold in low- and middle-income countries across the world. For many HIV-positive Africans the supply of, and enrolment on, antiretroviral treatment fundamentally changes the experience of HIV/AIDS and is beginning to transform AIDS, as has often been stated, from a death sentence into a manageable chronic disease. Improved treatment opportunities can prolong lives, stabilize families and livelihoods and lower barriers against testing. One of the factors facilitating these developments was the provision of huge amounts of financial resources for the purchasing of these drugs through new funding mechanisms and their distribution through public health sectors free of cost.

While the introduction of ART has been accompanied by great hopes for a 'new beginning' it has also brought with it a host of challenges and dilemmas for actors within healthcare sectors in international, national and local arenas, for health workers, and not least for ART users themselves. Such challenges include sustainable funding and drug supply, the scaling-up of VCT and providing access to treatment, establishing effective and durable collaborations between governments, research institutions and clinics, and securing treatment adherence and confidentiality.

Significantly, these developments overlap and coincide with the increased recognition amongst scholars and development practitioners of the role of religion and faith-based organizations in HIV/AIDS governance and development at large. In many African countries, especially in those with a strong tradition of missionary Christianity, religious organizations have been pivotal to healthcare and education long before the arrival of HIV/AIDS. As the impact of HIV/AIDS became visible, some of the first initiatives of self-help, such as faith-based support groups and home-based care programmes, emerged in the institutional vicinity of Christian healthcare centres and churches. In some countries with Muslim majorities too, religious leaders became active partners in AIDS advocacy, education and support. According to UNAIDS, one in five organizations engaged with AIDS is faith-based. Apart from providing institutional infrastructures through which HIV/AIDS programmes can be channelled, churches and FBOs matter because of their very social proximity to local populations and because of their manifold influences on people's practices. Thus, while religious organizations have a history of AIDS services, it must be emphasized that their involvement took on a new dynamic with the arrival of ART.

Institutionally speaking, religiously driven operations in the field of HIV/AIDS are increasingly carried out through what are now widely known as 'FBOs'. These organizations, however, merge two historically distinct organizational models: On the one hand, they have inherited professional ideas from mission-related healthcare services. On the other hand, they are increasingly modelled as NGOs as this model provided the greatest match with the institutional structures and demands of international development.

Development institutions and the incentives they provide by offering ART funds also contributed to the enhancement of the role of religion in HIV/AIDS programmes: FBOs have become major recipients of funds for implementing ART programmes. However, religion is also important in the context of ART because religious beliefs and values influence treatment choices. Finally, religious communities play a major role in mediating medical knowledge and organizing care and support.

A few facts suffice to underline these trends: Between 2002 and 2008, the Global Fund to Fight AIDS, Tuberculosis and Malaria granted $6.8 billion and FBOs already accounted for 5% of that. FBOs also received sub-grants from other principal recipients. In addition, faith-based groups are involved in Global Fund decision-making procedures through the country coordinating mechanisms. In 2006, FBOs accounted for 4% of seats in the country coordinating mechanisms. Likewise, faith-based groups received about 20% of the $18 billion distributed through PEPFAR between 2003 and 2008. For donors and development practitioners there is thus a need to take the increasing importance of FBOs and the opportunities and challenges arising from this into account.

This document summarizes the changing and sometimes contested role of religion in the current era of antiretroviral treatment in Africa. Based on findings from case studies carried out in 13 countries across the continent, it explains how and why FBOs have embraced biomedical treatment of HIV/AIDS, explores incipient changes in therapeutic cultures and points to emerging problems and challenges.[2] The case studies were presented during the conference 'PROLONGING LIFE, CHALLENGING RELIGION'. The conference was organized by Hansjörg Dilger, Marian

2. The list of papers and studies on which this article draws can be found at the end.

Burchardt, Rijk van Dijk, Thera Rasing and Josien de Klerk, sponsored by the "International Research Network on Religion and AIDS in Africa", and held in Lusaka in April 2009.

2. RELIGION IN ART PROVISION: OBSTACLE OR ASSET?

In recent years churches, FBOs and religious communities have been increasingly recognized as partners in development. In all of Sub-Saharan Africa the religious sector is a key source of associational life, greatly contributes to an active civil society, and plays major roles in education and healthcare provision. In rural areas the religious sector is in fact often coextensive with civil society. Because of this, religious institutions and communities are often instrumental in bridging the gap between international donors, governmental administrations, and local populations. In some countries such as Zambia as much as 40% of all HIV-related healthcare interventions are facilitated by faith-based organizations. In this section, we provide ethnographic evidence on how different kinds of FBOs have embraced ART, and how in the process relations between donors and FBOs have been changed. We show how FBOs have been transformed as a result of institutional growth and highlight ambivalent perceptions thereof by religious communities and leaders.

EMBRACING ART: INSTITUTIONAL GROWTH IN MISSION CHURCHES

Because of their long charitable tradition, their transnational and relatively centralized structure and their close pre-existing links to both African governments and donors, mission churches were quick in responding to emerging funds for ART. But they were also active in treat-

ment access advocacy. In 2001 the Ecumenical Advocacy Alliance and the World Council of Churches issued a Plan of Action on AIDS in Africa. Shortly after, the Ecumenical HIV/AIDS Initiative in Africa (EHAIA) was formed with the aim to provide technical assistance, training and small seed grants for churches. As a result, HIV/AIDS programmes became more mainstreamed and institutionalized within mission churches' operations across the African continent. How churches and FBOs became involved with ART provision, however, differs strongly from country to country and depends on a range of factors including infections rates, national healthcare traditions, the political environment, and access to donors and funds.

In South Africa the Catholic Church launched its Nevirapine treatment programme to prevent mother-to-child-transmission (PMTCT) called 'Born to Live' in 2001. The programme, implemented at four pilot sites, was carried out in cooperation with the Catholic Medical Mission Board and the drug company Boehringer Ingelheim and involved the issuing of an explicit 'call for action' towards the South African government. In 2004, by the time the government decided to implement a national ART rollout programme, the Catholic Church was already servicing about 3.000 patients at 22 treatment centres. Because of their efficiency, the provincial government of KwaZulu Natal even decided to supply drugs and refer patients to these centres. In 2005 the Catholic Church was the country's largest provider of treatment and care for HIV/AIDS patients, second to the government only. The changes in funding structure precipitating these developments are remarkable: While in 2000 the AIDS office of the South African Catholic Bishops' Conference had only one financial sponsor (CAFOD), in 2005 the church generated funds from about 30 different foreign donors.

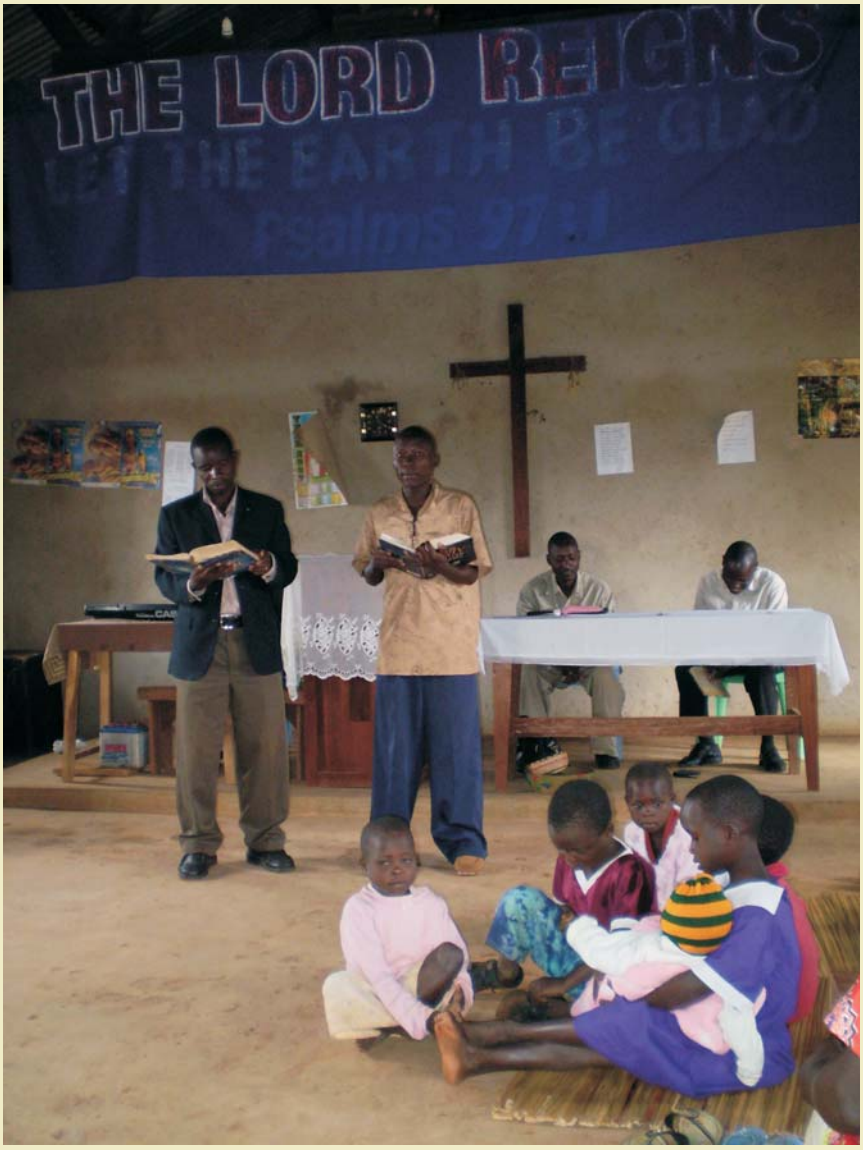
> *'The Catholic Church is at present successfully implementing PMTCT programs at four pilot sites countrywide, with expansion to a further two sites planned for the near future. These are holistic programmes that include counselling, nutritional support and treatment of opportunistic infections. The SACBC expresses the wish that these programmes can serve as an example to others wishing to join us in the battle against the spread of HIV, and we express our willingness to share our experiences with the state and any other institution working for the prevention of mother to child transmission.*[3]

In Uganda as well, community-based organizations linked to the Catholic Church readily adopted biomedical treatment of HIV/AIDS. As some of the Catholic initiatives had already been active in the fight against AIDS since the late 1980s and had developed comprehensive care and support programmes they were well prepared for implementing ART provision too. Based on the Catholic notion of 'holistic care' and with funds from the PEPFAR initiative, Catholic treatment programmes helped to raise the number of Ugandans enrolled on ART to 160.000, representing about 50% of those eligible.

EMERGING PLAYERS: ENGAGING (NEO-)PENTECOSTAL AND CHARISMATIC CHURCHES

Compared to mainline churches with their inherited charitable traditions, the burgeoning field of (Neo-)Pentecostal and Charismatic Churches was and partially continues to be characterized by a lack of

3. Report of the SACBC AIDS Office to the Plenary Session of the SACBC, August 2003, taken from paper by Kalipeni et al.


THE LORD REIGNS

institutionalized welfare structures and negative attitudes towards biomedicine. In addition, because of their comparatively decentralized nature most of these churches do not have viable structures for the implementation of larger development projects in place. By contrast, the Redeemed Christian Church of God (RCCG), Nigeria's largest Pentecostal organization has developed sophisticated institutional channels and is strongly committed to fighting AIDS. In 1999 church leaders established the Redeemed AIDS Programme Action Committee (RAPAC), which cooperates with the federal government in AIDS advocacy, peer education, stigma reduction and VCT and runs functional offices in five states. Significantly, RAPAC also initiated biomedical treatment through its PMTCT programme. Service provision is carried out in church-based maternity centres and clinics and involves education, VCT, and enrolment on ART for both mothers and newborns free of cost. RAPAC collaborates with Family Health International in the Global HIV/AIDS Initiative Nigeria, the largest comprehensive AIDS project ever implemented in a single developing country, and receives most of its funds from PEPFAR and through donations by individual congregants. Despite incipient engagements of Pentecostal churches, mission churches continue to occupy the most powerful positions in development networks. As these do not fully reflect patterns of religious membership "on the ground" anymore, it might be time to consider the strengthening of collaborations with Pentecostal organizations as well.

POSITIVE ATTITUDES TOWARDS BIOMEDICAL HIV/AIDS TREATMENT AMONG RELIGIOUS LEADERS

These encouraging developments have been underpinned by generally positive attitudes towards biomedical HIV/AIDS treatment among reli-

gious leaders. Findings from a qualitative questionnaire among leaders of various denominations in Malawi suggest that science is viewed as of divine provenance and not conflicting with religious claims; furthermore biomedical treatment is deemed important for alleviating human suffering and new partnerships strengthening the church' involvement are encouraged.

In the same vein the Ecumenical HIV and AIDS Initiative in Africa has challenged church leaders to be actively involved in the struggle for ART. EHAIA has in fact transformed into a major player in treatment advocacy on the international level and has also called upon religious leaders to pressurize governments to prioritize access to ART. Such mobilizations have been accompanied by innovations in religious thought and theology whereby issues of religion, science and technology have been discussed against the backdrop of the renewed presence of biomedicine in HIV/AIDS treatment. There is a broad consensus that biomedical treatment is perfectly compatible with Christian notions of the sanctity of life, that ART should not be seen as competing with but as manifesting God's power, and that ART should be included in theologies of healing. Such views are remarkably echoed in the way ART is interpreted in Islamic theology. In Islam as well, technical innovation is viewed as originating from God and biomedicine therefore by no means conflicting with perceptions of Godly power as is sometimes assumed. The significance of these theological reflections must not be dismissed, as they are central to the shaping of public discourse in many African societies.

CRITICAL VOICES

Despite these generally positive attitudes towards ART, there are also competing voices. According to the Malawian questionnaire, some religious leaders felt that ART helps to cover the 'moral problems' linked to AIDS, encourages immoral sexual practices and contributes to the spread of HIV because of its effects on patients' physical appearance. Research conducted in the Catholic St. Benadetta Small Christian Community in Dar es Salaam revealed similar ambivalences: while negative attitudes towards ART were not couched in a religious idiom, people expressed considerable concern about the possible effects of ART on HIV prevention.

> *'Although some people will not like this, ARVs are not good because they contribute to the spread of HIV. Those who are infected, some of them intentially spread the disease to others. They are able to do so because they look healthy. People who can buy ARVs are rich, have good income. They spread it to as many people as possible. I do not support the use of ARVS.'* (Catholic Congregant from Dar es Salaam) [4]

In a study carried out in Islamic northern Nigeria, it was found that in the eyes of some religious leaders and Islamic healers the fact that ART does not cure AIDS was seen as contradicting the hadith that "for every disease that Allah sent to humankind, he has also sent its remedy." As a result, ART was dismissed as 'Western' and 'un-Godly.'

4. Taken from paper by Msoka.

EXPLAINING RELIGIOUS RESPONSES TO BIOMEDICAL HIV/AIDS TREATMENT: INSTITUTIONAL PATTERNS AND CONSEQUENCES

Positive attitudes of religious leaders towards biomedicine and ART certainly contributed to the remarkable presence of religious organizations in HIV/AIDS treatment. However, to understand and explain how these organizations got involved requires a closer look at institutional specificities. In this context, it is crucial to distinguish between 'church-based' projects and organizations and 'faith-based organizations' (FBOS). Church-based projects often emerge from the compassionate, mostly volunteering engagement of congregants and clergy and it is based on longstanding social relations between givers and receivers. Faith-based organizations, by contrast, are detached from specific religious communities and include large organizations such as World Vision, Catholic Relief Services or Christian Care. The involvement in HIV prevention, care and support, VCT and treatment programmes has led to a major expansion of both kinds of organizations. The reasons for engagement, however, differ.

Responses by church communities often depend on the enthusiasm of a few pioneering individuals who mobilize others. More often than not the pioneers are in some way themselves affected by AIDS. As church-based projects grow in size and demand for their services increases there is a need to mobilize resources exceeding what is locally available. In order to improve the management of their operations and to qualify for funding from donors church-based projects usually give themselves a more formal structure, thereby sometimes morphing into FBOs. At this stage and given the availability of external funds, community groups may also embark on more sophisticated HIV/AIDS interventions such as VCT or ART programmes.

Alternatively, many small FBOs also provide their services so as to supplement the operations of church-affiliated or governmental clinics. HIV counselling, treatment literacy and adherence training or care are typical examples. In addition, both religious communities and FBOs often mediate between PLWA and biomedical treatment sites, either informally or through formalized referral systems. Informal referral systems were established, for example, by the Anglican Church in Kenya where church responses had otherwise been characterized by institutional inertia. In Ghana, the Word Miracle Church received funds from the Ghana AIDS Committee (GAC) to set up a VCT centre likewise referring people who tested positive to district hospitals for ART.

With a view towards the interactions between religion and governmental authorities in ART provision, established patterns of cooperation have often been replicated and positively exploited. In Zambia, for instance, state and churches collaborate in healthcare provisioning through public-private partnerships.

The strength and scope of churches' and FBOs' responses to AIDS, however, is also conditioned by the strength of the institutional umbrella bodies representing them at national and international level vis-B-vis governments and foreign donors. A study comparing church advocacy for HIV/AIDS in Zambia and Ghana found major national differences. In Zambia, mission churches and FBOs affiliated to them are strong in responding to AIDS and able to access funds for treatment programmes because the Christian Health Association of Zambia (CHAZ) is a powerful and energetic representative body at the national level. In 2007 alone, CHAZ gave sub-grants to 411 FBOs for HIV/AIDS programmes, including ART provision at 30 church health facilities. In terms of institutional power and political influence, their Ghanaian counterpart, the Christian Health Association of Ghana (CHAG) comes nowhere as near.

CONSEQUENCES OF ACCESS TO FUNDS FOR CHURCHES AND FBOS: CRITICAL PERSPECTIVES

For the reasons outlined above for churches and FBOs, involvement in ART provision provides a supreme opportunity for institutional growth. Importantly it also throws their character as welfare providers into sharp relief. While it seems that projects are often managed efficiently and adherence rates are high, this growth has also brought with it ambivalent consequences. First, smaller organizations may quickly reach the limits of their institutional capacities. After achieving access to funds and project acquisition, some FBOs needed to multiply their number of staff within a few months but faced constraints in terms of finding qualified workers. As a result, training needs strongly augmented.

Second, ART funds are often granted on a short-term basis. With PEPFAR, applications have to be renewed yearly. Sustainability is therefore not guaranteed and the laying-off of workers may have social costs attached.

Third, by way of responding to donor incentives some ecclesiastical bodies increasingly morphed into fund-raisers and project management institutions. Research into the Catholic Church's AIDS work in the South African province of KwaZulu Natal shows ambivalent reactions to this amongst followers. In the perception of local congregations and parts of the clergy, AIDS projects took on such a dominant role within community life that religious concerns such as pastoral care and evangelization were almost entirely replaced. The engagement was generally appreciated but capacities and attention to spiritual concerned seemed fully diverted. Internal fissures further increased because the embracing of ART went hand in hand with a tactful disapproval of African traditional medicine.

Similarly, a study in Uganda's Busia district shows that project management easily diverts clergy's attention away from pastoral work thereby undermining an important dimension of community life.

Fourth, while church leaders have been championed by donors not least because of their trustful relationships to local populations these are not given per se. Especially since the mushrooming of new (Neo-)Pentecostal churches, self-proclaimed pastors are sometimes viewed with suspicion by local communities. These trends are easily reinforced if such pastors are inadvertently seen administering large resources for AIDS projects. Leaving such specificities aside, church-based project are threatened by personalization, resource diversion or corruption just as those run by NGOs. Monitoring is therefore pivotal.

3. RELIGIOUS HEALTHCARE AND PUBLIC ADMINISTRATIONS: CRITICAL ENCOUNTERS

We have seen that through gaining access to funding for ART and other HIV/AIDS interventions, church-based charity organizations and FBO have experienced remarkable institutional growth. This growth and the institutional power that comes with it have also changed the matrix of relationships between state, donors and religious development actors within which ART implementation takes place. These changes in turn haven given rise to new conflicts that need careful consideration.

MARGINALIZATION OF PUBLIC ADMINISTRATIONS

Local HIV/AIDS projects are mostly coordinated through national HIV/AIDS policies or plans designed and implemented by national governments. ART rollout programmes have in general been integrated into these plans. Within the implementing structure, public health authorities are in theory the regulatory and monitoring bodies for biomedicine at both national and district levels. However, the increased reliance of foreign donors on NGOs and other non-state actors, precipitated by donors' overall dissatisfaction with African states' performances, also makes itself felt in the area of ART. One possible consequence is the increased marginalization and further weakening of public administrations.

A study in Uganda's Kabarole district revealed that ever closer alignments between donors and local ART implementing agencies effectively worked to supersede public structures on the ground. In the district ART provision began in 2003. Currently, more than 6.000 HIV patients are enrolled in the district's ART clinics. While most private or non-state health facilities are of Christian origin and two of the three hospitals are mission hospitals, the biggest power shift in the local health field occurred with the arrival of Catholic Relief Services (CRS) as a major donor of ART programmes. Receiving its funds from PEPFAR and UNICEF, CRS is the only donor with an office in the district capital and facilitates the rollout of about 2.000 patients.

> *'When we come to Uganda, or any other country, it's under the auspices of the catholic secretariat. We have our affiliation with the church. So that when we are working here, you find the bishop monitoring. The bishop can tell the director that they don't need me here. They will fire me. So the church is also involved. The diocese monitors our activities. So they are powerful. Whenever they want something, we'll listen to them.'* (CRS clerk working at the district office) [5]

Public administration was sidelined, for instance, when CRS decided that the ART implementing hospitals establish outreach posts to get closer to rural populations. Here, the district health department was not consulted but informed. Moreover, the boundaries within which outreach posts were to be established were not those of the district but those of the diocese. While religious donors thus emerged as powerful players, it was found that governmental bodies such as the district's department of

5. Taken from paper by Leusenkamp

health or District AIDS Committee were largely ineffective. As a result, governmental accountability for biomedicine almost evaporated.

On a more general level, power struggles between the state and religious organizations were also observed in the Busia District in southeast Uganda. According to national law, churches and FBOs are required to register as non-governmental organizations with the Ministry of Gender, Labour and Social Development. In the district, however, public administration lacks the resources to even enforce registration, let alone coordinate development activities. This has major repercussion for HIV/AIDS projects as in 2004 alone, 54% of all expenditures for social development in the district went into HIV/AIDS programmes.

Similar developments are also observed on national levels. The Christian Health Association of Zambia (CHAZ), for instance, is a huge actor in AIDS policy-making. CHAZ's influence is partially explained by the fact that it is a principal recipient of the Global Fund and PEPFAR partner. This implies that it receives its funds for ART provision and other HIV-related services independent from the state. While this gives CHAZ considerable power vis-B-vis the state it does not seem to have resulted in any overt conflict between the religious sector and governmental authorities.

On one hand, weaknesses of public administrations in ART governance result from donor decisions to sideline them. On the other hand, they also mirror the lack of resources and capacity of public authority in general. In Ghana, which has by any comparison one of Africa's most functional bureaucracies, the influence of faith-based bodies such as the Christian Health Association of Ghana (GHAG) on AIDS policy and governance was found to be relatively weak. This seems to be due to the fact

that its facilities are quite small and mostly located in rural areas and that the government pays roughly 70% of CHAG's employees.

DEFINING ELIGIBILITY: CHALLENGES TO EQUAL ACCESS

The involvement of FBOs in ART provision gives rise to new challenges regarding eligibility for access. First, challenges result from the establishment of parallel administrative structures as evident in Uganda's Karabole district. Here, CRS decided to establish ART outreach posts within the boundaries of diocese, not the district. As a result, people who live in the district but outside of the diocese are excluded from benefiting from these services.

Second, it is not always clear whether patients wanting to benefit from FBO services are required to be members of the church or faith communities to which FBOs might be affiliated. Most FBOs have non-preferential policies, but in a fair number of cases in practice there is a bias towards prioritizing co-religionists. Therefore the question is: who are the beneficiaries of FBO programmes? This question is important not only with a view toward establishing truly universal access to ART; it is also crucial for safeguarding the democratic principle that citizens have equal access to public funds. With regard to US-American funds for ART, there is evidence that changes within Federal 'charitable choice' policies during the Bush administration have partially undermined the principle of equal access by allowing FBOs to prioritize along religious criteria.

In the programmes run by RAPAC, the AIDS wing of the Redeemed Christian Church of God, in Nigeria the target group and beneficiaries of interventions are primarily church members. Although officially provisions for including non-members are in place, in practice this almost

never materializes. Similarly research in Uganda's Busia district found tendencies to prioritizing congregants in church-based projects and that in two cases donors approved such policies. Ensuring access to HIV/AIDS services regardless of religious membership criteria might not always be culturally feasible, especially in areas with strained interfaith relationships for instance between Muslims and Christians. If this is the case and local public administrations are unable to coordinate service provision so as to provide universal and equal access, development practitioners should place greater emphasis on enabling other coordinating bodies such as NGO councils to do so.

Challenges regarding eligibility, however, are not limited to ART provision itself but extend to the services surrounding it. Food supplies and mosquito nets are cases in point. In the study in Uganda's Karabole district it was found that although Uganda's national AIDS policies foreclose preferential access, CRS decided to limit the handing out of mosquito nets for malaria prevention to people who tested HIV-positive at the hospitals CRS supports. Another study conducted in a slum area in Uganda's capital Kampala revealed conflicts over food supplies. Public health experts regard to nutritional support as key to treatment success in resource-poor settings in general, and in poor households in particular. In line with this recommendation, a local Catholic AIDS initiative provided food supplies for participants in its HIV/AIDS programme. In the local community serviced by the initiative, however, poverty was so rampant that non-patients began to question the greater neediness of HIV-patients. Irrespective of these public debates, the food support component was at some point discontinued by the donors. This implied that Catholic health workers had to reconsider their ideals of 'holistic care'. Simultaneously the Ugandan government as well removed food supplies for PLWA from its policy agenda as ART was seen as enabling patients to resume income

generation. The donor's decision to withdraw from food programme therefore also left clients with no choice than to become 'responsible ART users' on their own account.

4. PLURAL FORMS OF THERAPY AND HEALING: ART IN CONTEXT

The remarkable enthusiasm with which FBOs and religious leaders have welcome, supported and embraced the introduction of ART is to various degrees mirrored in the perspectives of those whom they service: the users. However, while ART is crucial for prolonging life with HIV, it is often only one within a wide array of therapeutic resources people use for coping with disease and managing wellbeing. In this context, religious practices, religious membership and biomedical treatment of HIV/AIDS are entangled in complex ways. This raises a series of important questions that are often neglected in biomedical interventions: How does religion shape the treatment choices of patients? How might religion be helpful in complementing biomedical solutions to chronic disease? Which changes and challenges does biomedical treatment subsequently pose to the forms of religious participation of ART users? Answering these questions highlights ongoing contradictions between faith and biomedical science. But it also helps us to move beyond the dualistic thinking in terms of obstacle vs. asset usually employed in debates about religion and development. ART clearly poses new challenges to PLWA and understanding these challenges is key to considering the positive role religion might play in addressing them.

In general, HIV/AIDS treatment choices are rarely singular events. They often take shape over time as people gather more, and sometimes contradicting, information on available, suitable and affordable treatment

opportunities. Moreover, treatment choices are anything but static and often flexibly adjusted in the light of new information and opportunities as they emerge in different biographical stages. In the process, people might be convinced of the effectiveness of one treatment choice leading them to discard others. Convictions, however, might fade if effectiveness is not durable persuading them to look for alternative offers. Others, by contrast, flexibly combine various therapeutic resources in creative ways so as to suit their purposes.

In most African localities there are basically three major therapeutic paradigms people see, if variously, as conceptually distinct: traditional medicine, biomedicine and faith-based healing. Particularly the differences between religious practices and healing practices are often blurred; universal Christian practices such as prayer are locally invested with strong therapeutic significance and the visiting of churches is in local understandings sometimes likened to visiting hospitals. In the context OF HIV/AIDS, it is fair to say that the introduction of ART revolutionized therapeutic opportunities; more so, however, in urban than in rural areas. Nevertheless, two things are important to keep in mind: First, in Sub-Saharan Africa HIV/AIDS and ART meet with long cultural histories of 'home-grown' forms of healing and treatment. Despite people's innovativeness and flexible responses to new challenges and opportunities, it would be inadequate for development practitioners to expect people to forego non-biomedical treatment. Second, ART does not necessarily compete with other forms of treatment. What is needed is a creative dialogue between practitioners of diverse strands that places patients' needs at the centre of treatment efforts.

TREATMENT TRAJECTORIES

Often, series of treatment choices are organized into socially embedded treatment trajectories. Factors defining these trajectories are the availability of information, direct costs, associated costs such as for travelling to treatment sites and dispensaries or for the treatment of side-effects, alleged effectiveness and cultural acceptability.

> *'I started to search for information concerning this problem. Before ARVs were offered for free I heard about Chinese medicine for AIDS. I bought them. They were expensive but less expensive compared to the medicine from South Africa. They did not help so I stopped using them at some point. I couldn't afford buying them every month. About church healing, one day in my search for treatment I saw preaching on television. It was Pastor Angley, his preaching was so alive and convincing and there were testimonies of people who were healed. I decided to write him. I was not a good Christian but I became one after that. When ARVs started I heard about them in newspapers. I am now a member of two organizations of PLWA; one of them is a Christian organization. From these organizations I learn a lot and I encourage other PLWA to join them.'* (Tanzanian ART user and AIDS activist).[6]

In this context, religious communities often *mediate access to* ART providing information about where to find a treatment centre for instance. If churches have their own VCT facilities such referrals take on a more systematic character. In Zimbabwe, even African initiated churches, the traditional strongholds of faith-healing, have begun recommending ART to

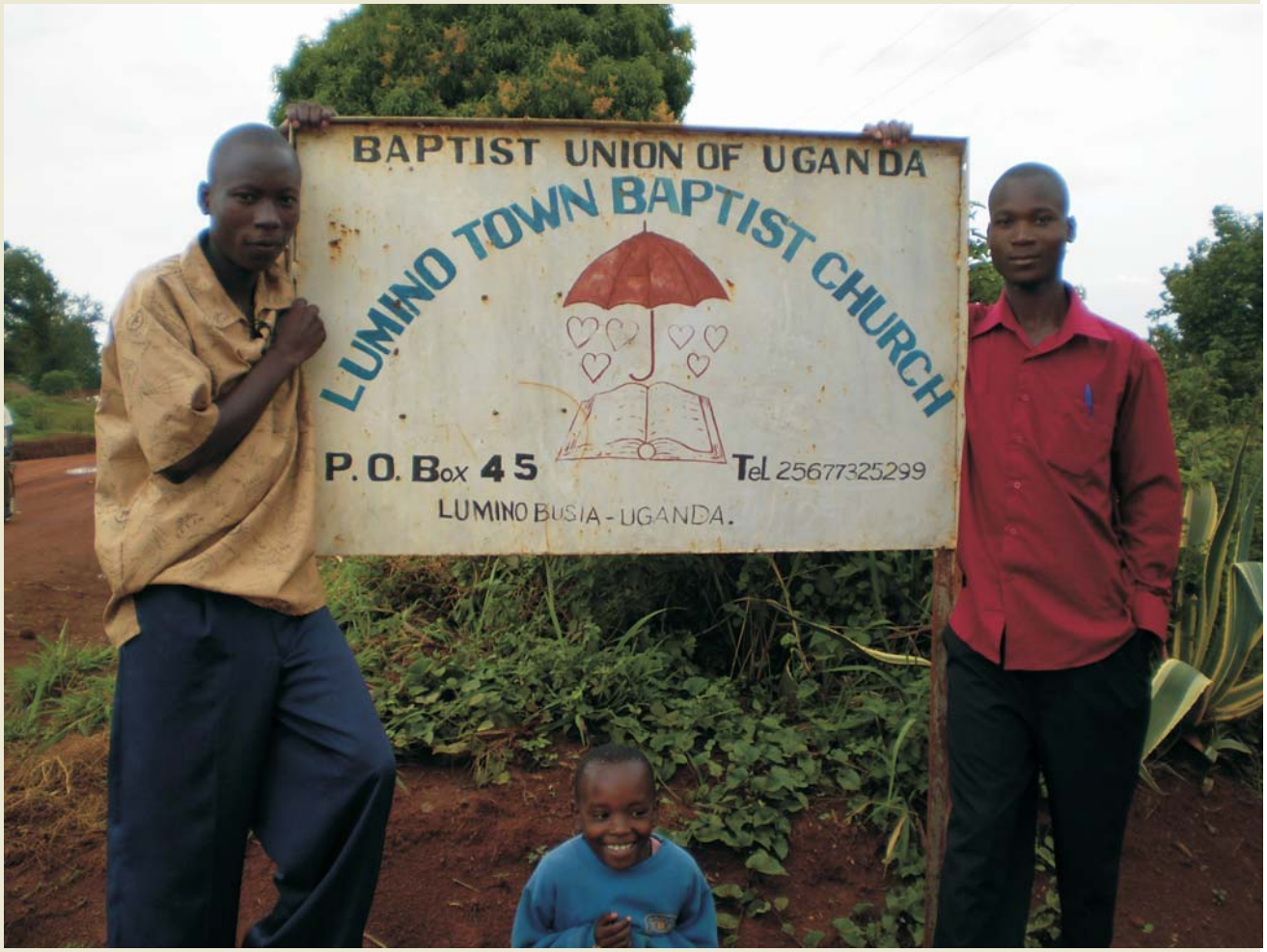
6. Taken from paper by Mrutu & Moyer.

PLWA who came for ritual treatment and referring them to clinics. Here, such changes are embedded in broader shifts away from 'miracle approaches' focussing on sudden recoveries towards more sustained interventions involving biomedical treatment as well as continued attention to spiritual concerns through ritual. According to a study carried out in Pentecostal churches in Dar es Salaam, Christian groups also use periods of sickness as welcome opportunities for evangelization visiting diseased individuals at their home and offering information, prayers and salvation. Again, we find that religious practices shape treatment trajectories and forms of coping.

COMBINING PRAYER, HERBAL TREATMENT AND BIOMEDICAL DRUGS

Instead of pitting different therapeutic resources against one another, patients often combine them in multiple ways. This has to do with the fact that one and the same disease is seen as having various dimensions and disease treatment is embedded into larger struggles for wellbeing. Patients may visit traditional healers or faith-healers for the treatment of opportunistic infections while simultaneously staying enrolled on ART. African initiated churches in Zimbabwe's capital Harare were found to treat symptoms of opportunistic infections such as herpes or swellings with mixtures of lemon juice, alter wine, honey, onion and ritual water while in other cases recommending ART enrolment.

This flexibility is also echoed in patients. While ART therapies are overwhelmingly appreciated as key to physical recovery, for many patients there are strong emotional, social and spiritual aspects attached to HIV-positivity. In the eyes of many ART users, neither biomedical substances nor staff at clinics attends to these aspects in a satisfying man-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ner. In this context, religious congregations are important because they provide a sense of community through routine forms of sociality as well as through prayers. Thus religious spaces may offer promising pathways for regaining hope, psychological strength and a meaningful perspective toward the future. Churches can be important places of solace and emotional comfort. This is often true even after ART therapies have been started. Visiting traditional healers, by contrast, provides patients with a strong sense of cultural continuity in the midst of disrupting experiences.

It is crucial to take into account that the treatment choices of many Africans living HIV take place within this therapeutic triangle made up of traditional healers, religious communities, and biomedical clinics. Moreover, research suggests that interactions between religious communities AND HIV-patients are crucial for shaping their attitudes towards traditional healing and biomedicine.

RELIGION AND GENERAL HEALTH-SEEKING BEHAVIOUR

Religions can directly influence the treatment choices and health outcomes of PLWA through their therapeutic offers and explicit attention to health issues. Such influences, however, can also be indirect. Social science research has shown that religious participation is often positively correlated with access to social networks, resources, and information. These factors in turn contribute to greater subjective attention to one's health and also to improved health levels.

Nevertheless, in practice other social factors may easily outweigh the positive influence of religion. A longitudinal study on the health-seeking

strategies of a cohort of former male students of a Catholic boarding school in Zambia shows that religious education had no positive effect whatsoever. In fact, here religious education was of little help for cultivating health-seeking competences, particularly those linked to openness, that are crucial in mediating access to health facilities, VCT and ART. Aspects of male gender models kept these men effectively away from testing facilities rendering them as vulnerable to HIV/AIDS as any other Zambian without religious education.

HOW BIOMEDICAL TREATMENT SHAPES RELIGIOUS PRACTICES

Religious membership, beliefs and practices shape attitudes towards biomedical treatment of HIV/AIDS. But treatment choices also bear on religiosity. Studies in Tanzania and Ghana suggest that some PLWA actively change their religious affiliations according to the attractiveness of religious offers. For ART users specific churches can be attractive because they accept or promote biomedicine and offer a non-stigmatizing and supportive social environment. For those having doubts about bio-medicine, Pentecostal churches appeal because of the faith-healing rituals they offer. Thus churches' attitudes towards AIDS become reasons for conversion. Various, mainly Pentecostal, churches across the continent have in fact actively fashioned themselves as faith-healing institutions.

> *'The prophet is powerful. I have seen more miracles since I came here about four months ago than I ever saw in my entire sixteen years in my former church. I know my time will come. Even now, I can see changes in all aspects of life. I am getting healthier, my family is relating better to me, and I have inner peace within, so why not? I will continue to come here and trust in God, you never know,*

He has plans to prosper me and give me an expected end." (Ghanaian HIV-positive convert) [7]

Yet in both cases we find that people tend to choose churches that conform to their treatment choices. This also means that contrary to expectations of biomedical science competing with religion in a zero-sum-game, biomedical solutions do not automatically diminish the importance of religion. Religious ideas and practices continue to play central roles in attaching meaning to disease, death, life, and healing. Moreover, attending to the religious agency of ART users also highlights how institutional change within the religious field is wrought from below.

ART, THE ABSENCE OF CURE, AND SPIRITUAL THERAPY

One of the major reasons why religion continues to be important for PLWA even after enrolment on ART is that ART is not a cure. For some HIV-patients, the absence of a cure for AIDS lends continued meaning to ideas of spiritual causation and hence to the search for spiritual therapy. According to research in Ghana, this also leads patients to embark on specific religious trajectories: people seek out churches and religious groups that cater for their needs. These religious trajectories are sometimes overlapping, sometimes even equivalent with treatment trajectories as outlined above. In the process, people try out various therapeutic options such traditional healers, herbalists, spiritual churches and 'Mallams' (Islamic traditional practitioners). Remarkably, people's flexibility implied that patients were less concerned about the religious prov-

7. Taken from paper by Kwansa.

enance of certain healing options than about their therapeutic values. The findings suggest that concerns with healing may take precedence over religious identity.

> *Aisha started the treatment at the ART clinic and was combining it with her faith in God through the ritual prayers (salah) and fasting during the Ramadan (sawm) until she heard about "a very powerful man of God" on radio. She usually leaves home around 4:00 on some Fridays to travel the about 75km to the remote part of the region where this prophet has his "temple" so she could be somewhere in front of the queue to get the special prayers. 'I usually get back home around 18:00, very exhausted. But I think it is worth it. There are several people who come and share their testimonies and I have seen on two occasions people who testified of being cured of HIV/AIDS. On radio however, I have heard much more of such testimonies. I don't really feel bad about going there as a Moslem. I see a lot of people who I think they may also be Moslems, but it is your healing that is necessary not where you get it. God can use anybody to bless you. If you have an eight-month-old baby like I do, you would have taken more desperate measures to live. I still make time to say my prayers anyway. I know my dad (a very staunch Moslem) would disagree, but he hasn't found himself in my situation so he wouldn't understand. I don't feel any less of a Moslem, only that it is becoming easier to go there now than when I started some six months ago.'* (Female Muslim ART user from Ghana) [8]

Similarly, amongst Tanzanian HIV-positive Pentecostals there is a widespread belief that they might be cured from AIDS through prayers and firm religious faith. These hopes are nourished by stories, circulating

8. Taken from paper by Kwansa.

widely through mass media and neighbourhood talk, of HIV patients being completely cured through Pentecostal faith-healing rituals. While informants in the Tanzanian study appreciated the benefits of ART, biomedical treatment was perceived as a 'temporary solution' on their pathway towards total recovery and cure. Here, religious faith was taken to provide a sort of hope that biomedical treatment seems to foreclose.

In Islamic northern Nigeria as well, HIV patients just as Islamic healers struggled over questions of cure. Some Islamic healers employ biomedical concepts such as viral load and CD4-count while simultaneously insisting on their ability to completely cure their patients. HIV patients participating in an anthropological study, however, were critical of the secrecy surrounding these alleged cures and demanded that healer make their formulas public.

The value of religion and spiritual therapy might derive from hopes for a cure; but it may also be more broadly linked to the need for psychological coping and stress reduction, for instance in the workplace. Anthropological research on the case of HIV-positive nurses working in an ART clinic in Uganda shows that meeting the emotional needs of healthworkers and 'caring for the carers' is a particularly pressing, and too often neglected, challenge for HIV/AIDS programmes. In order to address these needs, the nurses organized a 'secret' support group. The meetings became occasions for debating and collectively coping with stigma, work overloads, burnout, and ART side effects. In the process, the nurses developed for themselves a concept of 'being saved nurses' for which religion provided rhetorical templates. The group was deemed crucial by participants mostly because of the unlimited sharing and the possibilities to also express conflict. In this, it contrasted strongly with the largely prescriptive style characteristic of biomedical support groups that focus

on treatment literacy and adherence. The greatest benefit of group attendance was that the nurses were reconciled with their daily stress at work and increased their awareness for ART patients' needs beyond biomedical concerns.

> *'My religious faith has changed the way I feel and care for my patients very dramatically. I am more empathetic. [..]. This however has made me a darling of the patients irrespective of their religion as I share encouraging religious beliefs with them and this encourages them to go on. I also share with patients and colleagues my faith in the way I take care of patients and relate with workmates referring to several aspects of the bible. [..]. Patients are desperate, they need a Good Samaritan even if simply to give a hearty smile, touch or just being nice to them. They need encouragement beyond telling them to take their pills or that pills will help them. They need to learn things like true forgiveness, total love to self and others as this brings new joy into one's life.'* (HIV-positive nurse from Uganda)[9]

THERAPIES IN CONFLICT

Contrary to the 'combination model' in which various kinds of treatment are simultaneously sought and used for different purposes, some PLWA view different treatment offers as contradictory and irreconcilable. Sometimes these perceptions result from advice patients receive in their churches. Findings from the study on Pentecostal congregations in Dar es Salaam show that church officials discouraged patients from visiting traditional healers since this was seen as compromising belief in the

9. Taken from paper by Kyakuwa.

healing power of prayers. In general, conflicts between various healing traditions are pronounced where claims to total cure are made and deemed as unfounded by opponents.

> *'It was during the time that my child was sick. [..]. I took her to the hospital and she was given medicine to no avail. My husband decided we should have her tested for HIV. She tested positive. I also took the test and the results were the same, positive. I heard from people that there are traditional healers who can heal any disease, even AIDS. Of course I never told them that I was positive, but I think they brought up AIDS to show the power of the healer. [..]. I visited two different traditional healers; we were given different types of medicines. I was even told to drink urine, which I did. But at the end, it wasn't meant to be. My child died. I did not end there. Then I learned about God and his healing power. It was then that I decided to also join the Pentecostal Church.'* (Tanzanian HIV-positive mother)[10]

A reverse pattern was found in the northern Nigerian study. Here, an HIV-positive Muslim after having spent huge amounts of money on traditional healing virtually 'converted' to biomedicine. With the arrival of ART through PEPFAR funds, he enrolled on biomedical treatment and renounced traditional healing and its claims to having a cure. Similar observations were made in northern Tanzania where in some cases enrolment on ART went hand in hand with a strong condemnation of traditional healing. In the ethnographic context of northern Nigeria, rather polarized attitudes mirror broader conflicts between biomedicine on the one hand, and Islamic and traditional healing on the other. Practitioners of each side appear to view each other with a fair amount of suspicion, not least because of mutual accusations of encroachment in the other's

10. Taken from paper by Mrutu & Moyer.

sphere of competence and business. The findings also suggest that these somewhat hostile views are linked to broader trends towards increased Islamization that occurred over the past decade and also brought with them a substantial increase in the number of Islamic pharmacists and healers.

RELIGION AND TREATMENT ADHERENCE

One of the major challenges of ART therapy is treatment adherence. Many church communities and FBOs are taking up this challenge and have begun offering treatment literacy and adherence training. Likewise, religions generally promote behaviours that are beneficial for health such as the proscriptions against alcohol use in some forms of Islam and Christianity. They can also promote adherence when people take these proscriptions seriously. But ART users also began themselves to find creative ways of improving adherence through linking it to religious practices. ART users in the Tanzanian city of Tanga, for instance, likened drug intake to a religious ceremony; some secured adherence by combining intake with their daily prayers.

> *'I handle this matter [taking ART] like a worship. When you are sleeping you need to pray, when you are waking up in the morning you pray. So I haven't forgotten [taking the medicines] even once. Not even once I've missed it and I've never taken it even one minute too late!'* (ART user from Tanga/Tanzania)[11]

11. Taken from paper by Mattes.

Adherence, however, may be a challenge when drug intake clashes with obligatory religious observances such as fasting for Muslims during the Islamic holy month of Ramadan. Since intake must be combined with a meal, therapy and observance are virtually irreconcilable. Officially, Islam's holy book, the Quran, provides exemptions from the duty to fast for the sick, travelling and hard labourers. A study in Zanzibar, however, revealed that in practice making use of this provision may come with social costs attached: First, not fasting separates one from social life during Ramadan and may also carry stigma. Second, reasons for not fasting are often scrutinized and questioned by community members. As a result, for PLWA not fasting may lead to the unintended disclosure of one's HIV status. Third, Islamic provisions for exemptions from fasting imply special compensatory payments of *zakat* (charitable gifts) to the mosque community. PLWA who lack resources to do so could in theory resort to their families for help. Again, however, this requires disclosure and thus impinges on issues of confidentiality. As a result, some PLWA decide to fast despite feeling uncertain whether this might affect their health negatively.

RELIGION, ART AND DISCLOSURE

As highlighted above, the multiple links between disclosure and adherence indicate that despite the expectation that ART would 'normalize' HIV/AIDS, disclosure remains a critical issue. It seems that the introduction of ART has changed the challenges and obstacles linked to disclosure instead of abolishing them. While prior to the introduction of ART disclosure was primarily promoted to prevent new infections, create greater openness and reduce stigma, with ART it is seen as key to treatment adherence.

Particularly amongst spouses the disclosure of a positive HIV-status is often difficult as people fear loosing their partners in response. In the context of cohabitation, however, enrolment on ART after receiving positive test-results is almost inevitably linked some kind of – intended or unintended – disclosure. Critical issues linked to unintended disclosure are patients' visits of treatment centres, the storage of drugs and medical files and drug intake. As a result, such fears of unintended disclosure may act as barriers to enrolment.

> *'We are also wondering whether he [the informant's husband] had seen anything because I used to keep my drugs in the fridge, my files in the sitting room and sometimes some tins on the table in the bedroom and I would pick drugs of a month, sometimes two months, so there would be many tins of drugs in the house. I would sometimes swallow drugs when he was looking at me but he had never asked me why I was swallowing those drugs and I also kept quite.'* (Uganda non-disclosing ART user)[12] *(Taken from paper by Jenipher Twebaze)*

In Christian contexts, religion has gained a renewed significance in this regard. As most people marry in churches and churches have begun demanding HIV-tests from spouses as part of the marital process, pastors are inevitably involved in the dynamics of disclosure. In some countries such as Nigeria, the demand to produce HIV-testing certificates in the marital process has in fact become mainstreamed in Christian churches. Here, however, people are somehow caught between a rock and a hard place as churches are still sometimes seen as stigmatizing while simultaneously demanding 'telling the truth' as a primary Christian duty.

12. aken from paper by Jenipher Twebaze.

FAITH MATTERS

Just as governmental clinics, church- or FBO-based treatment centres place signposts announcing the availability of ART in front of their premises. According to research findings from Tanzania, some ART users found this unhelpful as it furthers disclosure that might be unwanted. Moreover, a study in Uganda found that religious leaders are in general highly involved in HIV counselling where negotiations over disclosure often take place. Strengthening pastors' skills to counsel HIV-patients and ART users in an empowering way is therefore key to enabling forms of disclosure that are both approved by patients and beneficial for ART success. Moreover, development practitioners should acknowledge that also in the era of ART non- or partial disclosure is not always a result of stigma. Non-disclosure may equally be a result of patients making use of their right to privacy and confidentiality.

5. NEW AGENDAS FOR DEVELOPMENT AND RESEARCH

The involvement of religious organizations in ART provision in Africa marks a new step in the relationships between religion and development on the one hand, and religion and science on the other. This is significant as during past development decades religion did not play a significant role in the way development was understood. These understandings, however, are changing quickly. Religion is recognized as an important force in development. In order to maximize the benefits of employing religion for social change that is both democratic and inclusive we need to address the challenges emerging from religious involvements. We suggest four areas that require further scrutiny:

- 1. We have seen that in some cases FBOs are highly successful in managing ART programmes and improving health outcomes for patients while in other cases they face challenges and constraints. More research is needed to identify the precise conditions favouring or undermining programme success.
- 2. There are indications that preferential inclusion into programmes by FBOs may engender new inequalities for some social groups. More research is needed in order to establish how such tendencies can be countered, or balanced through efforts to institutionalizing universal and equal access to ART.

- 3. Research has shown that many religious organizations are ready to incorporate biomedical healthcare models into their operations. It is much less clear to what extent biomedical healthcare institutions are prepared to take issues of religion into account. Many patients use plural forms of therapy that must not be easily dismissed by biomedical healthcare providers.
- 4. The increasing power of religious actors in development can create intensified competition between diverse ideologies. Research is needed to identify how religious ideologies influence patients' understandings of treatment and therapy. More specifically, we need to recognize that funds convey power to religious organizations and that these organizations have interests going beyond the pursuit of development goals.

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Suggestions for further reading

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