“Let us Embrace”: The Role & Significance of a Faith-based Initiative in HIV and AIDS Work

Liz Thomas
Barbara Schmid
Malibongwe Gwele
Rosemond Ngubo
James R Cochrane

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African Religious Health Assets Programme

Dept. of Religious Studies
University of Cape Town
Private Bag
7701 Rondebosch
South Africa
Email: arhap@humanities.uct.ac.za
Phone: +27 -21 650 3457/8

Interfaith Health Program
Rollins School of Public Health
Emory University
1256 Briarcliff Road, Bldg A, Suite 107
Atlanta, GA 30306, USA
Email: djones9@sph.emory.edu
Phone: +1 -404 727 5246

ARHAP
Research Report

“Let us Embrace”

The Role and Significance of an Integrated Faith-Based Initiative for HIV and AIDS

MASANGANE CASE STUDY

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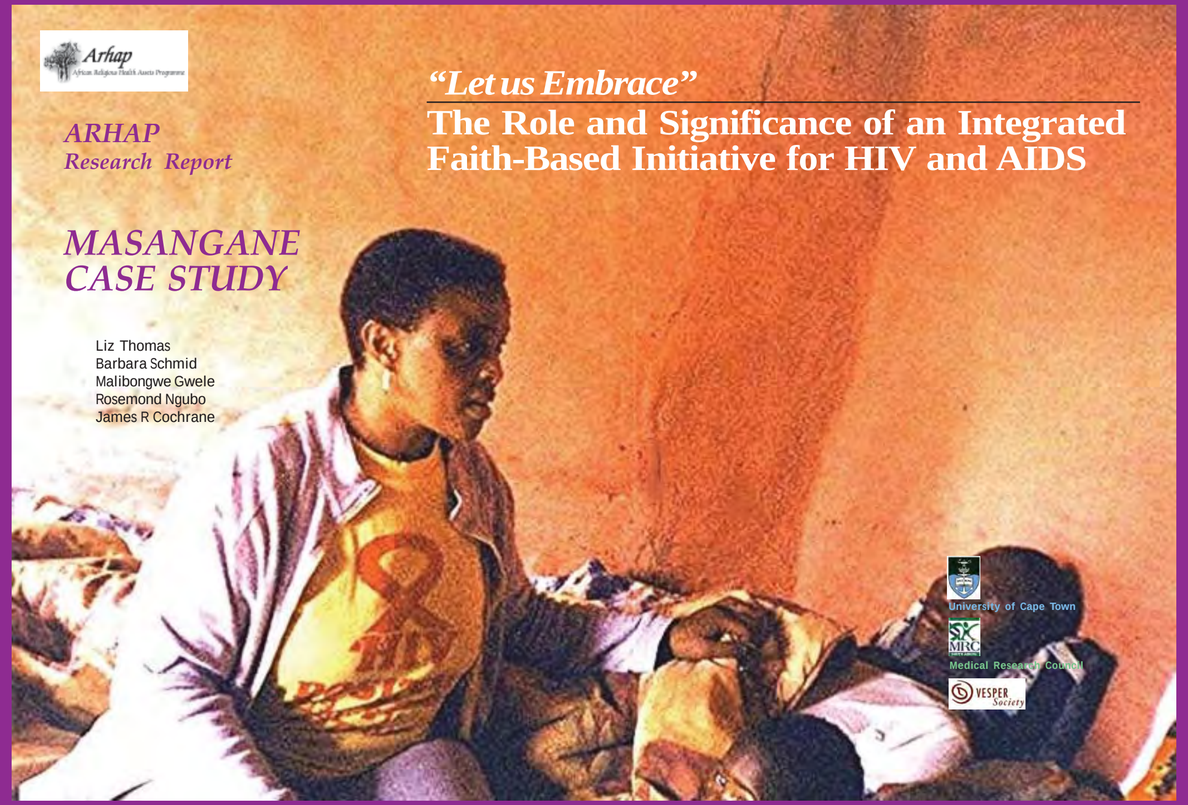

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EXECUTIVE SUMMARY

"Let us Embrace": Masangane Case Study - a Comprehensive, Integrated FBO Response to HIV and AIDS

Masangane is an AIDS programme operated by a faith based organisation in the Eastern Cape, South Africa. It provides a range of *integrated services* to a predominantly rural poor population. Though small in scale, Masangane has developed a successful programme providing anti retroviral treatment (ART) as part of its overall programme. This study is an evaluation of the project.

The data collection was undertaken when Masangane was the only source of free anti-retrovirals (ARVs) for a population living in the predominantly rural districts of the Eastern Cape, South Africa, which it served. Since the research took place, the State ARV programme has begun providing drugs from hospitals and clinics in the vicinity of the three Masangane sites. Nevertheless, the State ARV programme, operating in terms of the Operational Plan adopted in 2003, has been slow to deliver ART across the country, especially in rural areas. Estimates are that as at 1 December 2005 nationally, 85 000 people have access to ARVs through the public health service, providing for less than 20% of those needing them. The demand for treatment will be increasing as the HIV prevalence continues to increase.

Given the current and likely future demand for ART, a key issue is what the *potential role of faith based organisations* could be in helping to respond to this need. The research addresses this question in a number of ways. The aim of this study is to describe the activities of the Masangane ARV programme, assess the views of various stakeholders, evaluate the impacts of this faith based organisation, and to assess the 'value added' in its services due to its being faith based. The study also explores the practices of beneficiaries of the ART programme in their regular use of multiple health systems - biomedical, traditional, faith – simultaneously or consecutively. The report concludes with an overview of findings, followed by policy recommendations for public health and religious leaders in considering the potential role faith based organisations/ initiatives (FBO/Is) could play in ART, and in identifying how the 'added value' of Masangane's activities could be replicated. Finally, further research questions emanating from the study are identified.

Masangane's *continuum of care* includes a very successful treatment programme serving 85 people, operated in partnership with private doctors and run by a treatment co-ordinator, herself on ART. Key to their success is getting those who are very ill onto ARVs quickly, and the use of an effective treatment literacy programme, modelled on the MSF (Médicín Sans Frontières) approach. Adherence to ARV drugs is also very good. According to the beneficiaries this is in important ways associated with several factors: Linking the routine of taking the drugs to a daily bible reading ritual; being given crucial hope and encouragement by strong support groups and treatment supporters; challenging stigma theologically through enlightened leadership in the Moravian and other faith communities in the area; being welcomed (*Masangane = "Let us embrace!"*), supported and encouraged in their ART regimen. The Masangane treatment programme is complimented by its orphan support initiative and HIV awareness educational work in local communities, and in Matatiele by home based care provided by Noncedo, a partnering community based organisation.

The range of services provided is seen in a positive light by the clients as well as a range of other key actors. The activities are managed by a small team who have been able successfully to negotiate funding with church based agencies in Europe and the USA, manage the resources astutely, and simultaneously maintain a high standard of care. Masangane can justifiably be regarded as a vital *community and health asset*. The impact of Masangane extends from the improved health and well-being of the clients to their acceptance in the community where stigma has been reduced. Beneficiaries not only participate in treatment support groups that offer a sense of belonging, fellowship and dignity, but also often volunteer to work in the broader community.

To its credit, Masangane as a programme has been able to preserve a connection to the teaching, values and structures of the religious tradition within which it is embedded while maintaining a scientific approach to the actual treatment it offers. To be able to call on the resources of its religious tradition, and yet remain open to new possibilities in responding to AIDS; to offer a Christian embrace to those with HIV – wherever they come from – and draw them into a well controlled bio-medical treatment programme, is no mean feat. In this context, its *faith-based character* clearly adds considerable value, something that is difficult to measure, yet very clearly an important part of its success.

The *diversity and plurality of health-seeking approaches*, or what we here call mixing of health systems, among Masangane health seekers is common. Mixing strategies while on ART is a controversial, even dangerous matter. But it is more often than not the norm in the context in which Masangane works, perhaps even pervasive, and it has its own logic. This is a problem given the lack of mutual respect even, much less an integrated approach between the various actors offering different means of healing to those with AIDS.

Masangane itself might be seen as resting primarily on 'Western' ways of dealing with AIDS and this is certainly true in respect of its treatment practices and protocols. But it also represents something that has become increasingly part of public health thinking, namely, the need for a far more *holistic response to illness and disease*. In the case of Masangane, this includes its comprehensive range of responses to prevention, care and support beyond its bio-medical activity. The clients see considerable benefit in being associated with Masangane because of the importance it gives to the integration of their Christian belief system with healing, to the point where they regard its ARVs as more effective as a result.

Using the ARHAP framework, what appears to be highly valued is the integration of the drugs to address the physical condition of the body with the person's belief system and social context, referred to as the spiritual and social body. From a 'Western' medical perspective, what is valued could be described as the integration of the physical healing (control of the virus with ARVs) with the psycho-social aspects of the individual as well as re-integration/re-acceptance into the community. The *integration of care across the continuum of activities* offered by Masangane may well be what beneficiaries have been referring to when describing the Masangane drugs as 'different' and the reason for their reluctance to be transferred to public health institutions for their ARVs.

This takes us to the *potential role of FBO/Is in health care* especially in a context of HIV and AIDS and the roll out of ARVs in South Africa.

The study was commissioned by Vesper Society, USA, which has also funded most of the ARV drugs provided by Masangane to its clients. The research was undertaken by a team of researchers interested in the interface between public health and religion, under the ambit of the international *African Religious Health Assets Programme* (ARHAP).

Policy recommendations ask for the public health system to take greater cognizance of:

- The critical role that a faith dimension has on treatment, especially the value for clients of the integration of the faith component into treatment and support group activities
- The potential shown through the Masangane case for FBO/Is, in partnership with the State ARV programme, to provide for some aspects of an ART programme that are very time-intensive such as treatment literacy, stabilisation on treatment, support groups, and monitoring adherence
- The infrastructure, influence and respect FBO/Is often have in communities, and thus their potential contribution to addressing stigma and mobilising for treatment
- The need to assist in the education and training of religious leaders so as to be able to mobilise these important religious assets for health gains
- It is not suggested in any way that FBO/Is and their like should be seen or treated as a substitute for what the state and the public health system should and could do.

Further research questions emanating from the study include:

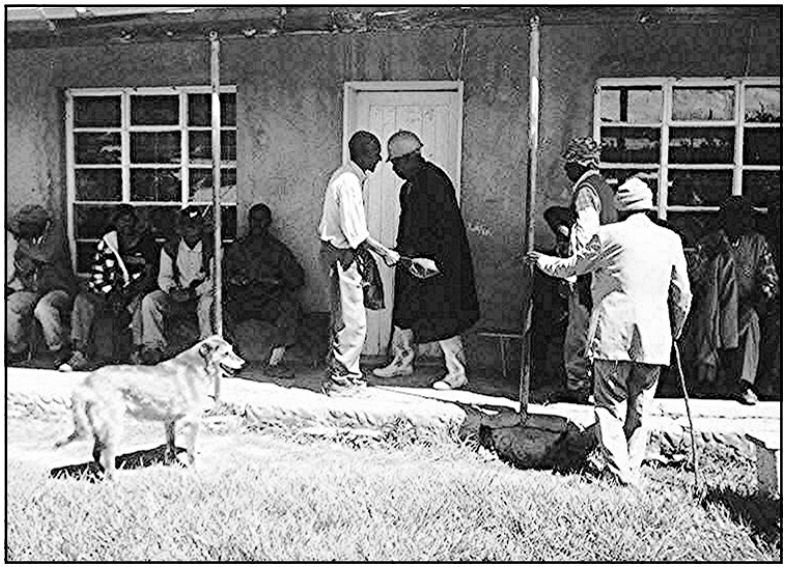
- The need to compare Masangane with other ART programs to be able to document lessons learned and good practice so as to inform the potentially expanded role of FBO/Is and NGOs in ART
- Exploring ways in which the 'added value' of religion in responding to HIV and AIDS can be monitored
- Additional evaluation of the cost effectiveness of Masangane compared to other programmes
- The use of Benefit Incidence Analysis as a way in which to explore the extent to which ART provision is in fact meeting the needs of the poorest.

April, 2006

University of CAPE TOWN
Medical Research Council
VESPER Society

List of abbreviations

AIDS	Acquired Immuno-Deficiency Syndrome
ARHAP	African Religious Health Assets Programme
ART	Anti Retroviral Treatment
ARV	Anti Retroviral Drug
CBO	Community Based Organisation
DIFÄM	Deutsches Institut Für Ärtzliche Mission (German Medical Mission)
FBO/I	Faith-Based Organisation or Initiative
HIV	Human Immuno-Deficiency Virus
HSRC	Human Sciences Research Council, South Africa
HST	Health Systems Trust, South Africa
MRC	Medical Research Council, South Africa
MSF	Médicíns Sans Frontières (Doctors Without Borders)
NAPWA	National Association of People Living With AIDS
NGO	Non-Governmental Organisation
NPO	Non-Profit Organisation
PEPFAR	President's Emergency Plan for AIDS Relief
PLWH/PLWA	People Living with HIV or People Living with AIDS
RHA	Religious Health Asset
SACC	South African Council of Churches
SAHARA	Social Aspects of HIV/AIDS Research Alliance
SAHR	South African Health Review
TAC	Treatment Action Campaign
UCT	University of Cape Town
UNAIDS	United Nations AIDS Programme
UNDP	United Nations Development Programme
WHO	World Health Organization



Gathering at a local homestead

Reading *Atlas.ti* **references in the footnotes**

Many of the footnoted references refer to transcribed (and often translated) qualitative interviews.

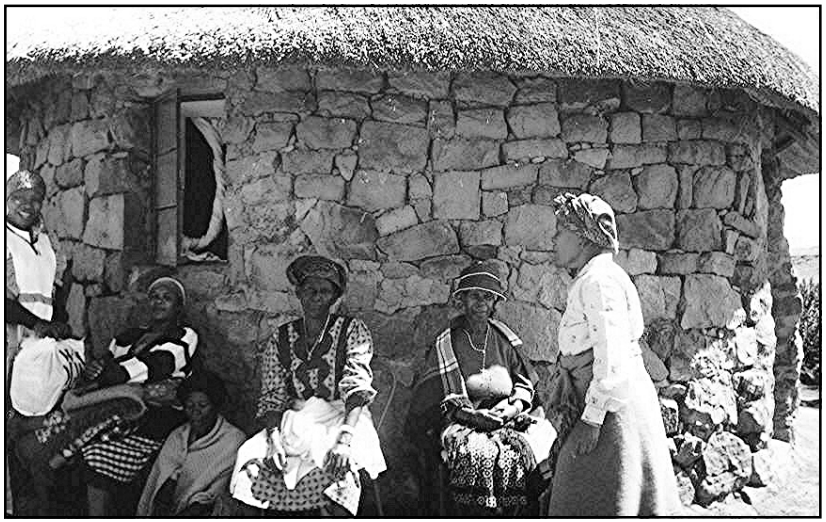
A. *Example:* KII – Rev Venter – 28:3 (259:265) →

- KII … type of primary document
- Rev Venter … name of primary document
- 28 … primary document number
- :3 … quotation reference number in the document
- (259:265) … coded text starts in line 259; ends in line 265 of the primary document

B. *Types of document:*

- KII = Key informant interview, people with direct knowledge of Masangane and its work
- FG = Focus group, conducted with groups of Masangane clients
- Interview = follow-up interviews with key informants or interviews with others who have relevant insights

A full list of names of primary documents (aliases of interviewees) is given in Appendix B.



Living in a rural area

Chapter 1

Masangane in Context

1.1 Introduction

This study is both an evaluation of Masangane, a faith-based integrated response to HIV and AIDS, and through it, a study aimed at deepening our understanding of the role of religious health assets in the face of HIV and AIDS, with implications for public health.

To achieve this aim, the report:

- Provides an overview of Masangane
- Explores the ways and extent to which Masangane can be considered to be a religious health asset
- Evaluates the role that the project plays and the value added by its being a faith-based organisation/initiative (FBO/I), and
- Explores lessons that can be drawn from the evaluation to inform ART roll out and the role of FBO/Is in responding to HIV and AIDS.

1.2 Aim of Masangane

In his introduction to *Buckling: The impact of AIDS in South Africa*, Hein Marais writes:

> [W]hat emerges is a horrifying picture of a society that is being ruptured and buckled into an antithesis of the humane, just and dignifying society millions struggled for and continue to strive toward.[1]

Masangane (isiXhosa for 'embrace one another') developed as a faith based response to the devastating impact of HIV and AIDS on communities in the Eastern Cape that were being served by pastors of the Moravian Church. Now Masangane provides an integrated response to HIV and AIDS by addressing needs for prevention, treatment, treatment literacy, orphans and vulnerable children. Masangane is considered to be a religious health asset (RHA) in itself, and a repository of varying religious health assets at another level. This concept, a significant shift in terminology from the standard "faith-based organisation", will be explained in Sect 1.6.6 below.

In order to provide the context within which Masangane has developed it is important to trace the national and provincial public health response to the HIV epidemic. These provide the backdrop to the Masangane initiative.

1.3 South African HIV, AIDS and poverty context

1.3.1 HIV/AIDS policy, context and response

South Africa, having emerged out of the darkness of apartheid, is overwhelmed by the HIV/AIDS epidemic. The political freedom of democracy and the growing confidence it has brought at some levels is dampened by high levels of poverty and inequality, increasing deaths from AIDS, and despair at the country's capacity to respond to the pandemic. Reasons for despair range from personal tragedies experienced at family and community level through to the seemingly ongoing political intransigence as well as limited capacity nationally to respond to the scale of the epidemic.

The HIV/AIDS epidemic is concentrated in sub-Saharan Africa where UNAIDS estimated in 2006 that more than 60% of the total number of infected persons are located.[2] Within this region, South Africa's national prevalence is one of the highest and it certainly is home to the majority of those infected, with current estimates varying between 4.5 and 5.6 million South Africans infected with HIV.[3]

The HIV epidemic in South Africa is predominantly in the heterosexual population. There has been a rapid rise in infected antenatal attendees from an estimated 24.5% infected in 2000 to 29.5% in 2004.[4] The increase varies between the provinces. Across the country, certain provinces have a more advanced epidemic and thus a higher percentage of those infected (see Figure 1 below).

Across the spatial divide, certain types of settlement are being highlighted as having higher HIV prevalence. The highest is in urban areas, and there people living in informal settlements have a HIV prevalence rate double that of those living in formal housing areas. By contrast, studies show the prevalence in typical rural areas to be lower.

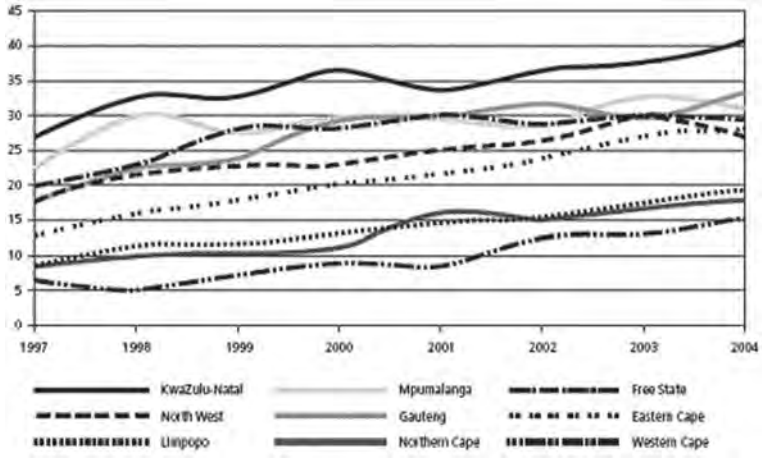


Figure 1: HIV prevalence among antenatal clinic attendees in South Africa by province 1997-2004. (Department of Health data). Source: Marais (2005) Buckling, *p30 (see Endnote 1).*

The difference in prevalence between metropolitan areas, smaller towns, the 'apartheid style' resettlement areas, and deep rural areas has not been assessed specifically. However, Lurie et al. have shown HIV prevalence to be associated with mobility,[5] and recent work by Singh has highlighted the migratory patterns of those no longer able to work due to ill health.[6] Poor urban households have been shown to use multiple strategies to address the impact of chronic illness of an income earner,[7] including 'repatriating' those who are chronically ill to rural family homes to die. Singh also stresses the potential role of faith based organisations in prevention, and in supporting the roll out of treatment.[8]

Certain groups show much higher levels of infection than others. Young sexually active women under 30 have the highest prevalence rate; this can be seen in the trends in the age profiles in the national antenatal data, collected at public health clinics nation-wide, as well as in numerous other surveys.[9]

Trends appear to indicate that the rate of new infections in young women is levelling off, especially in the under 25 age group (see Figure 2).

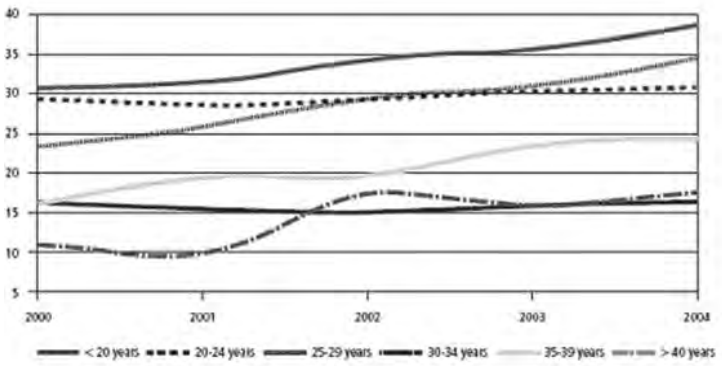


Figure 2: HIV prevalence by age group among antenatal clinic attendees in South Africa (Department of Health data 2000-2004). Source: Marais (2005) Buckling, *p31 (see Endnote 1).*

A national ARV roll out plan was developed in 2003, and by September 2005, 85 000 people needing ARVs had access to these life saving drugs through the public sector.[10] At the end of 2005, it was estimated that ARV treatment was available in 62% of the local authorities in the country, through 199 public health facilities.[11] In addition, estimates are that a further 70 000 people had accessed ARVs by August 2005 via the private sector, their employers or other programmes.[12] However, due to the scale of the need and the limited capacity of the state health system, estimates are that by mid 2005 less than 20% of those needing ARVs as measured by their CD4 count have been able to gain access to these drugs.[13]

Although the capacity of the heath service has been a constraint in enabling access to ARV treatment country-wide, certain areas have had the benefit of a quicker roll out programme. Concern is being raised about inequity in access to the drugs as well as the barriers to being able to receive treatment, especially among the very poor.

In the context of Masangane, key issues regarding inequity in access, the limited scale of the roll out, and the capacity of the health system, revolve around:

- Lack of staff, especially trained staff, to be able to implement the programme
- The long distances and high costs for those needing to get access to ARVs in more remote areas
- Long waiting lists with an estimated 20% of those needing ARVs being able to access the drugs through the state health system
- The impact that the high profile, vertical ARV programme (with a lack of adequate horizontal integration) has had on the morale and capacity of the staff of the public health system at a primary care level[14]
- Concern regarding the integration, sustainability and scaling up of the programme and its potential to undermine the health system.

As the Health Systems Trust notes, "Improving the efficiency and effectiveness of existing services is the first step to meeting the health needs of rural people."[15]

1.3.2 Eastern Cape policy, context and response

Having considered the role of the public health system in ARV roll out in 2005, it is important to highlight the disparities between urban and rural areas with respect to poverty, especially given the endemic poverty in the country. On a national level, 48.5.% of the South African population would be classified as in poverty; the figure is much higher in the Eastern Cape, as much as 68.3% according to UNDP. This also varies across the province with 61.2% of the population being classified as living in rural areas, where poverty is more extreme.[16]

As a result of deep poverty, it is not surprising that rural people bear the greatest burden of disease. Further, rural people in South Africa have less access to health care, and they often cannot travel to urban areas to access public health services there, nor can they access private health care owing to its costs. For the same reasons, the infant mortality rate is much higher across the country in rural areas when compared to urban areas (52.2 versus 32.6 in 1998), and in the Eastern Cape the overall infant mortality rate was 72 compared to the national average of 59/1000 in 2002.[17]

Turning to HIV prevalence, the Eastern Cape would appear to be lagging behind the national epidemic according to the ASSA model (2005).[18] It

is thus likely that the epidemic has not as yet reached its peak in the region. A number of studies suggest a provincial overall HIV prevalence of 10%.[19]

The prevalence for those in the sexually active age group is much higher, especially among younger women. The provincial HIV prevalence rates of women ranged from 20.4% in the HSRC Nelson Mandela 2005 study for 15-49 age group, compared to 28% in the 2004 antenatal survey by the Department of Health.[20] A consequence of the high HIV prevalence rate amongst women is the very high rate of orphanhood found in the Eastern Cape province, second only to KwaZulu Natal; in 2005, the HSRC found that 18.1% of children in the Eastern Cape were orphans compared to 19.8% in KwaZulu Natal.

Driving conditions in the area

Another factor impacting on HIV prevalence in the region is the role that the Eastern Cape continues to play as a base from which people migrate to other provinces for work. At the same time, there is an increasing trend of indigent people to return home to rural areas in the Eastern Cape when sick, but it is unclear to what extent this alters the provincial HIV prevalence rate. In this study there is anecdotal evidence of some of those now on Masangane's ARV programme having returned home to the region from workplaces elsewhere in the country because they were too ill to continue to work.

A number of ARV sites have now been set up by the state in the Eastern Cape. Indications are that as at February 2006 just over 15 000 people were on ARV treatment provided by the provincial Government. Its health department hopes to nearly double this to 27 000 people by the end of 2006.[21]

This is an ambitious plan given the fact that the Eastern Cape has long been identified as a province of limited capacity that struggles to provide the necessary basic health care. With the province's lack of resources, with a limited economic base and capacity, with structures constructed on the back of a number of previously separate administrative areas from apartheid history, and with its largely rural population, the challenges to the Eastern Cape Government of expanding the provision of ARVs are immense. At the same time, a study in 2004 has shown that in the province, 90.3% of the population is dependent on the public health system, compared to 85 % nationally.[22]

1.4 Role of faith based community in responding to HIV and AIDS in a context of poverty

Faith based communities from differing religions have very often responded to human need as a fundamental imperative arising from their tradition and beliefs. This was evident during the apartheid era as well, when many Christian churches, for example, played a key role in social justice issues. But the same churches have struggled to respond adequately to the HIV/AIDS pandemic, which has proved in some respects to be different due to the sexual stigma and connotations of sinfulness often associated with HIV infection.[23] Nevertheless, various religious groupings have played a role in helping to reduce stigma and to promote prevention, access to treatment, care and support.

In the Eastern Cape, a province that is predominantly Christian and strongly Methodist, there have been a range of responses. These have included broad initiatives through the SA Council of Churches in its Eastern Cape office, as well as denominationally specific initiatives. Some of these have been driven by local faith community groups, perhaps the best known kinds of engagement being through hospices and orphan care programmes. Other initiatives have come from national level, such as the broad-based Anglican programme.

Of these many initiatives, very few faith-based organisations have responded to HIV with the aim of providing treatment. The most publicised and largest in scale is the Roman Catholic Church which, at the initiative of the SA Catholic Bishops Conference, is using PEPFAR funds to make ARVs available to over 2 000 people across the country through 24 individual programmes. These were originally set in place to meet the needs of the dying, and are already part of a Catholic Church local home based care and hospice network of projects. As it happens, they have no initiatives in the Eastern Cape, though there is an ARV site providing drugs at Umzimkulu in Southern KwaZulu Natal just north of the province. No other denominations are known to have provided ARVs except the Moravians through Masangane.

1.5 Aims of the report

1.5.1 Aim of the study:

To understand the role of the religious health assets of the Masangane integrated AIDS programme for public health as a model for a replicable response to HIV and AIDS.

1.5.2 Objectives

- To describe the Masangane programme in its context
- To assess the strengths and weaknesses of the initiative as viewed by multiple stakeholders
- To assess the impact of ARV treatment on health seekers (and their family/ community) and the other activities of the programme (education, treatment literacy and mentoring, home based care, orphans and vulnerable children)
- To identify the 'value added' by the involvement of a faith based community in a HIV and AIDS programme
- To understand the impact of plural health systems on health seeking behaviour and choices
- To evaluate the Masangane project as a faith based organisation's integrated response to HIV and AIDS in a rural area, and
- To assess the potential replicability and scaling up of the programme by other FBO/Is and community based organisations (CBOs).

1.6 Association with ARHAP and its research framework

1.6.1 Association with the ARHAP programme

The evaluation of the Masangane programme forms part of an international cross-disciplinary research initiative, with a multi-country collaborative structure, aimed at exploring the religious assets that are and can be mobilised to promote health. This is the African Religious Health Assets Programme (ARHAP),[24] which coined the term 'religious health assets' used throughout this report.

The primary assumption of the research undertaken by ARHAP is that religion in its own right is important to the health of individuals and communities. This basic assumption lies in direct contrast to the secularisation thesis that has ruled the social sciences and academia in general for so long.

The research on Masangane forms one of ARHAP's case studies, each designed to explore different aspects of initiatives, programmes and organisations that rest on faith-based or religious origins and structures. Other current studies that dove-tail with the Masangane work include research being carried out at district, regional and national level in Lesotho and Zambia as part of a World Health Organization contract to map religious health assets (quantitatively and qualitatively).[25]

Some of the concepts utilised in this study are drawn from work in ARHAP. Here we clarify some of them as relevant to understanding the focus of this study:

1.6.2 Religious health assets and agency

The ARHAP model builds on the assumption that human communities have assets of various kinds, not just material, that are critical to their capacity to survive and grow. These assets take effect through the agency of individuals and groups acting to deal with their situation.[26] It is simply wrong to make the assumption that poor people are 'not able to do'. In fact, they are always engaged in strategies and struggles for survival, adaptation and freedom. What is still unclear is how agency is formed around faith or through faith-forming entities and religious organisation as it impacts on health, that is, just how religious health assets come into play. The critical issue in this context is how this relates to the work of FBO/Is in engaging HIV.

The term 'religious health assets' (RHAs) is related to the more common use of the idea of 'faith-based organisations' or FBOs. It is not the same, however. It captures two theoretical points: That the interface between religion and health can be understood in terms of both tangible and intangible assets; and that an asset-based developmental logic is the most useful approach to understanding the way in which religious or faith based interventions and activities engage with matters of health. These notions may be defined as follows:

1.6.3 An asset-based logic and approach

'Assets' carry value and may be leveraged to create greater value. 'Needs', by contrast, imply that we are seeking to identify and overcome what is found to be lacking. 'Assets' points to human agency in the local context, and prompts us to identify what is already there to work with, rather than beginning with lack or need – concepts that emphasise outside agency, or even undermine local agency. External resources remain important, but policy, usually driven 'from above', and therefore inherently oriented toward prioritising external resources, might be better served by an approach that mobilises existing internal assets, strengths and capabilities.[27]

1.6.4 Tangible and intangible RHAs

Religion may be an asset in a variety of ways. One tangible example is missionary involvement in setting up hospitals and clinics in Africa that are still relied on today and in more rural parts of Africa

are often the only healthcare facilities available. Here we may speak of tangible religious health assets.

However, religion can also have more intangible effects that could have great potential for impacting health in Africa if they were more clearly understood. From volunteerism and education to behaviour change and social capital building – little is known for instance, about how religious involvement can engender hope or resilience. Yet, ARHAP believes that what often makes RHAs different from other health associations, institutions or structures lies in what is not visible – the volitional, motivational and mobilizing capacities that are rooted in vital affective and symbolic dimensions of religious faith, belief and behaviour. This is one key focus of the present study.

1.6.5 Religion

Exactly how to define religion, what to include and what not, is central to the academic study of religion, and multiple definitions are available. Here, in relation to our purposes, we take religion to include a wide variety of comprehensive systems of beliefs and practices held to be sacred, usually (but not always) issuing in religious institutions, groups or organisations that range from fluid to codified, popular to formal, centralised to decentralised, communal to institutional. In Africa, this includes particularly African traditional religions, Islam and Christianity.

Technically, this is a pragmatic definition of religion, therefore, rather than a substantive one. Its relevance and usefulness lies not in describing some essential object – a "thing" given in reality to which we attach the name religion – but rather in acting as a significant focusing lens for reflection on human identity and difference in relation to a field of relations that includes person, culture and society. It functions as an analytical category, in our case, to speak of certain forms of Christianity and of African traditional life as expressed by Masangane clients, which shape their self-understanding in general and their response to health interventions in particular.

Field researcher in interviewee's home

1.6.6 Faith-based organisations or initiatives (FBO/Is)

Religion or religious entities are not always construed in terms of visible institutions, let alone representative ones. In the field of health, faith-based interventions are often expressed through clearly defined, structured organisations. But equally often they are rather expressions of a movement or an informal but enduring group, which may at some point turn into an organisation, or may not do so. Hence, in order that such activities are not declared or treated as invisible, when they are clearly important to faith-based interventions in health, we have throughout this study preferred to use the double acronym "FBO/I" to encompass both faith-based organisations (FBOs) and faith-based initiatives (FBIs) that are not organisations in any standard sense.

Thus, it is the case that Masangane began as a faith-based initiative, in this case of a pastor (Rev Mgcoyi), a field worker (Ms Magoloza), and a fund-raiser and catalytic mediator (Rev Cochrane), with Rev Matinisi joining early on. Typical of what happens in the church, they simply began with an initiative that was a response to a pastoral crisis. Over time – for reasons that are obvious in the history we give of Masangane – and again typically, the success of this initiative required an increasingly formal organisational framework and a move away from a loose or ad hoc intervention. Yet Masangane was doing crucial work for a long time before this point was reached. It is this kind of reality that we wish to foreground in using the acronym FBO/I.

1.7 Methodology

1.7.1 Research design

A mixed method case study design was used. This involved key informant interviews, in depth interviews and participant observation and focus group discussions. While the study primarily made use of qualitative methods, a questionnaire was also developed and administered specifically to quantify and understand in detail the views and circumstances of the beneficiaries of the project.

1.7.2 Methods used

Tools

The range of instruments were prepared, piloted and revised before being used in the field.

The objectives of the study outlined in Sect 1.5.2 informed the development of the tools as did the most suitable research methods given the wide range of actors involved in Masangane activities. For each objective, there was careful assessment of who would be the appropriate sources of information and the best research methods to use.

The tools developed included:

Tools	*No.*	*Interviewees*
Key informant interviews, semi-structured	16	Funders, doctors, decision makers in Masangane as well as health seekers
Additional unstructured interviews	6	Traditional healers and family members of clients
Health seeker ("client") questionnaires	77	Includes 59 Masangane clients on ARVs and 18 not on ARVs
Focus groups	2	One support group in Matatiele and one in Shiloh
Participant observation		Support group meetings and households identified from the health seeker questionnaires

Table 1: Tools used in the Masangane evaluation study

Qualitative data: Key informant interviews, focus groups, participatory observation

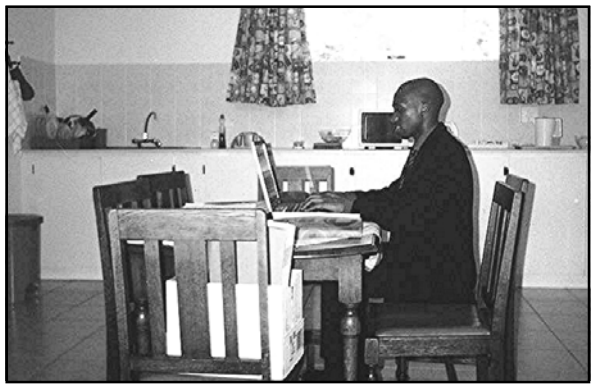
The primary source of data collected was from a range of qualitative instruments.

Data was collected making use of key informant interviews,[28] in depth interviews, participant observation, and focus groups.

We conducted 16 key informant semi-structured interviews and 6 additional unstructured interviews with traditional healers and family members of clients. These included all of the staff and key support personnel who instituted Masangane or maintain its work, some additional members of the management committee, two Moravian Bishops (one from the region and one from the Head Office of the church), the President of the Moravian church, the two medical doctors in private practice who are key to the treatment programme in Matatiele and Shiloh respectively, and the medical doctor from Médicín Sans Frontière (MSF) in Lusikisiki in the Eastern Cape, who has been a key advisor to the programme.

Most of the interviews and the participant observation were conducted by two Xhosa-speaking field workers, while other team members spent five days in the area. The handwritten records of the interviewers were typed up and the digitally recorded data was transcribed and translated. Together these sources provided a very rich electronic data set, which was analysed using *Atlas.ti* software. The coding approach was agreed upon by the research team and undertaken largely by those who undertook the data collection.

Besides the methods of collecting data noted above, we were given access to documentary records, annual reports, photographs and published pieces on Masangane, all of which were used to add to the description of the history and context of Masangane, and additional information on Masangane's work and operations. Photographs were also taken of key individuals and some of the religious practices and context of the study sites.



Field researcher working on data

Qualitative analysis software requires the mechanical task of loading and coding the data, which in turn required judgements about appropriate coding categories made by the researchers. While certain categories emerge from the data set itself, they are also governed in part by what the researchers are looking for. This is where the greatest leeway exists for different ways of viewing the data, even when using a standard coding list.

In our view, this is both a limitation and a strength of the data set: a limitation in that interpretive variations do occur; a strength in that it offers a rich set of interpretations, from different disciplinary traditions and frameworks of knowledge and accumulated wisdom, that display critical and necessary insights into the way in which a FBO/I such as Masangane works, and succeeds, in its integrated response to HIV and AIDS.

In short, the results are more likely to reflect the real complexity and ambiguities inherent in a programme such as Masangane and its context, even as it reflects the different perspectives one may bring to the data. At the same time, the controlled nature of the coding process, including ongoing discussions in the research team about codes and categories, allowed for a level of assurance about the results that ad hoc interpretations would not. Further, the multiple methods used in obtaining data helped to build up a complex picture for the research team, adding to the validity of the findings.

We provide for the readers of this report, in Appendix A, a critical perspective on the limitations, but also *the crucial value*, of qualitative research, as we have undertaken it in Masangane.

Quantitative data: Client survey

The client or health-seeker survey was carried out using a structured questionnaire, piloted initially at the Masiphumele clinic in Cape Town, and administered by ARHAP researchers in the field. Of some 100 clients at the time of the survey (88

on ART), 77 were interviewed (59 on ART, or 67%). Those included in the study were selected based on availability and thus do not represent a random sample however, given the finite population correction the standard errors are likely to be small. Give the small population size and the nature of the study, the data from the sample could be described as providing a reasonable reflection of the responses and experiences of Masangane clients.

The questionnaire[29] was developed to incorporate a number of themes. These included a socio-demographic profile of the respondents, self reported health and mental health, religious beliefs, health seeking behaviour and where appropriate experiences of using ARVs and Masangane's services.

Standard questions were used for as much of the data being collected as possible. These included validated measures for self reported health and mental health (using the WHO's SRQ20 questionnaire). New questions were developed for the ARHAP special areas of interest – notably those objectives of this study (see Sect 1.5.2) which explore the value added by Masangane's being a FBO, participants' plural health approaches and the impact of plural health systems on their health seeking behaviour. In the piloting of the whole questionnaire, responses to these questions were assessed very carefully with the added benefit of insights of specialists in religion and health seeking behaviour and anthropology who were part of both the piloting and pilot results assessment team.

Likewise the frequency data from the questionnaire was also the subject of much discussion by the research team, drawing on a multi disciplinary range of skills.

The data was entered into Excel and analysed using SPSS v13. Frequencies and cross tabulations were generated using SPSS.

1.7.3 Ethical issues

UCT Humanities Faculty Ethics Committee gave ethical approval for the study. The analysis of the quantitative and qualitative data has been undertaken and reported in a way to secure the confidentiality of the individuals interviewed through the use of code names. This applies to all individuals other than the key informants who need to be identified as they play specific roles, for example the doctors and nurses.

The core Masangane project team agreed to the study taking place. Before being interviewed, all participants were asked if they were willing to participate in the study and were given an Information sheet which provided further details of the study and contact details should they have required further information. The information sheet also reaffirmed that they were not obliged to participate and could have withdrawn at any stage. Interviewers were responsible for ensuring that consent forms were filled in and signed before any interview actually took place. Permission was also requested to make use of a digital voice recorder where appropriate.

The consent forms and interview sheets, transcripts as well as other data sources (e.g. electronic data files) have been stored safely in the Department of Religious Studies at the University of Cape Town.

1.7.4 Translation

The research was undertaken wherever possible in the first language of the interviewee. The focus groups were undertaken in isiXhosa and led by an isiXhosa first language speaker. Likewise, interviews of key informants and in-depth interviews also took place in the mother tongue of the participant except where the participants were comfortable to speak in English. Prior to piloting, the questionnaires were translated and back translated and were printed in English and isiXhosa.

Translations of transcripts were undertaken by the research team and in some cases by contracted researchers and checked for accuracy by a member of the research team.

1.7.5 Timing

The study largely took place during 2005. It has however also tracked the evolving changes which have taken place in Masangane during the period from May 2004 until February 2006. Following a preliminary workshop at Hout Bay in May 2004, the details of the research were planned at a follow up workshop in Morija in January 2005; and tools were developed during February and March with piloting and ethics approval following. Field work took place in April to August 2005. The data entry, translations and analysis took place over the subsequent 5 months. A preliminary presentation of the findings was presented at the ARHAP Colloquium in July 2005, at the 3rd SAHARA conference in Dakar, Senegal in October 2005 and to a DIFAEM workshop in Tûbingen, Germany, February 2006.

1.7.6 Different needs – different products

The research has multiple objectives ranging from academic to practical project evaluation. The multiple objectives will result in multiple products being generated in addition to this report. These include:

- Evaluation report of the project
- Report back of findings to key role players including the Masangane ARV programme and Vesper Society who are funders of both the programme and this evaluation.
- Presentation at the annual ARHAP Colloquium in Gauteng, July 2005
- At least two peer reviewed journal articles which

would provide the appropriate opportunity to be able to make a contribution to the theory ARHAP is exploring at the interface of public health and religion
- Circulation of lessons learned to other FBOs potentially involved in integrated HIV and AIDS programmes

Further outcomes were also envisaged: These included the presentation of the findings to inform the Eastern Cape public health and religious leaders, FBOs offering HIV/AIDS responses and national policy makers (see Chap 7: 7.6) as well as capacity development of the research team.

Given the above wide diversity of objectives and products, this report merely provides a very limited comment on the potential theoretical contribution of the findings. From preliminary assessment, the theoretical contribution of the research to the health and religion interface is exciting for the research team and will be explored further as part of ARHAP.

1.7.7 Research team

The team was co-led by Liz Thomas (MRC's Health and Development Research Group and the Centre for Health Policy of WITS School of Public Health) and Barbara Schmid (Religious Studies, UCT). Together they provided experience in the setting up of the study, management of field work, data analysis, report writing and project management. Additional support and writing, especially in the field of religious assets and analysis, was provided by Prof. James Cochrane. Two post-graduate students were responsible for the field work. They are Mr Malibongwe Gwele (Religious Studies, UCT), and Ms Rosemond Ngubo, (Anthropology, UCT). Further technical assistance in the field was provided by Kgetheng Dlamini and Mary Bennett of Johannesburg as well as Mary Baich of the Vesper Society, USA. Jill Olivier (ARHAP, UCT) assisted with proofreading and publication preparation and layout.

The study provided an opportunity for capacity development for the two senior students to obtain further field work and analysis experience under the supervision of the two co-leaders. The whole team also benefited from Atlas training.

1.7.8 Funding

Masangane as an ARV programme depends on multiple sources of international aid. Funding for this study was made available by one of the US funders of the Masangane ARV programme, the Vesper Society. An amount of USD 25 000 was allocated for this purpose. In addition, substantial contributions were made in kind by Religious Studies, UCT and MRC in the form of time of the research team.

Chapter 2

The Masangane ARV Treatment Programme – an Overview

2.1 Introduction

This chapter provides the reader with an overview of Masangane as a basis on which the ARV programme presented in the following chapters can be assessed. Masangane has been established around a number of objectives.

These and the background history of the organisation provide a quick sweep of the range of activities and indicate in part how they emerged in response to needs emanating from the community. The institutional context outlines the legal and management framework within which Masangane operates.

The roles of a number of key stakeholders and partners such as funders, doctors and churches are explained. The Chapter ends with an overview of the findings of the study regarding the profile of Masangane's beneficiaries, drawing from the quantitative study.

2.2 Aims and objectives

According to an undated Constitution, Masangane is an AIDS programme that has as its objectives:

(a) To render services to those infected and affected by HIV and AIDS as a service of compassion

(b) To address the needs of all ages irrespective of race, gender or culture

(c) To organise workshops on HIV and AIDS on all related issues including prevention, treatment, advocacy, counselling , home care and medication

(d) To engage in training of home carers, counsellors and similar skills to alleviate suffering, pain and poverty

(e) To motivate congregations, church and community organisations through the Moravian Church structures and its unions (women, men, youth, Sunday School).

(f) To strengthen family life, sound healthy living and offer support to needy persons or families

(g) To fundraise for its operations with the Department of Diaconics, the Provincial Board and the church officials of the Moravian Church.

When asked about the aims of the Masangane ART programme respondents almost unanimously answered: "To save lives – and to do so in rural areas". This reflects the two main concerns that the programme was initiated to address.

At a time when other churches were providing home based care to people dying of AIDS – most commonly in the poorest communities – and orphan support to those left behind, Masangane decided to follow another route.

Based on a theology seeking justice, especially for those on the margins of society, this meant to keep parents alive rather than care for their orphaned children, by providing them with ART. While the state was still reluctant to implement ART widely, and argued that poor, rural people would not be able to adhere to ART anyway, Masangane joined forces with MSF to demonstrate that it was possible, indeed, to run successful ART programmes in the rural Eastern Cape. This element of advocacy was a strong motivator for the ART programme of Masangane; once its aim of comprehensive state ART roll out has been achieved the programme will gradually refocus.

Mrs Magoloza talking to youth about HIV/AIDS

2.3 Background and history

The history of Masangane since its inception in 1996 shows the response of concerned Moravians to the needs of people infected and affected by HIV and AIDS. Not static in approach, the changing nature of the needs of the community over time led to the development of a number of responses. The objectives of the various versions its Constitution had over time show an evolving reaction to the epidemic, though Masangane, in common with FBO/Is generally had no constitution or strictly formal organisational structure for the first part of its existence.

It is not surprising that the initial call for the Moravian Church to respond to HIV and AIDS was through a Moravian church member, Sister Jabu Sikhonje who was also a matron at a regional TB hospital in Pietermaritzburg. She found increasing numbers of young women presenting at the hospital

with TB, but also showing signs of AIDS. At the time, 1996, the country was full of post 1994 hope and few people realised the extent of the HIV/AIDS epidemic.

Her concern was born of the reality that the young very sick people had not at that stage heard about AIDS, or about the route of transmission of HIV. Her appeal was to train people from her congregation to send to rural areas. An appeal to Rev Renate Cochrane, working in Cape Town, led to her committed, fruitful and ongoing involvement. Already involved in preparing Moravian seminarians in education and awareness programmes for their future AIDS ministry, Rev Cochrane was also able to bring administrative and fundraising resources to respond to the concern of Sister Jabu.

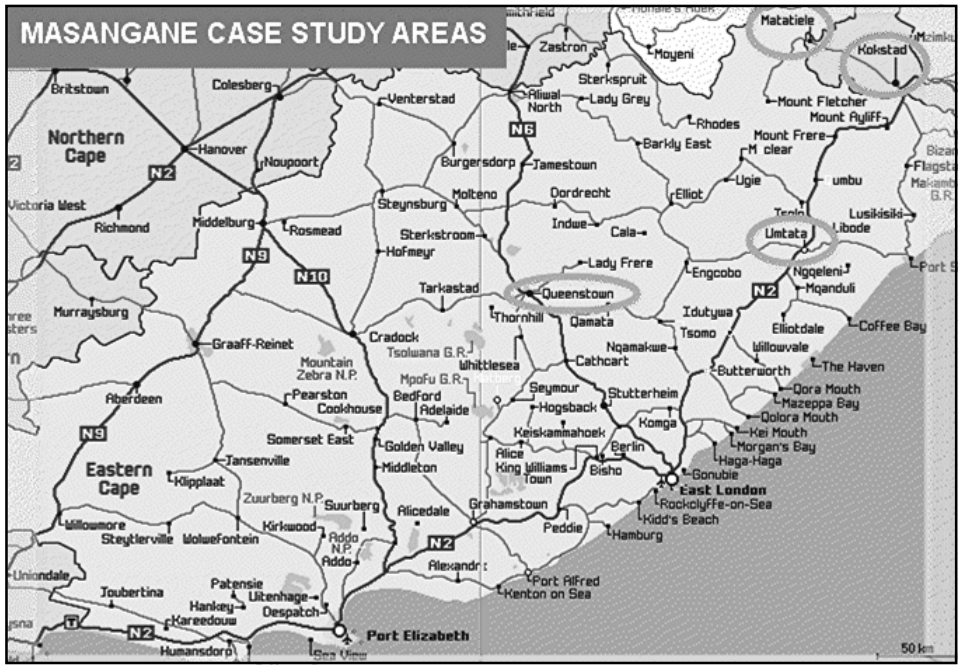
In 1996, Mama Magoloza, a Xhosa speaker, mother, wife and Sunday school teacher was trained and commissioned to work in the Maluti area of the Eastern Cape (Mt Fletcher). Providing education and raising awareness, she worked through church groups and bible studies to speak about HIV and AIDS, provide condoms, as well as serve the needs of those who were discouraged, sick, or dying.

The initiative grew with the appointment of Rev Ntombentsha Matinisi, (the first Xhosa woman pastor in the Moravian Church in South Africa) to a rural congregation in Rolweni, half a day's journey from Matatiele. Very poor access and lack of basic services in the area typify many other rural communities in South Africa. Her experience was that people were in denial about HIV, finding it hard to understand that one could be well even when HIV positive. As a result they unknowingly became part of the chain through which the virus was passed on.

Deep poverty as a result of increasing unemployment on the mines led to additional migration to cities, especially by men. Increasing levels of infection of men and women, illness, accusations of infidelity between partners, denial, and stigma in a context of poverty demanded skilled pastoral responses by ministers.

This was especially the case in a context in which illness is often understood to be a result of witchcraft. The death of a breadwinners resulted in increasing levels of poverty and hunger, as well as a decline in giving to the church.

One of the major issues Rev Matinisi noticed was the increasing numbers of orphans. Children orphaned are already stigmatised and it was clear that in order for this vulnerable group to continue schooling they needed to be provided with school uniforms and school fees. The orphan programme of Masangane emerged in 2001 to address this need.



Map of the Eastern Cape showing the areas in which Masangane works (circled)

While medical research has not as yet found a cure for AIDS, research findings around 2000 highlighted that mother to child transmission of HIV at birth could be prevented or the risk substantially reduced with the drug Nevirapine.

A pilot study in the Western Cape province of South Africa raised hopes about 'saving babies'. This became an important issue to people in the Mount Fletcher area where over 50% of pregnant mothers were found to be HIV positive.

While pregnant women were of concern, Masangane was also faced with increasing numbers of people who were ill, needing care, medical treatment and support.

The non-governmental organisation Médicíns Sans Frontières (MSF) began providing ART at a clinic in Khayelitsha, Cape Town. Once treatment provided by the NGO was shown to keep the virus under control, treatment became more and more sought after. Responding to the new opportunity, Rev Cochrane made contact with MSF and the first steps were taken towards the establishment of a Masangane ARV treatment programme under the guidance of Dr Herman Reuter of MSF.

2.4 Location/sites

Masangane serves people predominantly in the Eastern Cape region and has a number of sites from

which its ART programme operates. These are primarily Matatiele on the KwaZulu Natal border and Shiloh near Queenstown. An additional Masangane site is in Mthaha (at a minimal scale) while Renate Cochrane is based in Cape Town. One of the key obstacles to the efficient and effective running of the organisation is the remote locations of the sites and the distance between them. This exacerbates administrative and management co-ordination problems.

2.5 Masangane institutional context

2.5.1 Management

The management of Masangane according to the Constitution(s) takes place through the operation of a management committee with an executive. The Management Committee's membership and role has evolved over time according to the Constitution.

The Rev Fikile Mgcoyi, a retired school principal and ordained Moravian pastor, led Masangane from January 2002 until his death in 2005. Rev Renate Cochrane has held the portfolios of Communication, resources and fundraising and acts as project adviser. The Management Committee members are Rev Z. Tofile (acting chairperson), Rev N. Matinisi (treasurer), Mrs M Brukwe (secretary), Mr N Silinga and Mr T Mayekiso.[30]

The activities of the Masangane programme are described in numerous documents prepared for funders, reports for meetings of international bodies, as well as the annual workshop meeting of the Eastern and Western regions.

2.5.2 Legal status

During 2004/5 an application was made for the registration of Masangane as a non profit organisation (NPO). Once registered with this status, Masangane became a public benefit organisation (PBO). This is a requirement for all NGOs to be able to access state funding. The registration requirements necessitated that Masangane meet a range of administrative criteria.

2.5.3 Staffing

During the time of the research Masangane had a staff compliment of four. The staff members and respective roles at the time of the research are as follows.

Name	*Responsibility*	*Location*
Zoliswa Magwentshu	Treatment manager and co-ordinator	Matatiele
Nokhanyo Mswewu	Orphan co-ordinator	Matatiele
Pheliwe Potwana	Counsellor	Matatiele
Nomhle Xulubana	Administrator and acting co-ordinator	Shiloh

Table 2: Masangane employees

In addition, Masangane relies on the support of a number of volunteers. They have been paid a stipend of R800 a month to contribute towards the costs of transport etc., though changes were introduced to this system in 2006 (see Chap 3: 3.7).

2.5.4 Resources

Masangane has always relied entirely on funding from church bodies for the work that has been undertaken. The annual budget varies between the activities and has increased substantially over the past few years to cover the costs of ARV treatment. Masangane owns no buildings, barring a recently acquired container for use in Matatiele.

2.5.6 Masangane partnership with other actors

Masangane exists in part through the networks that sustain it, via the commitment of donors, doctors and people from the MSF, the TAC, and the Moravian church. The key partners who have ensured the ongoing successful operation of Masangane are introduced below. Their roles in the operation of Masangane as part of a network become visible in more detail in later sections and chapters.

One key element of the partnerships is the base from which Masangane operates at each of the sites. In Matatiele, Masangane uses a spare room in the surgery of Dr Nakin, a private practitioner working closely with the programme, and makes use of the local Moravian Church for support groups meetings. In Shiloh, the offices and meeting space are in a Moravian Mission owned house adjacent to the church.

Donors

From the outset, Masangane required externally sourced funds for the setting up and running of educational programmes; the need for fund raising grew as the proposed range of activities expanded, as described below (see Sect 2.6). Specific Church based funding was sought based on the networks of Rev Renate Cochrane in the USA and in Europe. Various agencies are responsible for funding specific activities. This makes reporting to funders onerous as each requires detailed information. For example, the orphan programme funders request regular updates on the circumstances of each of the orphans.

The donors who fund specific aspects of Masangane's work are:

Activity	*Funder*	*Location*
ARV	Vesper Society Difäm EMS Stuttgart	USA Germany Germany
Orphan Care	Difäm EMS Stuttgart Kassel Partnership Zeister Zendingsgenootschap Private donors	Germany Germany Germany Netherlands

Table 3: Funding sources

Doctors and MSF

Masangane began as an education and awareness programme, developed under the guidance of the Treatment Action Campaign (TAC), and housed within the Moravian congregations. In time this expanded to orphan support, and a "care for the sick" programme. Once it emerged that Masangane could possibly provide ARV treatment to those who had AIDS, partnerships with private doctors in Queenstown, Whittlesea and Matatiele developed under the auspices of the MSF. This specialist medical treatment is key to the ability of Masangane to provide ART. MSF, through Dr Herman Reuter who is based in Lusikisiki, continues to provide ongoing medical advice to those administering ARV treatment.

Moravian Church

The initiative of Masangane came from within the Moravian Church and it has remained an activity closely associated with this denomination. The relationship between Masangane and the Moravian Church at a local congregational level in the Eastern Cape is characterised as reasonably good, with several of the clergy and congregants very supportive of Masangane. The relationship between Masangane and the national structures of the Moravian church is more complex (See Chap 3: 3.13). The majority of those involved and benefiting from the project are not members of the Moravian Church.

Masangane – an island of hope

While Masangane could easily be described as an island of *hope*, it has on the other hand largely remained an *island* in that it developed and operated largely alone. The relationship with the TAC and MSF provided links with national level initiatives. On the other hand, links with local HIV/AIDS initiatives and church initiatives seemed to be less well developed. Further, the local public health service in Shiloh has played an important and supportive role whereas in Matatiele, the local district clinic and hospital had very limited or no awareness of Masangane.

2.6 Current range of activity

Masangane offers a wide, comprehensive range of HIV and AIDS related services. These are discussed in some detail in the various sections of the report; here we provide a brief overview:

Prevention

In its approach to HIV awareness Masangane follows the TAC model; most of its treatment educators have received their training at TAC workshops. The programmes are offered in the communities where the ART sites are located, and beyond that have been taken up throughout the Moravian congregations (See Chap 4: 4.7). A centre for voluntary counselling and testing has recently been set up in Matatiele and has become a popular venue for HIV testing.

Masangane provides clients with ARVs and condoms

Care and support

As mentioned above in Section 2.3, Masangane did not intend becoming a programme offering home based care for the dying; it does however work closely with the Noncedo home based care programme in Matatiele. Individual care is provided in the form of counselling and spiritual support, as well as in the buddy system which allocates a treatment supporter to each client (see Chap 3: 3.3) Further, the support groups offer clients fellowship and support in various ways. In Shiloh different groups are set up in the various villages and include both ARV users and others; in Matatiele clients all come to the centrally-run groups, one for those on ARVs and another for those not yet on ARVs. The non-ARV group offers HIV education, and prepares clients for ART through treatment literacy. The groups for ARV users extend the latter, and offer the opportunity to deal with issues arising out of the ART (see Chap 3: 3.6). Care and support of orphans was the first service initiated by Masangane; it is described in the following section.

Treatment

Here the range of services includes offering extensive treatment literacy, support through the

buddy system, monthly supplies of ARVs as well as medical advice and treatment of opportunistic infections. One of the special characteristics is that, in Masangane, the bio-medical treatment is located in a spiritual context and linked to Christian values and rituals (See Chap 5: 5.4).

2.7 Beneficiary selection: Criteria and process

2.7.1 For orphans

Children of school going age are supported; the programme provides them with school fees and school uniforms.[31] In order to qualify for the Masangane Orphan Support Programme children have to submit the death certificates of both parents.[32]

Selection of actual beneficiaries is done by the coordinator of the programme, in consultation with the chairperson. The amount of money in the orphan fund determines how many children can be supported.[33] There is a long waiting list.[34]

Because of the limited funds available, the programme is not advertised. Masangane volunteers who are familiar with the situation of local families identify children in need of orphan support. Since these volunteers are Moravians, often the first to receive support are from their denomination, but the programme is not exclusively for Moravian children.[35]

2.7.2 For ART

Selection for the ART programme is done by a committee which includes the treatment coordinator. Patient information is submitted in coded form, without revealing their identity.[36]

Selection criteria include:

- A CD4 count of less than 200; or an AIDS defining illness.[37]
- Personal commitment of the client to treatment. To assess this the medical history and adherence in other treatment programmes is evaluated during a home visit.[38]
- Family situation, age, number of dependants.[39]
- Only one person from any household will be supported.[40]
- Membership of a support group. The non-ARV support groups are intended as preparation for treatment of those who do not yet fulfil the clinical criteria.[41]
- Disclosure of HIV status to at least one person; this person will normally act as treatment supporter to the patient.[42]

The criteria are applied without undue rigidity and with great understanding for the conditions in which potential clients live, as this quote regarding the adherence criterion illustrates:

> *Like some other people have defaulted on TB medication, but we have to go beyond that, and go to the bottom of the problem. Why did this person default the medication? Because someone told me she defaulted TB medication, because there was no food to eat, and you can never take the TB medication on an empty stomach.*[43]

This Masangane programme, too, is not intended for the benefit of Moravians only or even primarily.[44] As with the orphan programme there is a long waiting list of potential clients. One of the Masangane doctors states that on average three people ask to be admitted daily.[45] This in spite of the fact that a government ART programme is now operating in the area. Masangane aims to regularly refer its clients – once they are established on the treatment – to these facilities in order to admit new ones onto ART.[46]

2.8 Characteristics of the beneficiaries

This section draws from the questionnaire administered to the beneficiaries of the Masangane ARV programme. It would be useful to compare the profile of the beneficiaries of Masangane with those on ARVs provided by the State. At this stage information on the profile of those on public health provided ARVs nationally is very limited. It is proposed that this be the subject of a further study.

The findings below provide an overview of the socio-demographic profile of the beneficiaries and their households as well as a number of facets of their physical and emotional health. The study also provides data on the impact of chronic illness and death on households. This study goes further by exploring the impact of faith and religious activities on well-being and through this data and the qualitative findings, provides new insights into the interface between HIV status, being on ARV treatment and faith/religious activities.

2.8.1 Socio-demographic profile of beneficiaries

Those on Masangane ARVs were largely middle aged, literate yet out of work people who had lived in the area for more than five years. Two thirds of the beneficiaries were women.

The mean age of those on ARVs was 38 years. A little over two thirds of those on ARVs were women (68%), and this group had a slightly lower mean age than the males (36 years and 39 years respectively).

Half (51%) of those on ARVs were the heads of households, one third (33%) daughters/ sons and nearly ten percent the spouse/or partner of the head of household. One in twenty (5%) were a father or mother of the head of household.

Of the group, 36.5% reported that they were married. This differed between the sexes with 32% of the women being married and 44% of the men. Overall, 64% had a partner who was alive. This varied slightly with 70.6% of the men having a partner who was alive compared to the women,

62.5% of whom had a living partner.

Over 90% of the sample were considered to be functionally literate, with over three quarters (80%) having achieved at least some senior school education. Nearly ten percent (9%) pf those on ARVs had some post school qualification.

Nearly two thirds identified themselves as unemployed and looking for work, with 13% working and nearly one in ten doing housework. One in twenty (5.6%) identified themselves as scholars. Two thirds of those getting ARVs were receiving grants. The grants were almost exclusively for disability.

Nearly two thirds (65%) had lived in the area for more than five years and the rest had resided in the area for between one and five years. Only 3.5% had moved into the area in the preceding year.

2.8.2 Household characteristics

Those on ARVs were from households with a mean size of 4.3 people. At least a third of the households could be classified as very overcrowded – the households living in one sleeping room with a mean of 3.6 people in this sleeping room.

The 59 people on ARVs from Masangane who were interviewed belonged to households where the mean household size was 4.3. While the majority of households had 3, 4 or 5 people in them, one in five households (19%) had more than 5 people in them and 16%, fewer than three people.

Three quarters of those of ARVs lived in brick houses and the balance, in traditional structures. The mean household size did not differ between brick and traditional structures.

Although three quarters of the houses were built of bricks, half of all beneficiaries' households relied on water from streams or shared standpipes in the vicinity. Electricity is available to over two thirds of the households but is only used by a third for cooking for cost reasons. Women and girl children were most often responsible for collecting fuel and water. The high HIV prevalence in the area and the sickness in the homes will put pressure on the ability of these households to perform the most basic of daily tasks.

Half the households had access to reticulated water in their yard, while one in five (20%) relied on water from streams (unimproved sources). Thirty percent shared access to piped water with surrounding households. Overall about 1 in 12 shared a standpipe with more than 5 other households. For those on ARVs, with compromised immune systems potentially poor quality water for domestic use may well be a problem.

Seven out of ten households had access to electricity, almost all of whom use it for lighting. However (most probably) for cost reasons, only a third use this source of energy for cooking purposes. The majority used cheaper sources of fuel for cooking; 13.6% relied on wood and dung for this purpose.

The households vary considerably in asset ownership – an indicator of wealth. While twenty percent of households do not even own a radio (one of the most basic of assets assessed), nearly half own a fridge and one in eleven own a car.

2.8.3 Health of beneficiaries

Respondents were asked to report on their health and their emotional health using a Likert scale of self rated health and a validated WHO instrument for emotional health (see methods section).

Despite their HIV status and compromised immune system necessitating them to be on ARVs, 12% identified their health as excellent with the greatest majority indicating that it was fair (48.3%) or good (27.6%). A further 12% identified their health as poor. There was a gender spit in self rated health. Two thirds of the men identified their health as good or excellent in contrast to the women where 72.5% identified their health as fair or poor. Overall, 15% of the women and 5.6% of the men identified their health as poor. Self-rated health was not associated with age.

There was a strong statistical relationship between their self-assessed health status and emotional health when measured by the SRQ20.

2.8.4 Impact of chronic illness on the household

Households where someone was regularly seeking treatment

Nearly one in five (18%) of households had others in their households regularly seeking treatment for their health. The mean age of the other person was 34 years of age.

Households where someone was chronically sick

In 55% of the households someone else in the household had been ill for a long time, an indication of a chronic illness. In 9% of the households, there was more than one person classified as chronically ill in addition to the respondent (the person being interviewed) who was selected as being on ARVs.

The mean age of those who were chronically sick was 42.5 years, skewed by three aged over 70 years (one at 98). Indicative of AIDS is the fact that two thirds (over 65%) of those chronically sick were under 40 years of age.

57% of those who were chronically ill in the households were female.

Death in the household during the previous year

Thirteen of the households had experienced a death in the previous year. This amounted to 36% or more

than one death in every three households. The mean age of those who had died (fifteen people in all) was 48 years. However, the mean age was skewed by a third of those dying being over sixty. Indicative of AIDS is the fact that over half of the people who died were under forty years of age, all in the prime of their potential life as parents and income generators for their dependents.

2.8.5 *Impact of death in household on respondent's emotional health*

While the mean mental health (SRQ) score across the respondents was 6.9 (out of a maximum of 20), there was a stark contrast in the emotional health (as indicated by the SRQ score) between beneficiaries who had not had a death in the household when compared to those who had one or more deaths in the previous year. This was statistically associated.

The one third who could be identified as being vulnerable emotionally included all those who had had one or more deaths in the household in the previous year. This raises a number of questions:

- To what extent are churches helping people to grieve?
- Do the support groups perform this function?
- To what extent does grieving impact on the person's ability to respond positively to ARV treatment?

2.8.6 *Faith and religious activities – impact on well-being*

When asked about the role that their religion/faith (*inkolo*) played in their well-being (*impilo*), over two thirds (70%) reported that it played a major role. It was somewhat important for one in five, (20.3%) and of very little importance for one in 12 (8.5%).

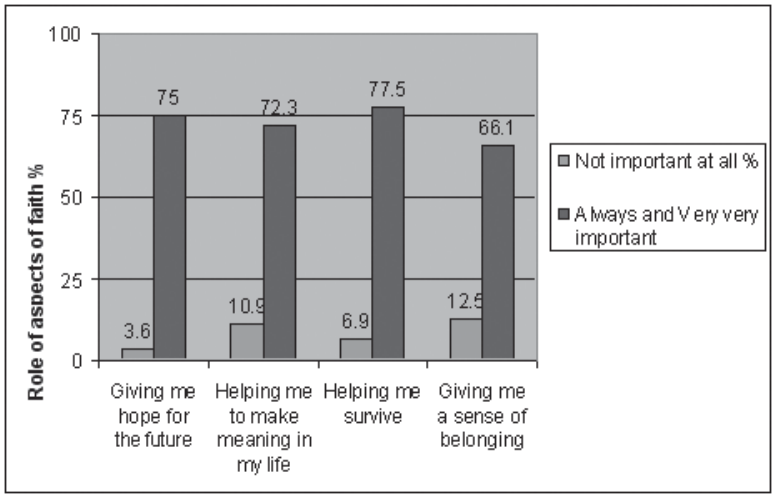


Figure 3: The role of faith in well-being. Note that the darker bars show 2 separate categories, cf. Faith is Always important *and Faith is* Very, very important, *collapsed into 1 with percentages added together.*

When asked how important their religion/faith was for them in a range of contexts, notable findings are as shown in Table 4 and 5.

For three quarters of the beneficiaries of ARVs, religion was *Always important* or *Very very important* in giving them hope for the future,[47] providing meaning (particularly in orienting one's life purposively), and helping them to survive.[48]

Although religion played an obviously key positive role (See Table 4) offering also a sense of meaning and belonging, it did not seem to raise taboos, limit carrying out some rituals or make those on ARVs feel uncomfortable about their sexuality to a significant degree for two thirds of the beneficiaries.

Those on ARVs were asked to respond to a number of questions relating to what religious/faith activities were important for their well-being.

Although there was no requirement that those accepted on to the Masangane treatment programme belong to any faith community, the beneficiaries were on the whole church attending

Role of faith in:	*Not important at all %*	*Always and Very very important %*
Giving me hope for the future	3.6	75.0
Helping me to make meaning in my life	10.9	72.3
Helping me survive	6.9	77.5
Giving me a sense of belonging	12.5	66.1

Table 4: Importance of faith in coping. Note that the last column shows 2 separate categories, cf. Faith is Always important *and Faith is* Very, very important, *collapsed into 1 with results added together.*

Role of faith in:	*Not important at all %*	*Not important at all or Sometimes important %*	*Very very important %*
Making me feel uncomfortable about my sexuality	42.6	66.0	7.5
Stopping me from carrying out some rituals	55.4	69.4	14.0
Raising taboos	58.0	70.0	12.0

Table 5: Importance of faith (negative influence). Note that percentages in Column 2 are included in the totals given in the next column.

(88%), making use of personal prayer (86.4%) and the bible (66.4%). Of those interviewed, four out of five (79.6%) reported using the support groups set up by Masangane. Half (49.2%) of the respondents were members of the long-established African Manyano Christian women's movement themselves.

Indicating a mix of religious practices, half (56%) said they sought ancestral guidance, and just under a third (29%) reporting the use of *muti* (traditional medicines) themselves. Traditional rituals were used by nearly a two thirds of the respondents (62.7%) and a quarter (25.5%) consulted *sangomas* (herbalists and diviners) while 15.3% said that they were sangomas themselves. These findings highlight the simultaneous use of multiple healing models, a topic discussed in Chapter 6.

2.8.7 Experience of ARVs

Disclosure of HIV status

Almost all the respondents said that they had told someone that they are HIV positive, and in the majority of cases (over 80% of the time) they had had a supportive response from the person to whom they disclosed. The most common people to whom disclosure had been made were a partner (80%), a parent (60%), a sibling (nearly 50%), another family member (46%) and a neighbour (44%). Parents and siblings were most supportive (in over 94% of the cases), followed by other family members and neighbours (over 88%) were supportive. Beneficiaries had found that one fifth of partners were not supportive when they had disclosed their status to them.

Two groups the respondents seldom confided in were counsellors/religious leaders (a surprise) and co-workers/employers. Only 25,4% and 16.9% of beneficiaries had confided in such people respectively, but those who did, reported an overwhelmingly positive response (in over 90% of cases).

Given the important role that respondents explained that religion played in their lives, it was surprising to find so little use of counsellors/ religious leaders in disclosure of HIV status. This is an issue that should be explored further but might be indicative of the way in which Masangane staff were not referred to specifically by respondents as counsellors.

Source and type of ARVs

Of those interviewed, 51 out of 59 reported getting their ARVs via Masangane and Zoliswa, three from Kokstad and four from the Sada clinic. One of Dr Nel's patients in Queenstown was also included. 17% said that they had been on ARVs before. The vast majority of recipients were on a twice a day regimen (81.4%), most of the rest on a three times a day regimen

Use of reminders to take drugs

The respondents were asked to indicate the relative importance of various reminders that could be used to help them take their medication. In addition to the obvious support and reminding by family and friends, other less likely aspects were also reported. These include the ancestors, God and church as factors that were very important in a number of cases.

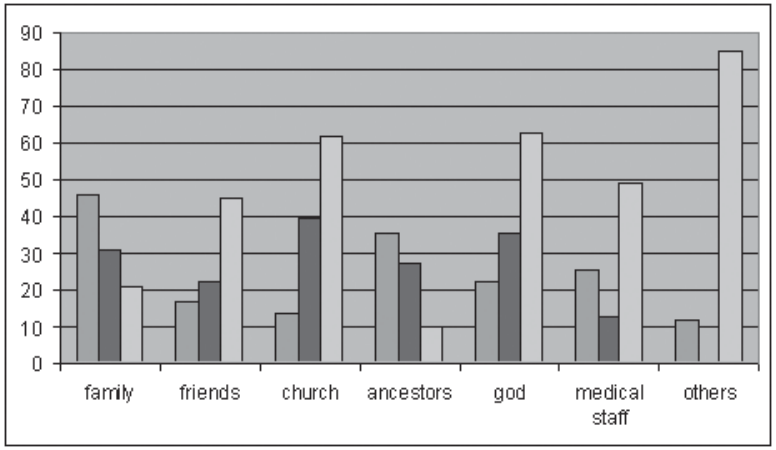


Figure 4: Relative importance of factors for adherence
Legend: Bar 1: Very, very important*; Bar 2:* Always important *and* Very, very important – *the 2 categories combined. Bar 3:* Not at all important.

2.9 Conclusion

Masangane has evolved in response to the emerging needs at community level. A series of important partnerships have developed which have facilitated and supported the expanding response to the impact of HIV and AIDS in a rural context.

The agency of key individuals has provided links to overseas faith based funding agencies that have supported Masangane's work over a number of years.

Masangane shows evidence of local community connections, partnerships with local private doctors and support from national agencies for treatment guidelines. The particular personal qualities and agency of the treatment manager and co-ordinator, previous chairperson and fundraiser has guided the organisation over time and ensured stability.

Common commitment by the core management team to the delivery of ARVs is underpinned by Christian values, such as respect for the dignity of all, as well as the determination to achieve the

maximum return on the limited funds available to the programme. This approach has at times been in conflict with the views of others associated with Masangane.

Masangane serves those in need and not only Moravians. The socio-demographic profile of the ARV clients shows that the majority are women, half of them being heads of households. As with others in the region, nearly two thirds are unemployed, though educated.

In addition to the respondent on ARVs, over half of the households included another person who had been ill for a long time. A third of the households could be described as overcrowded, a problem especially regarding the need for privacy for those with a chronic illness. In a fifth of the households the respondents are located in more remote settings, making them reliant on collecting water from streams and rivers. This will impact on the ease of providing home based care in this environment.

More than a third of the households had had a death in the household during the past year. The respondents living in these households were more emotionally vulnerable at the time of the survey than others who had not had a death in the household during the previous year.

Faith was reported as playing a major role in the well-being of over two thirds of the respondents and was found to offer a sense of meaning and belonging. The respondents used a range of religious practices.

In sum, Masangane serves the needs of the poorest of the poor and its beneficiaries would seem to represent the typical profile of rural people: unemployed, poor and predominantly women. From the quantitative data, the impact of HIV and AIDS is evident. Deaths and chronic illness in members of the households impact on the well-being of the household. It is likely that many of the women receiving treatment would themselves have cared for household members who are chronically ill or have died. Not surprisingly, depression was found in many women and this was linked to their own self rated health – reported as being fair or poor for nearly three quarters of the women.

It is within this context that the role of faith needs to be understood. Religion was reported as playing a major role in the well-being of over two thirds of the respondents as it offered them hope for the future, helped them to survive as well as giving meaning. Masangane responds to the needs of the community in what it does (providing treatment, care and support) as well as how these services are provided. The next Chapter assesses Masangane from the perspective of the various stakeholders.

Chapter 3

Assessment of Masangane as Viewed by Multiple Stakeholders

3.1 Introduction

A number of stakeholder groups were identified and interviewed in order to assess the work of Masangane:

Management: Masangane staff members and the management committee

- Comments from this group ranged widely across all topics reported below

Church leaders: Denominational leadership not directly involved with Masangane

- Concerns mainly organisational issues and the role of individual players

Health seekers: Users or "clients" of Masangane services,[49] including some volunteers

- Concerns mostly the services provided by Masangane

Donors: Representatives of organisations supporting Masangane financially

- Mainly concerned with organisational matters

Health providers: Doctors working with the project – directly or in an advisory capacity – and staff at local clinics

- Mostly on the modus operandi of the project

The bulk of comments of the stakeholders of all groups concerned strengths (with some weaknesses) regarding the activities offered by Masangane and the specific way these are approached and implemented.

A lesser number of comments dealt with management and financial issues within Masangane, mostly raised by informants from the church leadership group, and management and donor groups. Several respondents also commented on the key role played by specific individuals within the project, and on ties to other groups.

The main themes that emerge around anti-retroviral treatment (ART) have to do with provision and access, follow-up and monitoring, adherence, the role of support groups, and the use of volunteers and treatment assistants. Factors that impact positively on ART services include Masangane's comprehensive response to HIV and AIDS, and the role of core actors, of Christian values, and of ties to others beyond Masangane. Factors that tend to generate difficulties in Masangane, as expressed by stakeholders, have to do with management procedures, its relationship to its host Moravian Church, and the financial limitations.

3.2 Providing ART in rural areas

> *In the rural areas the AIDS thing is heavy and many more people will die if nothing is done about rural areas.*[50]

It is clear that working in rural areas poses challenges to the work of Masangane. Conditions in rural areas in terms of knowledge about HIV, lack of employment opportunities and educational programmes constrain the work.[51]

Participants in the Matatiele Focus Group make a distinction between the situation in the town itself – where the Masangane office is situated – and that in "rural areas" where there is as yet little knowledge or understanding of HIV, and it is consequently more difficult to disclose one's status because "you can find yourself with many enemies when you talk about your virus."[52] The difference is ascribed to HIV workshops taking place in Matatiele and "because they are living with many people who have AIDS and they know them and these people are even able to disclose."[53]

In rural areas there are also practical constraints making it difficult to reach people; concerns around these were raised by staff members affected by them. Clients live far from the project site, and often the roads are in poor condition. Masangane did not, until quite recently, have its own vehicles for conducting home visits. When public transport is available it often does not reach the homes to be visited but requires some, at times substantial, distance to be walked.[54] This makes home visits not only time-consuming; but also expensive and dangerous.

One of the church leaders mentioned that in rural areas where tradition is still strong, difficulties result from the reality of indigenous traditional patterns of relationship and authority and the way they limit the ability to communicate freely on topics like HIV and AIDS that touch on taboos.[55] In this context the women and the few young men who carry Masangane's message into communities would have little chance of being heard by older men. Here the role of Rev Mgcoyi, a traditional chief, was invaluable in opening up issues and challenging such taboos.[56]

Yet it is here in the rural areas that Masangane started its pioneering work, "providing education where people knew nothing or were in denial about HIV/AIDS",[57] bringing ART services within reach of people living far from even the most basic bio-medical services, and certainly not within reach of any means of accessing ART; and starting this service in an era when the South African government was not yet prepared to roll-out ART. The fact that they have managed to work in these areas and under these conditions, while addressing a very real need, is considered a special achievement, and it is mentioned as such, with pride, by stakeholders from the management and church leader groups.

So, I would say, that could be the difference, and the fact that Masangane reaches into difficult places where government and other organisations can't reach in rural villages, because many things happen in towns and rural people are neglected. So Masangane gets right to them.[61]

3.3 Masangane is quick to get people on ART

One of the real strengths of Masangane in the eyes of all stakeholder groups is the fact that their modus operandi allows them to get patients started on ART in a much shorter period than the government service. While government providers have to follow a protocol that offers, and subsequently tests people on, treatment literacy before admission to the ART programme, Masangane admits those with very low CD4 counts immediately.

In our area people know that Masangane is providing treatment, unlike in the Hospital where you have to be on a waiting list for six months. You'll hear people say: Why don't you try Masangane? They can help you so that you can get treatment and so that you can heal quickly. If you gonna wait for the government you will wait for a long time and maybe by the time you get it, you'll be dead.[62]

Treatment literacy is seen as a crucial element of the Masangane programme, but not as a pre-condition for being admitted into ART. In government programmes, however, patients have to go through a 6 week training period and take a test before being put on treatment – and should they fail the test the procedure has to be repeated.[63] Patients who are very ill may die during this period. Masangane's procedure for critically ill patients is to train a treatment supporter and initiate treatment immediately.

Through this approach many lives have been saved. As soon as the clients are well enough they become part of the support group and are taught all they need to know to cope with the treatment and to remain adherent.[64]

3.4 Effective follow-up and monitoring

Informants from the church leader and management groups pointed out that Masangane provides valuable follow-up services to its ART clients. These services include "[h]ome visit and counselling people and educating and even motivating them",[65] making sure that clients take the medication, and do it correctly. The follow-up is available even to those clients who have been transferred to government hospitals for ART. This is one of the important elements of the Masangane programme appealing to potential clients and making it more effective than that offered in the public health service.

RURAL HEALTH SERVICES

Rural communities (defined as living farms, commercial farms, small settlements, rural villages and areas outside of towns and cities) '...bear the greatest burden of disease, mainly because rural people bear the greatest burden of poverty'.[58] These communities are some of the worst off when it comes to accessing health services. In addition to problems with facilities, access to facilities is one of the major challenges. Further, the retention of professional staff in rural areas is another key concern at a national level.[59]

In a recent study by HST reviewing the key challenges facing Ukhahlamba (a health district located immediately to the south of Matatiele), inter alia two challenges were noted:

1. the burnout of professional nurses who are working alone in clinics in deep rural areas and, as a related issue, the recruitment and retention of professional nurses in such clinics;

2. the high cost of providing mobile health services, '... but (this service) cannot be done away with because it addresses problems in access to healthcare'.

One of the key issues identified was the need to '... ensure access to ARVs to far flung underdeveloped and poverty struck rural communities'.[60]

With the clinic, quality is poor. There is no quality. OK, there is in the sense that you will always get your treatment, just as much as you always get it with Masangane, but I mean, you know what is the basis of this: It is the follow up; it is the support groups. The support groups and follow up. That is the strength of Masangane.[66]

3.5 Very high levels of adherence

Masangane clients have achieved excellent treatment adherence; in the views of respondents from management this is the result of the good monitoring system that has been put in place. There are differences, though, between the three main sites: In Shiloh the only 'failures' are two men who reverted to drinking and died, while in Matatiele the adherence rate is about 90%. In Mthatha, on the other hand, three of Masangane's five clients have died after interrupting or stopping their ART – a clear indication of the importance of support groups and structures for adherence.[67]

Dr Richardson, Masangane doctor

The high level of adherence overall is related to the thorough treatment literacy provided to clients, the support groups and the follow-up by treatment supporters who visit clients in their homes to monitor and support their adherence.[68]

One of the doctors working with the programme reports:

I'm just looking at my list of patients and I can't see one that's defaulting…The main strength is the infrastructure that is supporting the patients…they do manage to keep the patients adherent.[69]

3.6 Support groups

The weekly support groups Masangane has established for its clients are crucial for achieving adherence and delivering follow-up, as respondents from the management and health seeker groups claim.

Through these groups the programme offers valuable services including treatment literacy training, follow-up visits to clients and adherence support. This is done through the buddy system which connects new members to a 'buddy' who has been on ART for some time and has the knowledge and experience to offer support to the newcomer.[70] The groups offer fora for discussing any problems clients face in their life with AIDS, for sharing successes, for belonging, and for engaging in various forms of income-generating activities.[71]

Dr Nakin, Masangane doctor

There are difficulties in this area as well, though: For many of the clients regular weekly attendance of the support groups is not possible as they cannot afford the transport cost.[72]

The intensive support that is available to support group members is a major strength of the project. Stakeholders in the health provider group feel that, while other ART programmes also offer support groups, they tend to depend on people showing up, while Masangane has a system that follows up on those who do not come and offers them whatever support is needed at that time.[73] It seems to us that the personal commitment to individuals, the intense follow-up and support they receive, is one area where small NGOs offering ART have a comparative advantage to big public health programmes. This is supported by anecdotal evidence that clients of the Masangane programme who have been referred to the public health facility in Kokstad lose touch with their support group and, as a result, end up less compliant, as well as being more easily talked into trying other (traditional) treatments. Two people, it is claimed, have recently died as a result.[74]

3.7 Extensive use of volunteers and treatment assistants

Volunteers are actually the backbone of the project.[75]

The fact that Masangane can offer so many services, including regular follow-up and monitoring, is largely due to the fact that the bulk of work is done by volunteers. Volunteers are recruited into the work of Masangane from a wide range of backgrounds, including religious affiliations other than Moravian. Most of the volunteers have come to Masangane as clients in the first place. They are PLWAs on ART, they come from poor rural areas – and because of that they understand the clients' needs and conditions and have a deep commitment to help them.[76]

For some church leader respondents, however, the reliance on volunteers, most of whom are themselves poor, is seen as a weakness of the

programme. The small monthly allowance is not sufficient for them to be able to do their work effectively.[77] The following quote illustrates this dilemma:

> *I asked to be assisted with money because I am using a lot of money out of my pocket because I have to visit a lot of places and I was the only volunteer here at Mt Fletcher. You see those mountains, I must go there. Just imagine if I have to take R60 to go there and R60 to come back from the R800 that I get as stipend from Masangane. I also need money to grow and establish my own family and I do not work.*[78]

It has been Masangane's experience that one cannot sustainably use volunteers who are unemployed and have no income.

At the end of 2005, therefore, Masangane decided to change to a modus operandi. Formerly they used unemployed volunteers, paying them a rather large stipend to cover travel and expenses; now they offer part-time coordinators who have other jobs (e.g. a parish pastor) an R800 per month allowance, employ six treatment assistants at R1000 per month, and previously unemployed care workers on a sliding scale (R500 per month for the first three months, R800 for a further nine months, and after one year, R1000 per month). In addition, teachers who work as volunteers get a R200 allowance to cover cell phone airtime and travel.[79]

3.8 Wide range of activities

In addition to making available ART and offering follow-up to PLWAs, Masangane offers a further range of comprehensive services, which is regarded as a strength.

Counselling

Proper counselling of clients is essential, from preparing them for HIV testing to accompanying them though the ups and downs of treatment. The reality generally seems to be that "[p]eople do not have time for counselling, either clients or organisations they don't have time for that; even the private doctors have no time; even the hospitals and clinics have no time for counselling."[80]

Masangane, however, is committed to offering counselling, and it has trained some of its volunteers as counsellors while maintaining an 'open door' policy to those who require any support.

As a result of its development in relationship to TAC and MSF, the counselling is directed to HIV awareness and human rights. The need for pastoral counselling is possibly not met sufficiently.[81]

A Masangane carer with an orphan

Training

The Masangane staff members and many of its volunteers receive ongoing training in AIDS awareness and treatment. In a rural area where educational opportunities are limited, this service does not only raise the level of AIDS awareness in the communities, but also offers opportunities to PLWAs to earn an income and possibly for further training.[82]

Support of orphans

Masangane started as an orphan support project and is continuing this aspect of its work. For parents in the ART programme it is comforting to know that their children will be cared for should they die. There is, however, also anxiety around this. One support group member – who is not on ART as her CD4 count is still too high – was not sure how and if her children would benefit from Masangane in the event of her death, since she had no proof of "membership" of the group.[83]

Others

Other services or activities mentioned as important by various stakeholders include:

- HIV/AIDS education and awareness
- HIV testing
- making sure that clients understand their sero-status
- case finding and management
- monitoring
- providing access to medical advice and laboratory tests (CD4 count and viral load)
- supporting clients through prayer and family therapy.

3.9 People still die

Against this appreciation of the work that Masangane is doing successfully under trying conditions, there is a concern that what they are doing is still not enough. Many people in need of the services offered by Masangane have not been reached. "People are still dying. I think this is our weakness…people are still stigmatising HIV/AIDS."[84]

This concern is discussed further in the concluding chapter where the report discusses replicability and scaling up.

3.10 Huge role of core actors

Some of the individuals involved in Masangane play a huge role in the project. Key informants from all stakeholder groups acknowledged the crucial

contribution each one of these players make to the project.

Renate Cochrane with treatment educator

- *Rev. Renate Cochrane*

The first to be mentioned is Rev Renate Cochrane, who in part initiated the project and still assists as fund-raiser. Respondents from all groups acknowledge her passion for reaching out to people living with AIDS, her willingness to listen to them and their needs, and her access to potential funders through her connections in Germany. A number of them state clearly that without Renate Cochrane there would be no Masangane. The church leaders raise this utter dependence of the project on one person as a concern, calling for the training of a successor to take over at least some of her roles.

It is evident that Renate Cochrane acts as mediator for Masangane, offering access to funding agencies in Germany and the USA, and to local groups like TAC and MSF and their ART expertise. Without doubt, had it not been for access to her extensive networks, the programme would not have come about nor would it continue to function. Apart from this role she was also regarded by Masangane workers as the mediator between their needs and Rev Mgcoyi, "the one person that he would listen to"; and has since his death, effectively taken on his role as well, though a new Masangane leadership team is in place and is gaining in strength.

- *Rev. Mgcoyi*

Other key players include Rev Fikile Mgcoyi, who brought valuable experience to his role as chairperson of Masangane with tight control over the running of the project.

His administrative experience as a school principal, his standing in the church as a minister, his authority in the community as traditional chief, and his reputation with funding agencies as efficient and trustworthy administrator of funds combined with his passion and commitment to advocate on behalf of PLWAs made him the ideal chairperson for this programme. It was he who initiated the move of the project from orphan support into ARV provision.

Rev Mgcoyi died during 2005. Since then some of those who resented his leadership style have come to understand that it was necessary when, without his tight control, the Masangane bank account was subsequently depleted. More recently, a relative lack of authority and experience among remaining Masangane staff has also meant budget shortfalls for specific line items. This occurred because urgent needs had to be covered for which there was no budget item or because the line item had been exhausted and monies had to be shifted around.

- *Zoliswa Magwentshu*

Zoliswa Magwentshu, responsible for the ARV treatment within the project, also has a role and personality that is considered one of the strengths of Masangane. Her dedication to helping others with AIDS after she had recovered from near death by receiving ART through MSF, her devotion to the project and its clients, the ingenuity with which she managed to get things going, are invaluable to Masangane. For all who live with AIDS she is a powerful role model, as one who is openly HIV positive, on ART and full of life.

At the end of February, 2006, Zoliswa Magwentshu left Masangane for other work for the Lutheran Community of Southern Africa.

- *Rev Ntombentsha Matinisi*

Ntombentsha Matinisi was one of the founders of Masangane and played a crucial role when the ART programme started in Matatiele. She was serving as minister there at that time and opened many doors for HIV awareness, while offering pastoral support to many infected and affected by the virus. Since her move to Mthatha her role has been more marginal, although she is in charge of the local, small Masangane branch there. At times comments by respondents – and the key players themselves – speak of a degree of tension between them.

> *Otherwise, there is a committee, supposed committee; I don't know how to put it because Mgcoyi is apparently running the programme.*[85] *And they don't see eye to eye, but Matinisi was elected as a treasurer, but I don't know if she knows a thing about what is really happening.*[86]

3.11 Christian values – compassion, support

For some of the health seekers Masangane's Christian approach, the care and acknowledgement they receive, is an outstanding characteristic. (See also Chap 5 which deals with this in greater detail.) They appreciate that this Moravian project welcomes all irrespective of their denominational affiliation. And reaches out to them with compassion – acting as a true "pastorate of the church", passionately doing what is possible to "make a difference in the lives of a few people."[87]

3.12 Ties or partnerships

A small project, with only four employees, even with its committed team of volunteers and management team, could not possibly achieve what Masangane is achieving without being part of a wider network of rich ties, the basis of significant social capital. Some of these ties were highlighted by respondents.

Most prominent are the ties to NGOs in the HIV area, such as Médicíns sans Frontières (MSF), the Treatment Action Campaign (TAC) and the National Association of People Living with AIDS (NAPWA). Masangane developed in close consultation with MSF and TAC. Operational procedures were developed in line with those used by these NGOs. Dr Reuter of MSF was often consulted concerning the best treatment for specific clients and offered telephonic diagnosis and advice. In return MSF called on Zoliswa Magwentshu, who had been recommended to Masangane by MSF in the first place, to motivate the Lusikisiki community about the effectiveness of ART and its impact on her life when MSF was starting its ART programme there. As both programmes have become established the contact is less frequent, but mutual support is still evident.[88]

Connections with the TAC have also been maintained, and many Masangane volunteers have benefited from TAC training and workshops. At times there have been strategic appointments, e.g. a TAC activist was appointed as chairperson of a support group in order to maintain a strong link to the TAC.[89]

Ties to local clinics and hospitals are more complicated. In Shiloh, relationships with staff at the local clinics were established so that clients could be sent there instead of having to pay for consultations with private doctors.[90]

In Matatiele the expertise of Zoliswa Magwentshu as well as the close working relationship with Dr Nakin has resulted in much looser ties to public health institutions, although there is some mutual referral system between the clinic and Masangane for clients needing specific medication that is available at the other institution.

Clearly, in this regard there is still work to be done. Masangane seems in some ways like an island, separate from community structures such as local AIDS councils, traditional practitioners' associations and other ecumenical AIDS responses. While the project has to date avoided publicity as it is unable to cope with significantly more clients, the synergy generated by collaboration with other groups may be assumed to be of benefit not only to all of these players, but ultimately to the communities they are serving.

3.13 Management procedures

Some weaknesses in management procedures are apparent to those looking at Masangane from outside (and Masangane people are not unaware of its capacity limitations). Representatives of funding agencies have pointed out that the infrastructure should be developed, specifically in respect of technology and financial security. They also highlighted a lack of technical skills that cause problems with organisational issues, financial reports and budgets. These respondents speak critically of a "charity mindset", which becomes evident for instance when committee members overstep their limits,[91] or in the expectation that services are provided or utilised without having to be paid for.[92]

For those working in Masangane other management issues come to the fore: "The way of dealing with people and it's also that there is no clear structure", autocratic decision making by the manager on issues referred to the committee,[93] lead to frustration and also to concern for the future of the programme.

Key informants representing Moravian Church leadership also raised discrepancies in management procedures in Masangane. They pointed out that constitutional procedures, such as calling an annual general meeting with sufficient notice, and making sure that officials are present for these meetings, have not been followed.[94] That this is not only about issues, but also about individuals, is clear from a perception on their part that Renate Cochrane, who was elected as secretary of Masangane, is seen as not preparing local people to take over that position.

A specific management issue raised was the decision making process on employment at Masangane. A good example may be found in the way in which the treatment project manager (Zoliswa Magwentshu) was appointed. Church leaders point out due process was not followed – there was no discussion, no advertisement or call for applications.[95] It is clear that there are people within the Moravian church who were keen to be appointed in that position, a position with a guaranteed salary way in excess of that of its clergy. On the other hand, it is also clear that a very specific person with appropriate skills and background (such as Zoliswa Magwentshu) was

needed to make this project viable.

The project managers admit that the process was undemocratic – but suggest that this is at times the only way to run a project like Masangane under the conditions in which it has to operate.

> *She [Zoliswa] wanted to work for Masangane but could not afford to wait for two or three months. She told us in July she was willing; she was employed the 1st of August. And there was no consultation; people were just told we've got someone.*[96]

If formal "due process" was to be followed, project managers argued, and the church was to have a direct say in critical appointments, they would likely not be made according to who was the best person for the job. "Due process" here seems to refer to processes that included decisions made about and for Masangane through various church committees or structures technically external to the Masangane programme per se. The sentiment expressed seems to indicate a lack of trust in why and how the church makes appointments of this sort, the other side of the tension to which we refer below.

3.14 Relationship between Masangane and the Moravian church

The preceding section hints at tensions in the relationship between Masangane as a Moravian project and the Moravian church authorities, and numerous comments from church leaders centred around this issue.

On the one hand there is a sense that Masangane is a project within the Moravian church, supported by it. Yet this support is limited, as pointed out by the national church leaders themselves, who note that they give insufficient active leadership. Indeed, it appears that none of them have ever visited the project until very recently, some years after its beginning. This may be a root cause for the other problems mentioned by church leaders interviewed, namely, that there is no real appreciation for the work of Masangane and its workers by the wider church community.[97]

A similar point could be made about material and other support. Masangane relies on outside sources for funds, as the church cannot generate sufficient funds for it. Even properties the church owns that it might make available to serve similar needs are not freed for such service.[98] A further way in which the church could support Masangane's work is by lobbying the government, "to get them to do what they are supposed to do", but this too is not happening.[99]

On the other hand, national church leaders complained that this project was too independent of the church, operating without consulting them and even without informing them. An example cited: The local Moravian vice-president was not informed that Masangane workers were conducting an AIDS awareness programme in congregations under his care.[100] There is anxiety that the project is not under the control of the church authorities, that volunteers rather than the church have the main say, and "these volunteers are not only Moravians".[101]

This anxiety may be related to the fact that this project has substantial fund raising potential. While the church leaders are pleading for "joint responsibility", Masangane management fears that they actually want to take over the project, particularly its fund raising capacity, in order to support other activities of the church financially. It appears that some church leaders have exaggerated expectations of amounts that could be leveraged.

One reason for this, it has been suggested, is in fact the University-led evaluation of the project represented by our research, which is seen as raising its profile, respectability and fundability.[102]

Church leaders hold Masangane management, and specifically Renate Cochrane, responsible for foregoing the more vigorous exploitation of this potential. On the other hand, she in turn appears committed to reserving funds raised for Masangane for its activities and staff alone.

3.15 Limited finance limits the capacity of Masangane

The donor base that Masangane has been able to establish, largely through the work of Renate Cochrane, is seen as a strength of the project, yet a fragile one as funders generally do not have long-term commitments and may withdraw their support, leaving the project in a serious predicament. This raises deep concerns especially given the need to guarantee sustainable access to drugs once clients are admitted into an ART programme. Masangane's own position is that the initiation of clients into ART, which they contracted with clients to sustain for two years, is a crucial first step in rolling out drug treatment, which has to be followed by the state taking over such clients as its own roll out programme gets under way.

What is seen as the bigger problem, however, is that funds are too limited to be able to do what needs to be done. The Masangane office in Matatiele was seen as being too small, and lacking space to conduct confidential counselling and HIV testing. After not being able to offer VCT for a long time, Masangane has obtained a container in the second half of 2005 where counselling and the actual HIV tests can be performed.[103]

A further result of limited resources is that places within the ART programme – as well as in the orphan care programme – are limited by funding and other practical constraints, resulting at times in conflict between those on the waiting list.[104]

In the context of deep poverty in rural areas,

the lack of personal transport, and the high cost of using public transport, has also been a serious hindrance to the work. This applies to health seekers and support group members of Masangane in particular. As mentioned above regular follow-up on clients is an integral part of the Masangane approach. Yet bad roads, long distances and expensive, unreliable public transport make this all but impossible without a project vehicle. Since completion of the fieldwork, a vehicle has been acquired by Masangane for work in the Matatiele area, and a vehicle for the Shiloh site will be available soon.

3.16 Conclusion

The various assessments by different stakeholders of Masangane highlight patterns that one might expect in its context (such as tension between activist initiatives and host institutions, competition for resources, skills scarcity). But overall, the picture is clear: Masangane represents a highly successful intervention, sustained now for several years despite all external and internal difficulties, as an effective integrated response to HIV and AIDS.

Moreover, this effectiveness is related to elements of efficiency as well, particularly in terms of access to rural people, speed of response, follow-up and monitoring, and high levels of ARV treatment adherence with a low drop-out rate.

If we add to this the positive benefits that are recorded through Masangane's good use of support groups for people on treatment or seeking treatment, its extensive use of volunteers, treatment assistants and care workers, and its comprehensive response to HIV and AIDS – going beyond treatment to include its earlier programme of orphan care, for example – then it is immediately apparent that an FBO/I such as Masangane is a community asset, and not just a health asset.

Or better put, because of its rooting in the local communities it serves and its multiple means of reaching or including them, some specific to faith-based initiatives, Masangane represents a holistic response to a health crisis. In this it offers a model with significant potential for linking, and thus aligning, the public health system to locally embedded and sensitive agents, including FBO/Is, capable of carrying out tasks relevant to sustainable HIV and AIDS interventions that would otherwise be difficult, if not impossible.

Nevertheless, the research presented in this chapter has also pointed to some limitations in the current Masangane programme. Masangane is meeting the needs of a very poorly served, largely rural population, and was able to make ARVs available well before the national ARV programme began. Masangane is well aware of the extensive demand for ART and other HIV and AIDS related services, but it does not have the capacity to meet these needs due to resource and personnel constraints.

Given the overall positive role of the services Masangane provides, the potential role of Masangane-type FBO/Is should be considered to complement the State ARV programme, especially in rural areas.

Further, urgent consideration needs to be given to the financial arrangement needed to provide sustainable ARV treatment to the current and future Masangane beneficiaries.

Currently Masangane is dependent on a few core actors who play key roles in the management of the programme. Management stability, based on a clear organisational framework, roles and responsibilities, is critical for the sustained operation of Masangane. Steps need to be taken to ensure that these are urgently put in place. The relationship with the national Moravian church will also need to be resolved to provide the funders with security regarding their commitment to funding of ARVs and not overall church activities.

The existence and success of Masangane must be attributed in no small way to the social capital in the form of bridging ties used to obtain extensive support and funds accessed through one key player, Renate Cochrane. Further, the international links to funders and national links to agencies such as MSF have provided the resources, support and encouragement to set up the initiative as well as maintain the project.

These ties could be described as helping the communities involved to 'get ahead'. The bonding ties of the support group and the commitment of the volunteers provide evidence of the importance of another aspect of social capital, helping communities to 'get by'.[105] Social Capital could be described as a key component of the existence and success of Masangane.

3.17 Summary of evaluative judgements: Assessment of Masangane as viewed by multiple stakeholders

§ *Rural Access:*

While the conditions of rural isolation and poverty make it difficult to provide a reliable ART service, Masangane has developed a programme and methodology that copes with many of these constraints in an exemplary fashion.

§ *Speed of treatment response*

Masangane uses its access as an FBO/I and its local knowledge to provide fast entry into ART with good support structures already in place.

§ *Follow-up and monitoring*

Follow-up, effective local support and education and counselling services make Masangane a preferred provider for health-seekers.

§ *Adherence*

Masangane is able to offer close monitoring services for ART, resulting in generally very high levels of adherence.

§ *Support groups*

An intensive "buddy" support system based on high levels of personal commitment enables Masangane as an FBO/I to offer services otherwise felt to be lacking but necessary. This however could be a limitation for scaling up.

§ *Volunteers and assistants*

The strength of Masangane as an FBO/I is also evidenced in its capacity to draw in significant numbers of volunteers and treatment assistants at low cost. This is also a limitation unless resources can be accessed to sustainably cover the costs of the volunteers, but it is also the case that costs in this case are relatively low compared to the costs of employment generally.

§ *Range of activities*

That Masangane is able to offer a comprehensive integrated response to HIV and AIDS, linking ART to counselling, training, orphan support, treatment literacy, education and awareness, and support for various treatment protocols and procedures, is a highly positive indication of its strength as an FBO/I. A lack of adequate pastoral counselling may be a weakness.

§ *People still die*

Masangane as a single FBO/I dealing with HIV and AIDS cannot address the scale of the problem, and its replicability is crucial to scaling up any overall FBO/I response to complement the State ARV programme. But replicability is not all: Advocacy to public health agencies and policy makers for a massive increase in treatment allied to an integrated, locally based and rooted set of organisations and structures, such as Masangane, is perhaps the more critical contribution.

§ *Core group actors*

Organisational tensions arise through personality clashes, different understandings of positions and tasks, and shifting lines of authority, responsibility and accountability – over time and as personnel and procedures change – a reality that may be regarded as 'normal' for NGOs, CBOs and FBOs.

Masangane is heavily dependent on a small number of key people, and when these people are no longer there, its sustainability and modus operandi are critically at risk. Succession plans and a move away from dependency on a small number of key individuals, especially evident after Rev. Mgcoyi's death, is a key problem to be solved.

Yet, key "mediators" are vital to the success of such projects or programmes, and this mediating role itself is part of the reason FBO/Is (or NGOs) work well. The importance of key mediators fits with social capital theory, through which they may be understood as the critical 'bridging capital' people who fill 'social holes' (where needed ties do not exist) that would otherwise make an initiative or intervention that much weaker.

§ *Faith values*

The enduring faith tradition within which Masangane sits and out of which many of its personnel operate is part of its strength.

§ *Ties or partnerships*

Though Masangane, in terms of employed personnel, is a small project, the ties it has to other agencies, to international bodies (including churches in this case), and to private health practitioners is a central feature of its ability to respond well beyond what one may expect from a FBO/I. Key have been the links to agencies with a depth of experience in raising HIV awareness and in the provision of ARV treatment as well as MSF's empowerment approach.

§ *Management*

Attempting to offer more than might be possible to deliver, an effect of a "charity mindset" in FBO/Is, raises difficult issues of sustainability, but this must be read in relation to equity in a context of historical dispossession and relative poverty, especially in the Eastern Cape.

When 'big funds' flow into poor churches, tensions invariably arise over who has access to them, who takes decisions about them, and – most importantly – who benefits from them.

Tensions around money, authority, decision-making, procedures and representivity, for example, may be seen as typifying FBO/I relationships, especially where the institution to which a local organisation of initiative is linked (the Moravian Church, in this case) is relatively poor or cash-strapped and a struggle for resources emerges.

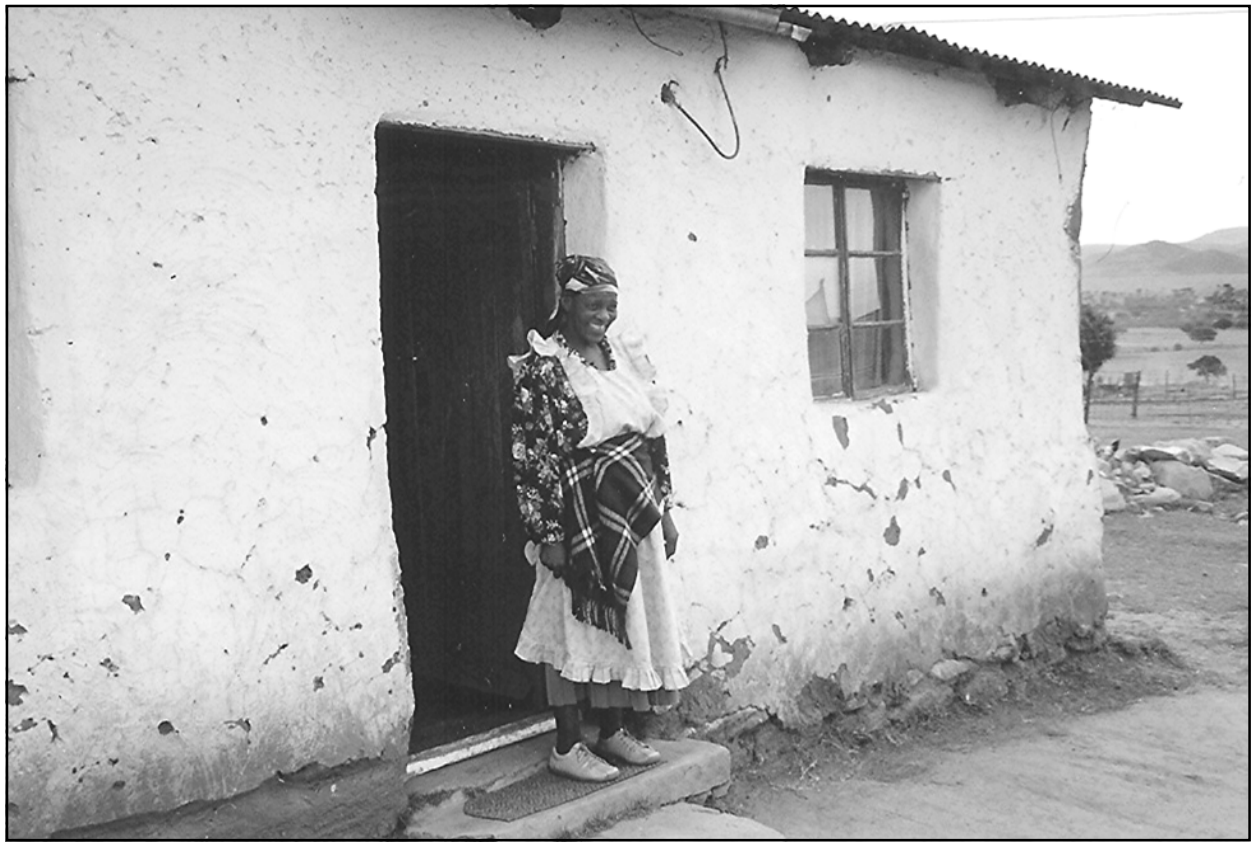
§ *Individual FBO/I versus host institution*

Faith-based initiatives such as Masangane, often begin as informal individual or local pastoral interventions (a common feature of what it means to engage in practical ministry). If they gain strength and resources, shift into becoming organisations with formal structures, this changes their institutional and operational character, which is likely to generate tensions around authority, status, kudos, and the like that must be managed.

Similarly, funding opportunities for FBO/Is (obviously very significant in the current climate of HIV/AIDS funding) are not without serious ambiguities: The possibility of funds opens up the potential for contestation over the control of the money and its use, not least between a particular initiative such as Masangane and its host or parent body, in this case the Moravian Church. The tensions that arise can threaten the viability of the project, its management integrity and its ethos.

§ *Limited finance*

Rural communities are especially disadvantaged in being able to gain access to treatment and ongoing follow up, attending support group meetings due to the out of pocket transport expenditure and other indirect costs. Despite the recently acquired vehicle, the sustainability of treatment to people living in rural areas remains a critical cost for Masangane and an inequitable barrier to service for those living in remote rural areas.



Expecting a visit

Chapter 4

Impact of the Masangane Anti-retroviral Treatment Programme

4.1 Introduction

One of the basic distinctions ARHAP makes in analysing religious health assets is between assets that are tangible and those that are intangible. (See Chap 1: 1.6.4) Tangible assets, like ARV projects or health centres, are easy to recognise and count, as are the number of qualified staff within such facilities, or drug delivery capacity. This is how one normally determines their impact on health outcomes.

We argue that intangible assets, such as the faith or sustained moral commitment of staff members, though less readily quantifiable, have an impact upon health systems and well-being and a contribution to make that is nonetheless crucial. While some of these assets are found more generally among programmes and health workers in the public health system, we focus here on Masangane with a view to delineating the specific contribution FBO/Is can make.

Tangible dimensions of Masangane's interventions include ART provision, training and counselling services, and support groups. Yet all of these have intangible elements: Conveying a sense of belonging, of pride and hope, for example (some of these aspects have already been described by the Masangane beneficiaries; see Chap 2: 2.8.6). In what follows, we begin with aspects of its work that reflect the most tangible assets of Masangane (sections 4.2-4.4), move to those that have both tangible and intangible elements (sections 4.5-4.6), and finally progress to those that are largely intangible (sections 4.7-4.12).

We may also consider Masangane's impact from a wholly different perspective, that of "body", and the different "bodies" that are affected by illness. Based on conceptions in the Sotho worldview, and going beyond an individualistic or merely physical view of the body, ARHAP distinguishes between an external, an internal and a social body.[106]

In short, our study assumes that health has to do with all three of these "bodies" simultaneously (so that, for example, an individual's physical health may be related to her/his mental health, the state of his/her relationships with significant others, and the social determinants of health). The impact of Masangane's interventions as described below should be read in relation to this holistic understanding of "bodies".

4.2 Health: "The resurrection effect"

First of all, health seekers on ART through Masangane speak of the change in their health status. The most dramatic claim, often repeated, is the "resurrection effect" of being on ART, where individuals have been saved from certain death, from being "ghosts" or "corpses" brought back to life, and are now "fat and healthy."[107]

Because many clients joined the programme at a stage when they were already seriously ill and appeared close to death, the change in their physical well-being is dramatic.

> *Last month I went home to Orlando; all the people came out of their houses. It was as if they are seeing a miracle, a person risen from the dead.*[108]

It seems that in the minds of clients, Masangane has become firmly linked to this effect: "Because once you are linked with Masangane people know that that is life, that person won't die."[109] In a context where a positive HIV status is so comprehensively experienced as a death sentence, this is a remarkable turn-around.

This health improvement is evidenced in medical indicators such as individual CD4 counts, which in many cases have improved dramatically. Masangane workers mentioned a case where the figure improved from 2 to 139 in the first six months of treatment.[110] And there are many similar resurrection stories.

Other factors mentioned allude to individuals' health improvements: Recovering from being weak to being strong; from weight loss to weight gain; and as respondents put it, from being very, very sick to being well. We heard about many who have "become beautiful" again.

As one example of this comprehensive sense of improved health, clients report that their sexuality "comes alive" again.

> *For the first time I said to myself 'I like that girl; if I can get better I am going to propose to that woman', things like that. That is an inspiration because I had no hope, sick from AIDS…Now you go to a support group, people are healthy, beautiful and HIV positive and they like you, they talk to you, they treat you with respect. It gives hope it really makes you feel alive.*[111]

There are a few cases when this change in health can have detrimental effects on clients; they regain health sufficiently that they no longer take their illness seriously, and return to unhealthy behaviour – drinking alcohol or stopping their ART – putting their own life and that of others at risk.

First and foremost then, Masangane impacts on those around it through the fact that the provision of ART, and the support that goes with it, saves the lives of people who were close to death. This is

obvious in the case of individual persons, and we have already discussed this.

But equally important is the effect of the visible transformation that people see on the wider community within which the individual lives. From this flow most of the other effects that we observe in the case of Masangane, the *indirect* impact that ART has on the community, which will be explored further below.

4.3 Demonstrates that ARVs can be provided quickly, safely, in rural areas

Masangane has shown that ART can be provided in a way that is rapid, effective and safe (see Chap 3: 3.2 and 3.4). Many within Masangane are especially proud of having demonstrated that this can be done in a rural area that is under-resourced and lacking in infrastructure; an area where the government was reluctant to offer ART due to the numerous constraining factors.

> *[T]here have been mixed messages, that first of all people from the rural areas cannot take anti-retrovirals because, in the first place, they are not educated…The minister once said, the MEC for health in the Eastern Cape, that they don't have watches, clocks, so they won't be able to take the ARVs. He said that was one of the challenges. So we proved that wrong, because people are adhering to their medication.*[112]

Masangane has been able to provide drugs quickly to those in a state of very poor health thus saving their lives whereas the state is not able to respond to the individuals' needs quickly enough. Repeatedly clients testified: "If I should have had to wait for government I would have been dead."

Remarkably, a small project like Masangane, lead by a few committed people, has succeeded where the setting up and accreditation of state facilities has been very time consuming and onerous. Masangane's existence and success was an effective – and intended, according to its founders – form of advocacy against this *status quo*.

4.4 "Breadwinners go back to work"[113]

Masangane's work is mainly among rural people living in areas governed previously by Apartheid Bantustan administrations. These regions were historically faced with high unemployment rates and significant levels of poverty, and this legacy persists in the new dispensation.

As a result many families depend on *one* person for income. When this person becomes sick with AIDS and is no longer able to work, the impact on families is enormous.

As Masangane offers such people ART they regain their health. Former breadwinners are once again able to return to work, or at least have the physical capacity to seek work once more. We can expect that this will in turn have significant impact on their families.

THE THREE FACTORS MENTIONED ABOVE ARE TANGIBLE EFFECTS OF THE PROGRAMME. IT IS CLEAR, HOWEVER, THAT ARV TREATMENT ALONE, POWERFUL AS IT IS, IS NOT ALL THERE IS TO THE 'RESURRECTION EFFECT'. SOME ASPECTS OF THE TREATMENT PROGRAMME IMPACT ON CLIENTS' MENTAL STATE AND ATTITUDE, IN SUPPORT OF THE MEDICATION, FOR EXAMPLE. WE MOVE THEN TOWARDS THE LESS TANGIBLE ASPECTS OF ART AND OF THE MASANGANE PROGRAMME.

4.5 Knowledge

A further impact on the lives of the clients is that they become empowered through the training they receive, mostly in the support group, and through counselling. They receive information about healthy living, appropriate treatments for common infections and their potential side effects. It is remarkable how well-informed Masangane clients are about their health status; how readily they share bio-medical terminology and pharmacological data relating to their condition.

Family members of ART clients are encouraged to become part of support groups, in order to be equipped to act as treatment monitors, or simply so that they understand the predicament of the relative who is HIV positive.Through this Masangane's introduction of treatment literacy and HIV/AIDS education extend beyond the individual on ART into the community.

> *I have only sisters and brothers; my parents passed away. They also understand about HIV because I am always talking about HIV.*[114]

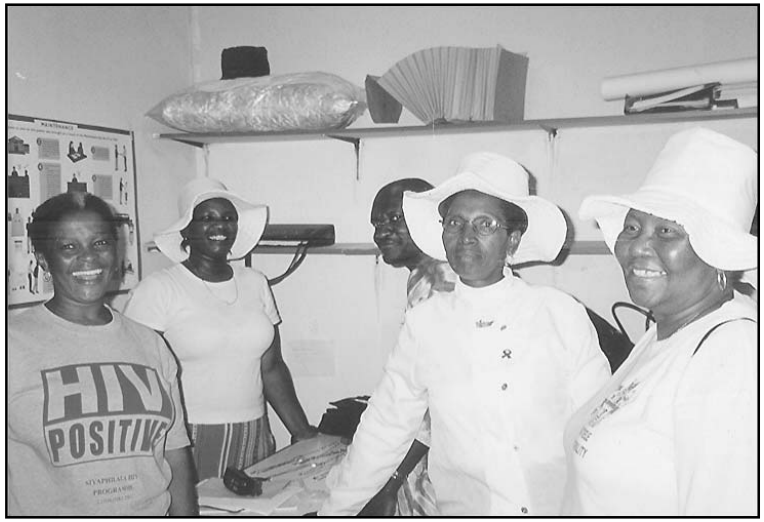
In this way the level of HIV awareness in the communities is raised significantly. A body of community members who are informed about HIV and AIDS is therefore being developed – a powerful antidote against stigma and false beliefs, but also against fatalistic submission to the increasing devastation AIDS wreaks in many rural communities.

4.6 Empowerment

One of the common AIDS slogans states "In the fight against HIV, knowledge is power." It is clear that by offering affected and infected people knowledge about HIV and AIDS, Masangane is empowering individuals and communities; this is

addressed in the next section.

On another level empowerment occurs as the programme offers both formal and informal training opportunities to those within it. In rural communities, where resources of all sorts are limited, this has created opportunities for improving skills and generating income for a number of people.[115]



Noncedo orphan care workers from Noncedo, with Zoliswa

The training consists mostly of workshops in AIDS awareness and treatment literacy offered locally, but a number of Masangane volunteers have been sent to training workshops in other urban centres. Masangane office workers were offered training in administrative skills. Members of the Masangane treatment and education team have received training to enhance their knowledge about AIDS treatment, but also their counselling skills. A few have been exposed to international support groups and donors through visits to Germany.

4.7 Awareness: "They are conscientising people around them"[116]

One of the less direct impacts of the programme that one becomes aware of is the contribution to HIV awareness within the communities. This has challenged and changed attitudes and thinking, and also, more importantly, helped to fight fear.

Yes, Masangane does bring about more awareness and acceptance of people living with HIV/AIDS for example by visiting and conducting workshops in churches and by bringing people who are HIV positive to the public, that made people understand that HIV/AIDS is with us.[117]

The awareness developing in these communities around Masangane includes the acknowledgement of the reality of AIDS, not only in the form of an identifiable virus, but also in the way PLWH/A are seen and treated. It is evident from the quote below that the information shared by Masangane goes beyond clinical data about HIV and AIDS. The fact that people with AIDS are open about their status, and that they are getting healthy, is what challenges perceptions about the nature of HIV and about the people infected by this virus.

> *That is one of the things that made people to change their way of thinking about HIV/AIDS, because some of us used to see people living with HIV/AIDS as outcasts so that they neglect them but when they see them healthy, beautiful and good looking and see no need to neglect them; instead welcome, live, support, sympathise with them in what they have. Even through education Masangane made people aware about the fact that in reality HIV/AIDS is alive and it kills but there are ways of preventing it.*[118]

AIDS is no longer seen as an essentially fatal disease as the hopeful reality of ART is lived out and witnessed. Nevertheless, suspicion lingers and some are not that easily convinced:

> *Even those who know us, think the doctor buys us to say that we are HIV positive. …. They don't believe that I am HIV positive. They said 'It is Dr Nakin who buys you, he told you about that.'*[119]

Not all respondents agree to what extent awareness of the project, and the impact this has on HIV awareness, has reached beyond the direct neighbourhoods of the Masangane offices into the South African Moravian community. One denominational leader claims that, at most, knowledge about Masangane has reached a few resource persons in congregations further afield who have been exposed to the project and have received training relating to HIV and AIDS.[120]

Another Moravian leader states that the project is raising awareness of HIV in the Moravian church worldwide: "Making people aware, making also the rest of the Moravian church worldwide aware."[121] The Moravian Church has now asked all of its dioceses in South Africa to develop HIV and AIDS programmes and to employ coordinators for this work. There is good reason to believe that this shift is not coincidental, but derives from a heightened awareness among Moravian leaders nationally, born of their knowledge of Masangane

It is clear, too, that the experiment that Masangane represents is having an impact within the Lutheran family of churches in southern Africa, specifically in attempts to learn from or replicate the project in some way in Mpumalanga, South Africa, and in Madisi, Malawi. More recently this has been extended with requests for replication in an area near Bulawayo in Zimbabwe, Maseru in Lesotho, and in South Africa, to Dalton in KwaZulu Natal, and Stutterheim in the Eastern Cape (See

Chap 7: 7.5.4 regarding the potential replication of the Masangane model).

4.8 Decreasing stigma

Whereas before there was a strong perception and belief that being HIV positive equated imminent death, now, through the success of the treatment programme, communities know that being HIV positive does not necessarily result in death. The reduction of stigma occurs then not only among the immediate confidants, support group members and family of Masangane clients, but also more widely within the community, even when there is no direct connection to the particular individual who has been recognised as HIV positive.

> *At first it was difficult to talk about AIDS, people discriminated against you, even in the taxi no one would want to sit next to you because you had AIDS and people thought it is contagious. But now it is easier to talk about it because there is help.*[122]

Further, the treatment literacy programme has given people in communities courage and confidence to have HIV tests done in order to be informed about their status.

Thus the fear and stigma is challenged and changed, and hope and confidence restored. It is widely recognised that increased levels of HIV testing in communities is an effective means of preventing the spread of HIV. In this way, too, the influence of HIV positive people speaking out about their status and the change ART has made in their lives is seen as invaluable.[123]

The lived reality of people on ART in communities has also made it easier for people to accept HIV positive test results. Previously many considered committing suicide after receiving this 'death verdict'; now they know that it is possible to live positively, even when HIV positive.[124]

The AIDS awareness implemented by Masangane workers impacts on different groups in the community. Primarily it can be seen in the families of beneficiaries where changed attitudes, shaped by increasing knowledge and understanding of the HIV positive person's condition and needs, engender more supportive behaviour. One factor in this is that the sickness of a family member with

"HIV positive and beautiful"

AIDS is now – with ART – experienced as a normal sickness; "they are sick as anybody's sick."[125]

In traditional communities powerful taboos exist around sexuality, often reinforced by religious teachings; this limits open discussions and the transmission of factual information. Here too Masangane has made inroads through its awareness work; people are "talking openly about sexuality in the community."[126]

Others in the community, it is reported, are encouraged through the work of Masangane to make their contributions to fight stigma and support PLWAs. Thus the principal of the school attended by a young Masangane client has taken the initiative and instituted a support group for children living with HIV.[127]

Churches too are mentioned among transformed community structures. Several interviewees spoke of the impact that they believe Masangane is having on churches in terms of changing attitudes to PLWAs and changing perceptions on HIV-related matters. They mention churches showing loving acceptance of PLWAs where previously "people were thought of to have been punished by God" and had to seek safe and accepting community elsewhere;[128] that sex is spoken of more openly;[129] and that the desire to know more about HIV has grown: "They want to know what steps they can take if there is this someone who is sick."[130]

This wider impact does come about through Masangane workers, who talk "openly and freely" about HIV and AIDS in community workshops conducted in churches. Often it is the people living with HIV and AIDS who bring about this change through their testimony. Some Masangane clients are committed to making sure their influence spreads to other churches:

> *For example if someone in our church has died we invite other churches and we meet and have prayer meetings in that house. Then we share and talk about this thing openly because other churches are very stiff in accepting HIV/AIDS in our communities. If they see what we do, they can learn from us.*[131]

There are also instances where the clergy are the ones who bring their congregants, apparently suffering of AIDS related complications, into contact with Masangane.[132] And yet – not surprisingly – there are voices stating that discrimination and stigma still persist in some churches; that in some cases ministers still use people with HIV to illustrate negative points in their sermons.[133] However, it is evident that the situation has changed in many churches, and quite dramatically in some.

It is not always clear how directly this impact can be attributed to Masangane, because its staff does not have any specific strategies directed at

influencing other churches. The evidence suggests that impact is achieved through the range of people who are accepted for treatment by Masangane (beyond the Moravian Church to which it is affiliated) and their personal influence in their congregations, or by word of mouth from others who know such people.

Beyond that, the progression of the AIDS pandemic, the advocacy work of groups like TAC and MSF and the roll-out of ART nationally are gradually changing perceptions in the country. However, without denying the influence of numerous factors on changing attitudes in churches (and communities), some credit certainly is due to Masangane for these changes reported by people connected to the programme.

4.9 Overcoming self-stigma, becoming role models for others

Crucial not only to the clients themselves but also to their communities is the evident decrease in self-stigmatisation.[134] We see clients confidently, even proudly, disclosing their HIV status.

> *That is so different to us who are living with it now, who are bold to say I have HIV/AIDS and I am still a person, nothing has changed; I am just sick. ARVs have helped us to be able to do that.*[135]

> *I do not know why it bothers them. It is my virus.*[136]

These quotes tell of people who have recovered their dignity, who act and speak boldly and have no need to hide their status. By doing so they become role models for others who might still be battling with the issue of disclosure or who are without hope and ready to give up on life.

A primary role model and inspiration is Zoliswa Magwentshu, the sister in charge of the programme in Matatiele, who is herself openly living with the virus and on ART. She is an inspiration and a role model of positive living to many of the PLWAs who have come to Masangane for help.

4.10 Belonging: "Embrace one another"

The "resurrection effect" of ART is not unique to a FBO/I such as Masangane, of course. But it is evident that the impact Masangane has on health seekers goes beyond better physical health. An important means of such impact are the Masangane support groups: "You know [when] I got treatment [I became] fairly better, but I could feel that I am really living once I joined the support group."[137]

These groups offer clients the experience of no longer being an outsider, an embarrassment, a disgrace. Here they are part of a group where they are embraced,[138] where they belong. (The name Masangane means 'to embrace'.) Here it is possible to talk openly about HIV and AIDS and all the myriad ways in which it impinges on one's life, because all are affected.

To term this *embrace* one of Masangane's *intangible* assets may seem inconsistent. What we stress by using this terminology is that the institution of support groups – which are indeed tangible, countable structures – offers its members something beyond the membership card, a sense of belonging, fellowship and dignity that is crucial to their health and well-being.

4.11 Hope

Another strong impact of the Masangane ARV treatment on the lives of individuals has been to give them hope through seeing others who are HIV positive and who, rather than dying from AIDS, have recovered remarkably and survived:

> *This project … has helped the families, it has helped also the affected because, people have gained hope; they see now the reason for living.*[139]

The treatment programme has been able to give families the hope that was dwindling as a result of witnessing too many AIDS-related deaths around them. It is the hope that even if they or their family members became infected, that would not necessarily imply death, whether physical death of AIDS or, long before that, the social death resulting from stigma and isolation.

4.12 Passion to serve others

A commitment to serve and help others, especially those who are infected and affected with HIV and AIDS, is another impact the Masangane ARV treatment programme has on the lives of individuals.

This is evident in the lives of Zoliswa Magwentshu and her close co-workers, whose passion to support the work through counselling, encouragement, educating, establishing support groups and running the Masangane office, is evident. Knowing the painful reality of living with HIV – painful not only physically, but also emotionally, socially, economically – and having experienced a total turn-around through ART makes them passionate to help others to have that experience. Because of this Masangane is able to rely almost exclusively on volunteer support.

> *I never knew that today I would be helping people, so I would like to help everyone, everyone who is HIV positive, because I know the pain…I know how it feels to be sick with HIV.*[140]

4.13 Conclusion

It is evident then that the impact of Masangane is complex. It is there in tangible structures as much as in their intangible effects in people's lives. It touches various bodies: The physical bodies of its clients, and through that their psycho-spiritual bodies, as well as their social identities. Beyond

these the impact is felt in widening circles of the social body – families, villages, schools and churches.

Key to this has been the tangible evidence of the benefit of taking ARVs and the resulting 'resurrection effect', with people becoming 'beautiful again' and being able to work. The wide range of education provided – from treatment literacy to beneficiaries and their supporters through the support groups, to skills development for staff – has contributed to the empowerment of the beneficiaries and the broader community.

Masangane's impact reaches far beyond its direct clients and has changed many lives in the communities where it is functioning. Through the ART programme, social, family and community relations are being restored. There is evidence of this knowledge impacting on the broader community through institutions such as schools and churches; and of Masangane impacting very positively on stigma in the community. Through its awareness and education programmes, and through encouraging affected family members to come to the support groups and be informed and educated about HIV and AIDS, acceptance and re-acceptance of those living with HIV is achieved.

Furthermore, the renewed hope of the beneficiaries through regaining their health has contributed to their self acceptance and many have become positive role models for others. Support groups offer a sense of belonging, fellowship and dignity that is crucial to the health and well-being of beneficiaries. This has often led to a commitment to serve others and is one reason for the well established volunteer support for Masangane.

4.14 Summary of evaluative judgements: The impact of the Masangane anti-retroviral treatment programme

§ *Health: "The resurrection effect"*

The impact that ART has on people's well-being is not specific to Masangane, of course, but the embedding of this treatment in religious images, symbols and narrative constructs appears to enable clients to comprehend their condition in very positive ways that also have resonance in their wider community, with additional positive impact.

§ *ARVs can be provided quickly and safely in rural areas*

Masangane has shown that despite the difficulties, beneficiaries with very low CD4 counts have been able to gain access to treatment quickly, preventing death.

§ *"Breadwinners go back to work"*

Access to ARV treatment through Masangane has enabled many of the beneficiaries to be able to work again. This is very important in an area where poverty is pervasive.

§ *Knowledge*

Masangane ART clients, their treatment supporters and in many cases their families have become treatment literate. Some understanding of treatment issues has also filtered into the broader community. Knowledge about treatment and the positive experience of the resurrection effect has also had a positive impact on stigma.

§ *Empowerment*

Through the provision of training to beneficiaries, volunteers and staff, Masangane has contributed to the skills base in the area.

§ *Awareness*

Masangane has raised HIV and AIDS awareness in a limited range of actors in faith based communities. There is an interest by other faith communities to replicate and/or learn from Masangane's ART response.

§ *Decreasing stigma*

The growing awareness of HIV and AIDS and the positive results of ART have had many positive impacts on the communities. Evidence from the study suggests that testimony of those on Masangane ARVs as well as the workshops conducted by Masangane workers has facilitated a more open environment within the churches and other community groups.

§ *Overcoming self-stigma; Becoming role models for others*

HIV positive people on ART have recovered their dignity and confidence and in this way have shown important leadership as role models in their communities. This is especially the case where Masangane staff themselves are openly living with HIV or AIDS.

§ *Belonging*

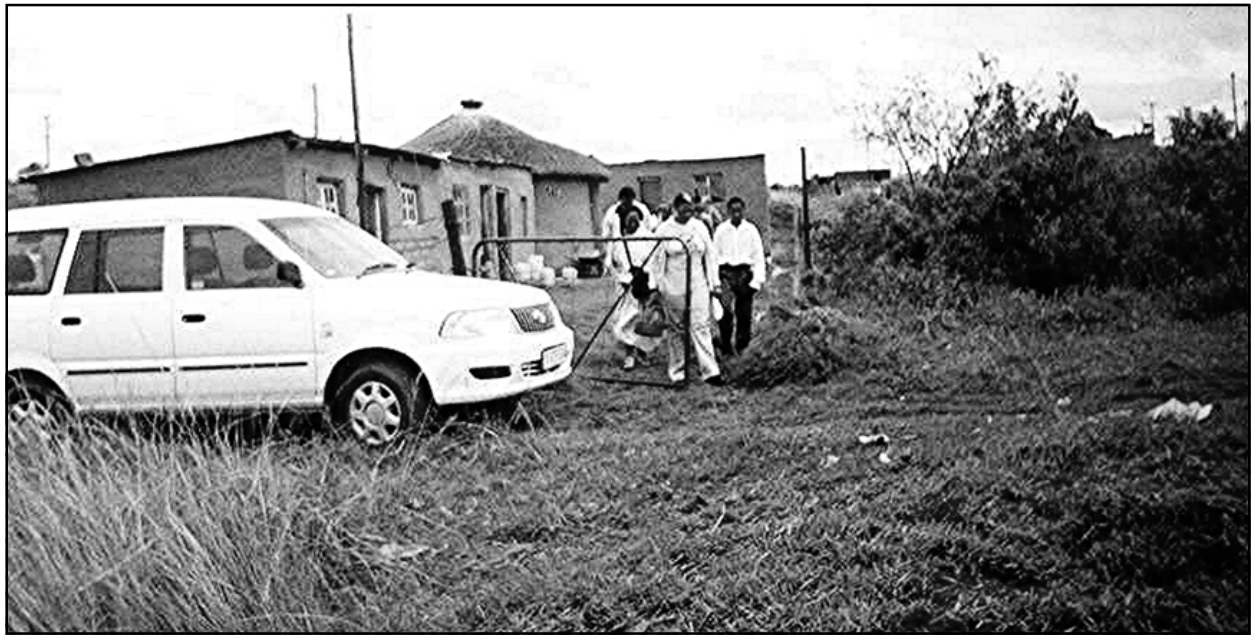
Membership of Masangane support groups offers a critically valuable intangible asset – that of a sense of belonging, fellowship and dignity. These are crucial to members' health and well-being.

§ *Hope*

As Masangane provided ARVs to beneficiaries, this offered hope to others who were infected as well as hope to members of the community which had already experienced the devastating impacts of deaths due to AIDS.

§ *Passion to serve others*

Many on ARVs have been inspired to help others. Masangane benefits extensively from the commitment of those who volunteer their time to help others.



Home visitation, part of Masangane's support

Chapter 5

The 'Value-Added' of Masangane as a FBO/I offering ART

5.1 Introduction

If we suggest that religious health assets (RHAs) hold distinctive advantages specific to their religious character, then the functioning of Masangane's anti-retroviral treatment (ART) programme and its outcomes, as a particular case study of RHAs, needs to be shown to embody such distinctive advantages as a faith-based organisation or initiative (FBO/I). This chapter probes the evidence for this.

ARHAP's most basic hypothesis is that religion adds particular value to a programme (even as it may cause impediments to its functioning), value that has significance for public health policies and practices, value that can be leveraged or built upon to strengthen public health responses to the critical challenges it faces.

A full justification of this hypothesis would require further comparative studies with other FBO/Is in health and with similar bodies that are not faith-based. The limits of this study exclude direct comparative research at this stage, though extant literature provides some support for what we have discovered[141] ; and we anticipate that possibilities for comparison will arise through ARHAP's work in other sites. Nevertheless, our research has produced enough to allow us to make a number of tentative claims. (For recommendations that flow from these claims, see our concluding Chap 7: 7.6 and 7.7.)

This chapter describes the ways in which the difference an FBO/I makes is experienced or observed by stakeholders, considering mainly the way in which Masangane does its work. Among other things we probed this issue by asking respondents if they thought there was a difference between the service Masangane is providing compared to other secular NGOs or government services; and by asking whether they saw any link between perceived strengths (and weaknesses) of the programme and the fact that it was faith-based and connected to a church.

In evaluating the answers to these questions we had to consider that, in this context, most health seekers and members of the Management committee have had little opportunity to compare Masangane services with other secular options as there are few – if any – similar local services. The exceptions are those clients who have been transferred to government sites for their monthly ARV supplies. Masangane staff and key informants from the health sector had more access to comparative data or experience.

In unpacking the data, we discuss "assets" that are most clearly *tangible*, moving to increasingly *intangible* ones. This follows the analytical framework of a continuum of religious health

Masangane as a FBO/I

Masangane is identified as a Faith Based Organisation or Initiative (FBO/I) by virtue of a set of 'family resemblances' (Wittgenstein) that we may regard as characteristic of FBO/Is:

1. Most of those seeking health through Masangane make reference to their faith and beliefs;
2. Most of its staff and volunteers overtly acknowledge that they are people of faith and that this is one reason for their involvement;
3. It was launched under the auspices of a religious body, the Moravian church;
4. It gets the bulk of its funding from religious agencies, churches in this case;
5. It knowingly utilises elements of its host faith tradition in its work, which links it to a religious reality that endures over time, thus providing a dimension of sustainability;
6. It thereby also rests in an acknowledged and long-standing framework of life-giving values and norms of action and responsibility held and asserted by its members and many other people around them, adding an institutional quality otherwise rare, seldom explicit if not absent from other kinds of organizations.

assets from tangible to intangible ARHAP presented in Chap 1: 1.6.4.

5.2 Access to communities and potential clients

You are doing community mobilization through churches.[142]

The value of Masangane being a faith-based organisation is linked to what the church offers by virtue of its local rooting in communities. For the organisers of Masangane the church, with its congregations, situated often in otherwise hard to access rural communities, acts as a helpful point of entry into them. Masangane first made itself known in Matatiele on this basis, utilising church meetings of the Moravian or Lutheran congregations to introduce its vision and spread information. And that is how it has gained access to new geographical areas for its awareness and treatment work.

It is workshops here at church and the opportunity that the church gives itself to mix with people that are sick. It would be a workshop and they will invite other churches and all the people that are sick. Be taught about everything about HIV and AIDS. Masangane also gets a chance to talk about themselves and their origin and how it helps other people.[143]

Congregations offer access in a way that is seen by our respondents to be different from that of other community based organisations, primarily because of a greater implicit confidence on the part of congregants in those who visit, speak to or work with them if they are from the same denomination. They are then not mere strangers external to the community that congregants value. And there is likely to be greater trust that they will remain in a durable relationship with congregants rather than enter into an ad hoc, temporary or fragmented encounter with them.[144]

Further, in accessing communities, treatment educators find it helpful to be able to use the facilities of churches for conducting workshops, though this access is likely to be greater if there is more than a utilitarian connection here but also a respectful engagement with their traditions, such as that embodied by Masangane. It is seen as part of the church and, hence, as acting in relation to the self-understanding of the church. This also enables some Masangane clients, acting as advocates for ART, to use their participation in congregational activities as a means to reach others with their message.[145]

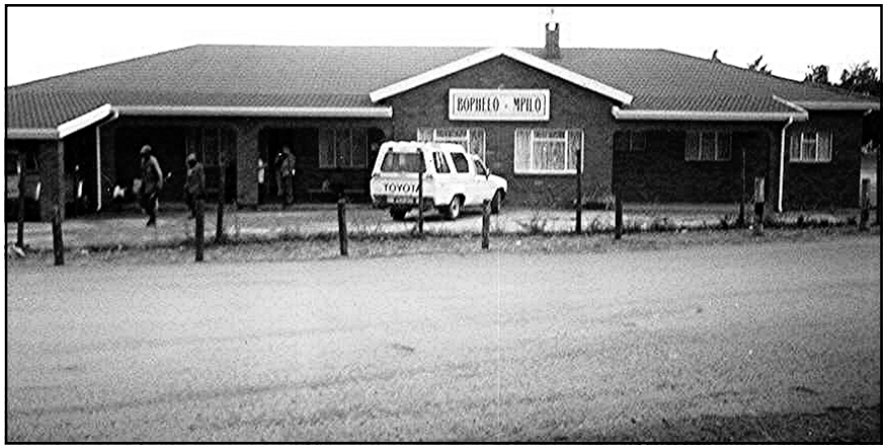
5.3 Advocacy through access

While Masangane directly and indirectly works against stigma and negative messages about HIV, it does so within a context – the churches – typically characterised by views that generate stigma and negative judgement. Representative of this attitude is the not uncommon pronouncement by prominent religious leaders in certain faith communities, still resonant in the areas where Masangane works, that AIDS is God's deserved punishment on sinners. It also rings in the minds of many people living with HIV, warning them that the church may be a very unsafe place for disclosing their status. This is clear to members of Masangane, and they seem conscious of the fact that they are in a position to counteract such stigma and negativity in the congregations to which they have access.[146]

Even in church they [Masangane] have a role. During the time for announcements they stand and talk about Masangane and they pray about it. They are not afraid to talk about HIV in church.[147]

It is really something good and it lifts up the stigma that is stuck around HIV/AIDS so that we can feel free. Even in the communities as they have said there are families who are afraid to be seen when they are sick and I think if the church continues to be actively involved and not leave this to Masangane only, people will be open too.[148]

Beyond the advocacy role actually played by the church, some roles the church could potentially play have been indicated by respondents. These include motivating private doctors to engage more actively in ways that the doctors who work with Masangane demonstrate, and finding ways of mobilizing the best traditions of what were originally mission hospitals[149] (in South Africa, under Apartheid, most of these hospitals were taken over by the state).



Location of Masangane's office in Matatiele

5.4 Motivated, committed staff and volunteers

A common view on religion is that it taps into deep-seated anthropological, psychological sources of personal motivation and commitment and that, suitably directed, this is likely to add value to people's engagements in service to others or to an organisation or initiative. The case of Masangane seems to bear this out.

The vital contribution of its committed workers is in no small measure driven by their sense of themselves as faithful people living out the mandates that they see as given by their Christian tradition. This is true of the Masangane employees, voluntary workers who make up the bulk of the Masangane team, and church officials involved in the management of the programme. Only the last category is exclusively Moravian, so this is not just a factor of one denominational heritage at work, but a reflection of a broader common understanding about key values and norms in the faith tradition (Christian, in this case).

The 'value added' by the faith of its workers is reflected in the attitudes they bring to the task: Commitment, passion, caring, willingness to work hard for little compensation in order to make a difference to the lives of others.[150]

A Moravian pastor in the Masangane team speaks of being an "instrument of hope" diagnosing, in a way analogous to the doctor's stethoscope, the real pain of a patient, a significant metaphor for the added value of religion:

> *And I can understand as a Pastor, you really have a big task to know where the doctor is using stethoscopes to find out what is wrong with the person; but when you see the soul of the person, what is the pain, you know, you really feel that you know, people really need to understand that God is there, even in this suffering of theirs. You are that instrument to bring that hope.*[151]

Masangane acts as an "instrument that brings hope"

Attributes of commitment and motivation are, of course, not exclusive to people of faith in general, or Christians in particular, and one can find some rather un-Christian attitudes within this project too (see Chap 3: 3.11 and 3.14). Yet there is no denying that those who know Masangane or are involved in it see these attributes as natural outcomes of being part of a FBO/I.

Masangane workers also bring their faith into their work with PLWAs. Respondents repeatedly point out that this is a valuable ingredient in the service Masangane offers, even when they do not quite agree with a particular expression of faith.

> *I've listened to quite a number of meetings, workshops which Zola was conducting; she was always quoting from the Bible, so she does this out of, out of faith, and out of love for the work. And I think this is a great advantage that she's able to make use of her faith in improving the health of other people, so that people don't rely only on tablets.*[152]

5.5 Liturgy, rituals, love and care: "Things that bind"[153]

Interventions in health (or any other sphere of human life) that encompass more than the technical-rational or instrumental dimension, but also include the emotional, affective and imaginative dimensions of human being, are ipso facto likely to be deeper in their impact on attitudes, behaviour and practice. For this reason, liturgical and ritual actions – what we might call the "performative" dimension of religious traditions – are not inconsequential in considering how health interventions work. In the case of Masangane, its faith-based church connection brings with it a performative style that shapes meetings and other activities including treatment practices, as we note below.

Support groups and workshops conducted on church premises call on the church traditions for their style of meeting. Prayer, scripture readings and singing of worship songs, at times adapted to become songs against AIDS, are used widely. These, the faith they grow out of and the impact they have on clients were mentioned by support group members as Masangane "services" which the clinic cannot offer.[154]

One specifically Moravian liturgical tradition has been introduced into Masangane treatment practices in a rather unique way. Moravians worldwide use standard daily devotional texts that guide faithful practice through readings, one each from the Old and the New Testament. This is provided to members in the form of a small book. Masangane has linked ARV adherence to this book as an ingenious support measure for treatment protocols, as reported here by the Masangane tretament manager:

> *We also give them textbooks. That helps them to take their medication. Tell them to read their Old Testament in the morning, that is when they are taking their medication, also to read the New Testament in the evening, when they are taking their medication.*[155]

The clients, whether Moravian or not, find this helpful and encouraging.

> *I must say there are these books that we have to open up and read each day before we take our pills. You read on the specific day that you are in. You read, pray and drink your pills.*[156]

Given the frequency and strength with which interviewees commented on this practice in our qualitative interviews, we may judge that it adds great value to Masangane's ability to encourage

adherence to treatment protocols. Moreover, this link of ART – sometimes resisted if the patient fears being exposed as HIV positive – to a spiritual discipline, helps counteract stigma and claims made by some religious leaders that taking ART is an act of unbelief.

In other words, a religious legitimisation of treatment takes place, a strong positive act. This double effect – a systematic treatment ritual and its implicit undermining of stigma – offers an important clue to the way in which rituals and liturgical practices of an FBO/I might support health practices generally.

While neither the church in general nor the daily readings were mentioned in the individual structured questionnaires as something that helped the majority of clients with treatment adherence, the focus groups reported that Church rituals and participation in church activities are considered valuable to Masangane's patients in other ways. Through them they are supported in their struggle with AIDS and offered a space of comfort, a place to submerge themselves temporarily in another reality, drawing on the support of the congregation and rituals such as holy communion.

> *I get a lot of joy from going to church because when I get there people are always happy. I forget about many things and the problems of my home that sometimes boggle my mind. I get advice and they give me hope about life. They tell me it is not the end of the world to have this disease.*[157]

> *My church is African Gospel. They are born again Christians, they pray so much for this virus to go away. They give me love. Sometimes they would fast for me to be well, they would pray for me. I felt like the church was my home. They showed me the love that they have for me.*[158]

These testimonies make it clear that churches and their like, often justifiably criticised for propagating stigmatising messages, are just as much vital sources of care, nurture and hope.

5.6 Spiritual support

Support of its clients in support groups and through counsellors plays an important role in the work of Masangane and in the lives of its clients (see Chap 2: 2.6, Chap 3: 3.6 and 3.8). In this regard, Masangane offers more than treatment advice, solidarity and income generation – as our respondents stress, the spiritual support offered and received is crucial.

> *You do not impose religion on a person but if a person needs spiritual support it is there.*[159]

Respondents have difficulty defining the exact nature of spiritual support, though most of them clearly regard ART offered with faith as superior to ART alone. The notion that ARVs from Masangane include a spiritual quality that other ARVs do not have has been reinforced by responses to the Masangane treatment coordinator from Matatiele. She was visiting Moravians who are in the Durban metropolitan area seeking help with ART, and encountered resentment from them about having to go to government facilities for ART that they consider "inferior" to Masangane's. This perception persisted even though they were clearly told that the drugs from both sources are medically and chemically identical.

Statements that amplify on the presupposed spiritual quality of Masangane's ART programme include the belief that treatment offered by an FBO/I "makes people to be healthy spiritually",[160] that God is acting and healing through Masangane, and that it delivers "something….which is expected from the church" or from God.[161] In our reading of the interviews, the dimension of "spirituality" refers primarily to an experience of healing, holding and helping people that makes a connection with a transcendent reality, God – a loving God rather than a judging one – that gives strength to people for the task of living a life with AIDS and all the challenges that brings.[162] Some describe this in terms of making a new beginning, whether in their faith or in their daily life:

> *And they see now, yes, there were rumours that when you are HIV positive you are punished by God. But now when they see that the church opens their hands, you know, so that people must have a shoulder to cry [on]; someone is listening to their pains and sorrows – and I feel that that strength, it also gives the chance to the people to realise and to reshape themselves.*[163]

Not everyone sees any particular spiritual quality, however. Some respondents regard care for the affected as the main issue, not faith or church connections which they regarded as irrelevant:

> *I think Masangane is doing the same thing as the clinic, the government hospital…If you have care about the people who are HIV positive, I think you can run the programme, even if you are not of faith.*[164]

Another respondent, while not denying the value of the spiritual component of its work, sees the real contribution of Masangane's programme in the linking of support to empowerment of the clients through education and information. While this may be unusual in faith based support groups it is not surprising here, given that Masangane has followed the MSF/TAC model.

> *I mean it didn't centre around prayer, it didn't centre around the support groups, they were not spiritual support groups. But as I understand it, the support groups were education support groups.*[165]

Clearly, both views are present – that spirituality is central to what Masangane adds, and that it is not that important. Generally, we might conclude that the special contribution of Masangane as an FBO/I lies in offering comprehensive support to its

clients, and that for many this includes spiritual support. Some further indications of this are captured in the comments below:

> *I have not been here for a long time but I have seen the way people encourage and support me. I feel free, they encourage me, they advise me. I carry home with me the encouragement that they give.*[166]

Actually, these comments could be made about any support group and not just one rooted in an FBO/I. Other bodies involved in ART, such as MSF and TAC, report similar experiences in the support groups they run. The "spiritual" dimension reported in Masangane as valued and of added value might be reflected in these groups as well, albeit couched not in faith-based language, performances or idioms.

Clearly, then, we need to be careful about what we mean by spiritual support and about its link to FBO/Is. At the same time, it is counter-intuitive – and contrary to what some people at least value – to suggest that the faith-based roots of a programme such as Masangane are of little consequence in this respect. These roots are in fact likely to be important for those to whom faith matters, and we have good grounds to say that it matters to a great many people in a country such as South Africa.[167]

5.7 Reach out to the marginalised and neglected

A number of respondents are very clear that what motivates Masangane as a project and inspires its vision and many of its staff and volunteers is something essentially religious: "We are in that mission of Jesus".[168] Masangane's purpose, as embodied in its name, is to embrace those affected by AIDS. In this respondents see it as following the example of Jesus, inspired by his care and love for those on the margins of society. Alternatively, it is said that those who claim to follow Jesus have no alternative but to be involved in reaching out thus.

> *I am sure it is like that because in his ministry Jesus' main focus was people who are despised (vulnerable and marginalised), sick and those people who are outcasts. So those are the people Jesus was very close to, for example in the bible it is the leprosy which can be associated with HIV/AIDS where people were despised and people were instructed not to go to them but Jesus made a way to people like that. So by what we are doing at Masangane and the church we are in that mission of Jesus Christ; that we must come close to people, love each other and not segregate from each other just because one of us has a certain condition.*[169]

For the clients, this motivation is strong. They witness to experiencing the love of God through and in the work of Masangane, where they do not feel like outcasts, but like people who matter and who are cared for and about, irrespective of whether they themselves are church members or not.[170]

5.8 Inclusivity

Another aspect that church leaders regard as relevant to Masangane's work is the inclusive nature of the church, in as much as it has "different kinds of people, poor and rich, it welcomes everybody".[171] In the same way as differences in other areas of life are put aside in common worship, Masangane is experienced as an inclusive community. Clients, staff and volunteers from all walks of life and denominations, and indeed even those who are not Christian, are equally welcome in their view.[172]

Masangane's clients and support group members echo these sentiments in highlighting the importance of this element to their experience. They regard it as part of what makes Masangane special, and as something that clearly demonstrates its Christian nature.

> *What I can say is, ha, when you walk through that door you feel welcome and loved dearly. That to me shows it is a church organisation.*[173]

> *Also to show that it is connected to the church they do not discriminate [treat people differently]. Even if you do not belong to this church and you are sick they do not send you from pillar to post, they give you treatment at the same time.*[174]

This last remark emphasises the experience that is so common for many poor South Africans in countless situations – to find no help when they approach institutions and, instead, be sent 'from pillar to post'. To be accepted and welcomed in an organisation to which one has no official claim, speaks to them clearly of being "under the protection" of the church.[175]

Rev Mgcoyi, Mary Baich and Beate Jakob

5.9 Credibility

In bringing HIV awareness and information about AIDS and its treatment to congregations, Masangane gains credibility from being associated with the church and having its workers introduced in church services by the clergy.

As you stand in front of people, now what you are saying, it does make an impact in the lives of people especially in the rural areas (ja) because many people believe exactly that the minister when he or she stands there, is talking what God wants him or her to speak out.[176]

This approach is evidence of huge trust in the church and its clergy and, while one may want to challenge absolute faith in the clergy and point out its potential for abuse, it does demonstrate the great potential churches have for supporting AIDS awareness and for fighting (or promoting, unfortunately, it must be said) HIV-related stigma.

In this regard Masangane, by virtue of its link with the Moravian church, benefits from the credibility of the church. This opens doors not only to its workers, as we have already noted, but equally importantly, to the message they bring in and through congregations.

I would say it is the fact that Masangane is a faith-based organisation which is able to reach congregations and receive warmer welcome than community based organisations…Now Masangane is composed of people they know and some are members of the church therefore it becomes easy to listen and welcome the messages or what they say.[177]

One could say that FBO/Is can offer religious legitimacy for positive attitudes and responses to HIV and AIDS, in the same way that they might promote stigma and negativity. This other, potentially positive side of the coin is important, not just in theory but in practice.

Many respondents in this respect clearly distinguish Masangane from secular NGOs, but also from government agencies which they seem to regard with more suspicion than those who speak or act on behalf of the church.[178] This is probably in part due to the role of the Church in social justice in the recent past and the kudos it received as a result.

At least one respondent was quite direct: Believing that the church 'guarantees' that there will be no corruption "because the church preaches truth and honesty" whereas in other institutions resources might easily get diverted to other purposes than what they were intended for.[179]

Whatever the naiveté of the speaker about corruption in churches, the standard normative position against corruption or fraudulent behaviour that is intrinsic to their religious tradition remains relevant.

And even government itself seems to agree on the value of the credibility that churches and church-related bodies offer, the confidence this engenders for FBO/Is for which reasons it also wishes churches to take up the role of offering support to people living with HIV.[180]

5.10 Norms, values and rules

The church is a presence in Masangane's work – by making its buildings available, by its 'ownership' of and support for the project and by the fact that most of the staff and volunteers are members of churches. Tangible impacts such as these do also have less tangible outcomes. For instance ecclesial norms and rules shape any programme with such an ecclesial 'body'. We do not mean here the general set of norms and rules that govern church membership, but a specific orientation, urged upon members as part of a disciplined Christian life, that is relevant to the spread or control of HIV.

But I think the involvement of the church is important, because it gives the structure a format, it gives a set of rules, which I think, is essential in this.[181]

In particular, admonitions about personal control in sexual relationships, and the use or abuse of alcohol enter into the way in which Masangane relates to those whom it treats.

Some rules, primarily to do with proper treatment protocols, do in fact function in Masangane as regulations to which clients on ARVs are expected to adhere, for which reason they enter into a formal contract with Masangane when they enter into the treatment programme itself. Most clients value the rules as such.

Another area in which the values of the church were mentioned is that of fostering an attitude that helps people accept their HIV positive status. While this could be seen as fatalist, the quotation here demonstrates that it is regarded rather in a positive context:

All the power and strength come from God and that is where you get your self esteem, your self control from. They say whatever God has given, you should accept it.[182]

Occasionally, however, these rules and norms of the church are considered burdensome, as something attached to the programme that is conditional and not helpful. At least one respondent, himself on ART and somewhat resentful of the lifestyle this imposed on him, commented:

You know when treatment is funded by the church you get these rules and regulations: This is how you should behave, you should not smoke, you should not drink. It is not like I am proud of, or I am into, drinking, I drink sometimes and I do not like to hide myself.[183]

This signals a wider issue that impacts generally on the difficulties in achieving full adherence to treatment protocols, namely, the ongoing importance of individual agency in making choices or shaping behaviour, and this cannot be ignored.

5.11 Conclusion

In probing what value is added by a specifically *faith based* health intervention such as Masangane's ART programme, some practical advantages become

evident.

Setting up a community programme is much easier if this can be done through an existing structure in the target communities. The church is not only present in these often remote areas, but it has its infrastructure to offer, and conducts meetings that can be utilised for promoting the programme.

Further, a FBO/I approaching the community through an established church benefits from the credibility of this institution, and through it, has access to a volunteer base. These tangible assets available to those establishing FBO/Is within a religious denomination offer a definite comparative advantage.

The norms and rules that religious bodies propagate have become the substance of other major initiatives in the field of HIV prevention or control, in particular through the famous ABC model,[184] and more recently (especially as part of the PEPFAR programme) through the emphasis on 'abstinence only' programmes. Though the ABC model has been used in Masangane's educational programmes, Masangane's stress is less on advocacy of the model than on combating stigma (through education and through the effects of its treatment programme), supporting AIDS orphans, and extending the lives of the parents so that their children do not become orphans in the first place.

The norms, rules and regulations they do propagate (which have to do with adherence to ARV treatment protocols primarily) function mainly in support of these activities. For those on ART, the support of some sort of intact family is thus strongly emphasized, as is care for each other, monitoring through a buddy system, openness in confronting HIV positive status, and support from families and friends for those who do acknowledge their status. Virtually all of these norms or values are linked to religious ideas or beliefs in the Christian tradition about compassion, love and hope although they a re by no means exclusive to Christian groups.

Apart from the one expression of discomfort with Masangane's religious nature mentioned above, only positive comments were made by respondents regarding the role of the church – and this in itself ought to be probed further. We also have to consider that it may be difficult for those benefiting from a church programme to voice their concern with areas of the programme with which they are uncomfortable.

In other circles there is much concern about the role of churches regarding ART, especially of churches who undermine ART programmes by their teaching. Thus they may proclaim that "the blood of Jesus is sufficient for healing" and no medical treatment is required for those with AIDS; or go even further in suggesting that entering into an ART programme in itself constitutes an admission of disobedience and lack of faith.

To its credit, Masangane as a programme has been able to maintain a connection to the teaching, values and structures of the religious tradition within which it is embedded while maintaining a scientific approach to the actual treatment it offers. To be able to call on the resources of its religious tradition, and yet remain open to new possibilities in responding to AIDS; to offer a Christian embrace to those with HIV – wherever they come from – and draw them into a well controlled bio-medical treatment programme is no mean feat. And in this context, its faith-based character clearly adds considerable value. While it may be difficult to measure this contribution, it is very obviously an important part of Masangane's success.

5.12 Summary of Evaluative Judgements: The 'value-added' of a FBO/I offering ART

§ *Access to communities and to potential clients*

The link of an FBO/I to a broader based religious body which has existing local presence, such as a church denomination in the case of Masangane, offers opportunities for strong local access (to congregations, for example) based on trust in the motives, commitments and ideological foundations of those who act on behalf of the FBO/I – thus, the FBO/I is likely to reach potential clients more effectively than most other agencies.

§ *Advocacy through access*

Through its access as an FBO/I to local congregations and related groups, Masangane is able to advocate for greater openness about and understanding of HIV and AIDS, and to work thereby against stigma; similarly, it can play an advocacy role among local doctors to encourage them to offer their services in innovative ways.

§ *Motivated, committed staff and volunteers*

The 'value added' by the faith of the FBO/I workers is reflected in the attitudes they bring to the task: Commitment, passion, caring, willingness to work hard for little compensation, in order to make a difference to the lives of others. Faith leaders are able to be instruments of hope to those in need.

§ *Liturgy, rituals, love and care*

The performative (liturgy and ritual) and affective (love and care) dimensions of religious or faith community life, which bind people together in ways that they regard as vital, function positively to guide health behaviour (e.g. adherence to treatment protocols as in Masangane's use of Moravian twice daily devotional readings to govern the taking of ARVs) and provide needed care and support.

FBO/Is may be able to support ARV treatment and other health practices through the use of rituals that provide religious legitimisation of treatment and undermine stigma.

§ *Spiritual support*

The faith-based roots of FBO/Is provide particularly rich resources, languages, performative practices and idioms to engage with and sustain the intrinsically "spiritual" encounter that people experience in support groups, making it more durable and lodging it in an enduring tradition. In socio-psychological terms, the dynamics of "belonging" are enhanced and have the potential, at least, to anchor this belonging over time (that is, through incorporation into a history of belonging) and through space (that is, in relation to other groups linked to the same religious tradition).

§ *Reach out to the marginalised and neglected*

Given that HIV/AIDS invokes taboos, evokes stigma, and provokes marginalisation of people known to be HIV positive, a faith tradition that encourages its adherents to respond positively to those who are marginalised and neglected can be a potent tool for action appropriate to that vision, as is the case with Masangane as an FBO/I consciously relating itself to an exemplifier such as Jesus.

§ *Inclusivity*

It is considered especially valuable that an FBO/I such as Masangane is, as part of its self-identity, inclined to welcome all and sundry in a context where many people feel pushed from "pillar to post".

§ *Credibility*

FBO/Is such as Masangane, in their interventions in health, are able constructively and effectively to draw on the credibility offered by their host or affiliate religious body because it is (often, though not always) generally more trusted than many other institutions in society in local contexts. This includes their "power to speak" to people – a huge potential – and the enabling environment provided by the host or affiliate religious body.

§ *Norms, values and rules*

Norms, values and rules in FBO/I environments often carry weight; and even if this is so only to the extent that individuals accept them, it remains a potentially important dimension of how health interventions, including ART, are delivered or received. Though there is obvious room here for abuse, so too is there and for gain, Masangane being an example of the latter.

Chapter 6

Plural Health Systems and Health Seeking Behaviour of Masangane Clients

6.1 Introduction

Our research at Masangane makes it clear that one of the most critical issues to deal with in health care (in South Africa as elsewhere), concerns the plurality of health systems that define the context within which interventions are made and policy is developed.

Lazarus, in an intriguing comparative study with Native American views on health promotion, sees the South African context as comprising "parallel systems" that "live alongside one another", but where respect and resources are differentially distributed between them.[185] Our research sustains this claim regarding the way in which people view and utilise the options available to them.

> *Some go to traditional healers, some to faith healers, some to doctors and some to untrained private doctors.*[186]
>
> *Just because, as I have said, towns are at a distance, where hospitals are; people here in rural areas get help from the traditional healers; they commonly go there, or maybe because of the knowledge they have about herbs, opt for self help. Most of them do that.*[187]

These quotes, from interviews with people on ARVs, point to the three major approaches to health that impact on the context and ethos within which Masangane operates – traditional healing, faith healing and 'Western' biomedicine, each with its own provider and set of practices. Each also appears to have its place for health-seekers.

To understand this is particularly pertinent for the reception and implementation of health interventions, for few people ever use only one system of healing,[188] usually preferring to *mix* health systems strategically. This is our focus here.

The discussion begins with an introduction analysing the views of respondents, almost all of whom are on ARVs or treatment supporters on traditional African healing systems. It then considers the evidence for plurality and mixing in the context of Masangane, the reasons people give for mixing, and the implications of conflicting or competing health systems in that context. Masangane's response to such plurality is then explored, leading to the question of whether different approaches to health can be reconciled.

Pavement display of a traditional healer's wares

6.2 Traditional paradigms of healing and illness

It is a widespread premise in an African context that any persistent illness requires super-natural intervention or at least further explanations of causality than material ones. In the case of AIDS, the long duration of the illness, its 'mysterious' qualities (a virus that hides itself, uncertainty about its origin, its current incurability), and the fact that people are infected long before there are any signs of this, all pose an explanatory challenge.

Clients of Masangane were found to be very well informed about the biological and physiological aspects of HIV and AIDS. Explanations that remain at that level are, however, seldom treated by them as complete, as they do not go beyond the physical to answer questions such as "Why does this happen to me?"

The tensions that result from competing or even contradictory explanations occur within individuals and families, as the following account from one Masangane client illustrates:

> *She left her husband and came to live with her grandmother at home. The grandmother wanted to cut her and she refused and said not now, next week. In the evening the grandmother went away and came back again, and said, " Hey wake up….I must cut you", and Sibongile said: "No you can't do this because I'm HIV positive". But before she could tell the grandmother she was forced, because the grandmother wanted to cut her. She told the grandmother and the grandmother said "Ha! Do you mean to tell me that you are prostituting just like your aunt because she died of AIDS. You had many men in Johannesburg". So she said, "No, it's not like that". She explained and she then came to the support group.*[189]

When Sibongile entered the Masangane treatment programme, she moved onto ART. Her grandmother's reaction then was to recount the death of an aunt on pharmaceuticals of one kind or another. That some people nevertheless die after being put on ARVs, for whatever reasons, appears to sustain the suspicion evident in this narrative, a point to which we return below.

Of course, all treatment protocols are limited or imperfect, but this is precisely the point. No single one offers a complete 'explanation' for illness, which is never viewed in an African cultural context as merely biological or physiological, nor as something whose cause is limited to an individual body.[190]

The potency and pervasiveness of multiple levels of explanation for illness, including HIV/AIDS, and the tensions that accompany a conflict of worldviews, may be conveyed by three further narratives from respondents, all of whom are on ARV treatment:

> *Sometimes people who have AIDS would say they have something in their chest [they present with chest problems], and once they say this, the traditional healers say it is* sejeso *[it comes from someone who wants to kill, bewitch or otherwise hurt you]. Then they will start taking such a person to traditional healers. If they have a problem with their feet then they would say* ba behetswe/ ba tlotse kae kae *[they have stepped on something that was meant to kill or bewitch them, or they have ingested something meant to hurt them].*[191]

> *When I first started getting sick I thought that I have a Xhosa sickness [that is, something needing traditional healing]. I had blood coming out of my nose. I used to say to my mum, why don't you go by the municipal offices and get me that herb in order to make me a neck string [a necklace that is believed to offer protection]. I am feeling cold.*[192]

> *Grandfather started taking me to traditional doctors; he said this is not AIDS. AIDS is not like this. … my grandfather said no,* ubekelwe *[something has been dug somewhere to make you like this]. We went to so many people and one in Dongwe said I am being bewitched by my boyfriend's girlfriend.*[193]

Here it is worth noting Murove's claim that "while Western medical practices tend to see disease in terms of the functioning of the body, in the African context, disease is understood in terms of a causal relationship between 'visible' and 'invisible world'"[194] He also points out that "the traditional doctor has a holistic approach whereby diseases and suffering are understood as caused by a situation of disharmony in human, environmental and spiritual relationships".[195]

The point about these indications of cultural influences on health and healing is that they are socially embedded. They sit within deeply rooted views of the world and of the person; views that are both widely present and unlikely, for all practical purposes, to be eradicated. Whatever the difficulties that result, this reality needs to be accommodated, both for its own sake (the challenge to a positivist scientific view on health is obvious) and for the sake of effective interventions in the HIV and AIDS context.[196]

6.3 Evidence of the plurality and mixing of health systems

All respondents interviewed in Matatiele, Shiloh and Mthatha were clearly aware of the presence of other health systems alongside the dominant 'Western' biomedical system offered by public health authorities – in particular, traditional healing and faith healing. So, for example, one focus group of health-seekers, when asked "What is the first place that you normally think of going to when you are sick?", responded variously: To a clinic, the doctor's surgery, a person known to be a healer, or the church to pray.[197]

They differ however in how they think about and adapt those health systems in what appears to be intrinsically personal health-seeking behaviour, and when they mix approaches to healing, they do not necessarily do so in ways that integrate them.

6.3.1 Simple and complex mixing

Both qualitative and quantitative data highlight a certain general pattern of behaviour. Most respondents adopt 'Western' medicine first when they are not well, and when it fails they adopt another strategy, either together with or to the exclusion of biomedicine.

This is *simple mixing*, a sequential use of different health seeking approaches, as opposed to *complex mixing*, where respondents use different health systems simultaneously.

Simple mixing may be evident in responses from members of the focus group who, when asked what happens when they do not get better after going to a clinic, hospital or medical doctor, commented that "you go to Sotho Doctors [Traditional doctors]", "Or you go to a person who prays for people. I go to church."[198] This sequential patterning of strategic choices appears to apply in most instances.

Complex mixing is also evident among Masangane health-seekers who acknowledge using different health systems concurrently, in some cases even after they have begun ART. As one doctor we interviewed suggested, in desperation, people will try any thing to get well:

> *I do think that people with HIV make use of any opportunity that they get. People usually are quite desperate and in need of help. And if they get offered herbs…if they get offered multi-vitamins, then they will try that. If they get offered ARVs from a church group they will try it. And if they get offered ARVs from MSF, they will try it.*[199]

Clearly, individuals are actively adjusting their responses to illness according to changing factors and experiences (success or failure) all the time, and no one health system has full sway, including the public health system with its dominantly biomedical orientation.

6.3.2 Mixing while on ART

Our survey data on Masangane health-seekers reveals that almost all the respondents who are now on ARVs tried approaches from multiple health systems before they learned about their status. Even when on ARV treatment, though Masangane has good monitoring systems and issues warning about mixing treatments, there are at least some indications that clients mix ARV treatment with something else:

> *I once mixed with* hleka *[a traditional medicine]…My feet were swollen and I could not walk, but since using it, all the pains I had are gone, only a little bit is left. Even now I am still using it. Even the pills. I still take my pills, then after an hour I take it. I wait for the pills to settle in my body. Even in the morning I do the same. I feel alright. I realised that there are other small illnesses and* hleka *has taken them out. That's what helped me…The pain I used to have is no longer the same. I am better. There is an improvement.*[200]

We cannot make medical judgements about this account, but from the point of view of the health-seeker mixing can be regarded as successful and necessary, at least in dealing with minor illnesses or side effects of the ART for which traditional healing has a reputation. We may reasonably assume that this is not an isolated case. Some members of the health-seekers' focus group also expressed their interest in mixing systems by pointing to frustrations arising from what they feel are unhelpful constraints on mixing through the treatment literacy training they get on the use of ARVs:

> *I think there are some of the things that we can mix but we are just afraid.*[201]

Whether from lack of trust, or because of a desire to cover all bases, it appears that the reality is that in most places people are mixing health systems when they are sick, as much in the case of HIV/AIDS as in any other disease. This is so even though Masangane clients are aware that mixing treatments can be dangerous, and people are believed to have died due to the complications caused by drug interaction while mixing treatment strategies, as one narrative indicates:

> *You know there is a police man who died. I used to know this guy. About two months ago I was talking to his sister and she was telling me that, hey, Sukwini, you were right this medicine must not be used with any other medicine. This guy was using this medicine together with another traditional healer's medicine together with some treatment from the clinic or a private doctor.*[202]

Indeed, despite the dangers, the evidence of the detrimental effects of mixing traditional healing with ARVs is neither obvious to health seekers nor taken for granted by them:

> *Also the other one, his CD4 count was 3. He was very, very sick. That was before he came to Dr N [and was] still with Dr P. He was very sick. And the mother didn't believe in ARVs only. She was also giving him traditional herbs. And he died. I won't say it was because he took the herbs, because his CD4 count was low.*[203]

6.3.3 Patterns of mixing: "Window-shopping"

Masangane staff are intensely concerned about treatment literacy, but they are also aware of how their clients actually make choices and Masangane staff are unwilling to be dogmatic about clients' choices in general:

> *There are people who come for advice first, because they've heard about the traditional medicines from outside. And then they come and ask: "Because I am using ARVs, can I use this?" So – I tell them about drug interactions. Not actually that traditional herbs will kill, no, I don't say that …. I just tell them about drug interactions.*[204]

We have suggested above, following both our qualitative and quantitative data, that our respondents tend to seek out 'Western' medicine first when they are sick. But an anecdotal comment suggests that many people may well first attempt traditional healing, perhaps not only because it is accessible but also, as at least one Masangane doctor mused, because 'it is in their system':

> *Look, one has got to be realistic…I have heard that 70% of people will go to a sangoma before they go to a Western doctor. You can't take it out of the system.*[205]

This is an untested figure, of course, yet the doctor's comment no doubt reflects a general tendency. His reference to being unable to counter the turn to traditional healers because of the 'system' within which client health-seeking practices are located is the point. Alongside the public health system, there is another, often competing, sometimes contradictory, system at work among local people, and it has efficacy whatever one's 'scientific' attitude to it.

In short, what cannot be "taken out of the system" is the plurality of health-seeking norms, attitudes and behaviours that make up the healthworlds[206] of Masangane clients. This they often speak about as "window-shopping", in itself an instructive metaphor for looking at what is on offer, deciding what you like most for a particular need, and purchasing accordingly (with cost also being a concern).

> *Maybe the grandmother she is going to 'window-shop'; bring this person from this doctor, because they don't trust that the first doctor gave the results properly. Then they are going to visit another doctor. And the money is going…*[207]

6.3.4 Reasons for mixing

As one reason for mixing health systems, respondents named *desperation* or *frustration* in the search for wellness in the face of a perceived failure of 'Western' medicine. Perceptions of failure

seem to be connected to one or more of the following factors: The length of time one waits for medication; delays in visible healing once on medication; ormedical staff admitting their inability to deal further with one's illness. Similarly, some people become frustrated early in their ARV treatment when they see others progressing well, and try anything that could help them get better. This narrative from one respondent is not atypical:

> *When one finishes the treatment [for shingles] with no change in her/his health condition, she feels one should opt for another strategy…I had shingles in my face. The clinic failed to treat me and I had to go to the traditional healing, and I was treated successfully. I was taking treatment for these shingles at the clinic for a long time and I was getting worse rather than better, so I was advised to see a traditional healer and was cured.*[208]

A second reason for mixing has to do with *access*. A frequent comment from respondents on the use of traditional healing mentioned living at long distances from towns, and hence from hospitals. People in rural areas, far from public health facilities may turn to traditional healers simply because they are close by.

Yet distance is not necessarily decisive, because the same people appear to respect the healing power of traditional herbs and might opt for them in any case. Traditional healing and medicine is seen as having an *intrinsic value* of its own, a third reason for mixing. Indeed, some respondents tell us that people use traditional medicines relevant to certain illness even though they can be costly and less accessible than treatment available at a public facility; and at least one doctor suggested that clients might spend more on traditional healing and medicines than what they normally spend on Western doctors.[209]

In this context, *claims of effectiveness* by traditional healers who maintain that they are able to treat or even cure HIV and AIDS come into play, as one respondent demonstrates:

> *While with traditional healers, there is a woman in Nqamakwe; I know for a fact that her medicine has helped numerous terminally ill AIDS patients rise up from their beds. … I have two people at my support group in Umtata who have used it and survived… There is even one girl here just up the street who has used it; she can testify to you.*[210]

Nqamakwe is a long way from Mthatha (formerly known as Umtata), Shiloh and Matatiele but people nevertheless make an effort to see this traditional healer despite her being neither accessible nor affordable.

A *lack of trust in public institutions* is another factor shaping health-seeking strategies, as one respondent articulates, reflecting on personal experiences:

> *They do not trust government hospitals. Things like the conduct of nurses who are serving time and not people. In all they do not trust clinics and hospitals, and some are saying there is a lack of discipline from the side of nurses. So because of the conduct of nurses, people prefer not to go there, and prefer to eat herbs that are immeasurable. And those who can afford it, go to private doctors.*[211]

There is another side to this, namely, that the public health system in South Africa provides services that are largely not adapted to an African cultural milieu. Its approach excludes competing explanatory frameworks that are still important to a great many people. Lack of trust may be a consequence of such mono-explanatory views of health. Indeed, many clients of Masangane do not separate themselves from their culture.

Nor do they therefore see traditional healing as a specific health system as we do here, but rather, as integral to their *cultural embeddedness*. One Masangane treatment supporter, himself well educated about ART, argues that:

> *…because so many people have been brought up going to traditional healers, so it is not something that you can change. In fact even if you try to change that, then you make them not to listen to you. It is just that you have to explain to them, 'use one at a time'.*[212]

Our survey shows, on the other hand, that some Masangane clients would not adopt traditional healing or undertake related ritual acts for any type of illness. Generally, one explanation for what may appear as alienation from, or rejection of, their own traditional cultural systems could lie in the exclusive nature of 'Western' Christian beliefs as propagated by certain movements in the area, which are strongly disparaging of traditional cultural practices. Here there is a negative judgement of one health system that would work against practices of mixing 'Western' and traditional health strategies.

In sum, strategic, pragmatic and cultural factors interlock with each other in how and why people choose to mix health systems, and any reductionist view of these interlocking factors is probably misplaced in most cases. In what follows, we explore some of the ways in which this plays itself out in the context of Masangane.

6.4 Some effects of competing health systems

6.4.1 Secrecy and mutual suspicion

The disjunction between health systems, in the context of a public health system dominated by a 'Western' scientific paradigm, also produces silences and secretive activity about traditional health approaches. We can be reasonably certain that our own research is a reflection of a public transcript played out on the stage we present, and that, offstage, there remain 'hidden transcripts'

among Masangane clients that we are unable to probe.[213] That these hidden transcripts exist, however, can be discerned in disguised or coded form, or through oblique referencing, in the material we do have.

The *views of doctors* on the use of traditional healing systems point to this reality; they also express the suspicion, if not outright rejection, of their value or efficacy. As one of Masangane's support doctors suggests:

> *Look, I guess there are people who are doing that. I haven't actually had anyone actually confessing that they are actually doing that. But I guess they are doing that. People are trying anything.*[214]

The conflict of health systems remains problematic. From the point of view of the biomedical paradigm, in respect of HIV, Dr Nabiso points to his stance as medical doctor very clearly when he says:

> *Look personally I have a problem with that. I do know scientifically: It is only ARVs that work and these other things don't work. I discourage it. I tell them straight that they don't have to go to that extent. Because scientifically it has been proven that ARVs work. The traditional medicine doesn't work as far as I am concerned. So I discourage these people going there.*[215]

At the same time, it seems that traditional healers are increasingly being drawn into cooperation, according to Dr Suttner, who notes that things have changed particularly since treatment became available and as a result of education by MSF in the area:

> *…now traditional healers are asking people 'have you been tested for HIV?' 'If you haven't been tested you must go to a clinic to get tested.' 'If you have been tested, what is your CD4 count?' You know, those are the questions that traditional healers now ask patients, which is a tremendous shift towards traditional healers accepting … clinical medicine.*[216]

Dr Nabiso, on the other hand, has the experience that "there are people who claim that their trust in God is going to heal them; they won't take ARVs."[217]

The views of traditional healers were harder to come by in our interviews, but also confirmed the workings of secrecy:

> *The client comes to me, and things happen in that way, it's my secret you see? Just like that, and that's where it ends, there's nothing I can say.*[218]

On the other hand some traditional healers boast of winning the battles that 'Western' medical doctors have failed to win, believing that their medication ensures faster and more effective interventions for certain illnesses.[219]

The *views of Masangane workers* are not much different from those of the doctors they relate to. One worker argues that his culture has such secrecy embedded within it:

> *I mean in an African culture you do not tell people that I have been to the traditional healer and he gave me this and that because usually if you go to the traditional [healer] there is to some extent a belief that it is [about an] evil spirit. So you do not want people to know that you sought help from a traditional healer.*[220]

6.4.2 Suspicion about other religious groups

Elsewhere, in an earlier chapter, we reported on evidence that religious bodies, churches in particular, offer a measure of credibility upon which the Masangane treatment programme can rest, enhancing its effectiveness. But there is also a high level of suspicion among Masangane workers, supporters and clients about some religious groups, especially those who undermine ART.

For example, the use of blessed or holy waters to treat people who are sick, including their use as an internal cleanser, is seen as dangerous for people who are HIV positive.[221] Worse, in the view of some respondents, are churches that preach a message that "being born again" is sufficient for healing ("give Christ a chance"), on which basis people are told to stop taking ARVs. One Masangane client confessed to following this advice after joining a particular church group, after which she became "very, very sick". On returning to Masangane's programme, she recovered again.[222]

A local faith healer in working dress

Masangane workers report similar incidents, including "a lady teacher, who stopped taking antiretrovirals because she was healed by Jesus…After 6 months her CD4 count was down again."[223] Another Masangane client is scathing about such groups, seeing them as "money makers" to whom he is not even prepared to listen, especially "since I got to know that there is a perception that HIV is cause by the demon I really do not want to listen to them."[224] At the same time, we should not overstate the position. As one church leader noted,

while some groups such as Zionist churches mix 'Western', traditional and faith healing practices, most churches nevertheless encourage people to use standard biomedical interventions in compliance with protocols.[225]

6.4.3 Self-help as option

ARHAP has a strong interest in the agency of individual people and hence in the way they, perhaps more cannily than is generally assumed, make choices and fend for themselves. In this regard it is worth noting the view of one of the pastors in Masangane's management team about "self-help" as an option that many people choose to exercise, especially in the face of access and cost difficulties.

6.4.4 Immune boosters, vitamins as alternative health approach

In the South African context, ART programmes cannot escape the well known controversies surrounding the confusing position of the national Minister of Health's views on the problems of anti-retrovirals and the benefits of nutrition. This is fuelled by the activities of groups such as the Rath Foundation, who promote food supplements as treatment for AIDS. But this tends to obscure a general consensus, even among those attacked by the Minister and Dr Rath such as the TAC, that nutrition and natural immune boosters are a sine qua non of any intervention that takes seriously the environmental and social determinants of health. It is not surprising, therefore, to find several Masangane interlocutors referring to this.

Dr Nabiso confirms that many people are taking immune boosters and purchasing vitamins in significant amounts, though he is not particularly sanguine about its value,[226] while Masangane's treatment coordinator sees it as "an 'in thing' to be using it".[227] Dr Pinyane, on the other hand, was quite clear in his views on the use of immune boosters: They were "defeating a lot of the work we are doing", and are also far too costly:

> *…the current price on this treatment [ARVs] is about R360. You know, patients were spending R500 or R600 on this rubbish …. it is one of the few moments that I get heated up, I tell them it is a total waste of money and it is a money making racket on the part of the doctors.*[228]

6.5 How can we reconcile different approaches to health?

That the dynamics we discuss in this chapter are not particular to Masangane is shown in a conversation from the field with our researchers that offers two striking examples of how complex this terrain is, how readily personal and 'professional' convictions about HIV and AIDS may differ, and how trust in bio-medical treatment and faith-healing may be in conflict, even in one and the same person.

> *Nomfundo, a young MSF worker, accompanied us on a field visit. On the way she told of members of her congregation who had AIDS, but were reluctant to access treatment. Their church proclaimed that God heals all disease, including AIDS. To go for ART would comprise an act of unbelief. Nomfundo told us that she spends much energy encouraging these members, a number of whom are government employees and can access ART through their medical aid, to do so. She was proud that she had succeeded to convince some to change their approach, to enter the ART programme – and live. When asked what she would do if she should discover that she was HIV positive, Nomfundo said: 'I will never use ARVs. For me the power of God is enough to heal me.'*
>
> *Upon reaching the clinic the doctor told us of one of his ARV-patients. He is a pastor of a church in which no-one knows about his HIV status or his participation in the ART programme. His message to his congregation is consistently that, with faith in God, there is no need for anyone to turn to ART.*[229]

So far this indicates that people are often living parallel lives shaped by complementary or competing discourses. Generally Masangane clients and their wider communities live in the contemporary world, yet remain informed by and well vested within their traditional worldview. In the face of illness, and HIV and AIDS in particular, people straddle two or more worldviews. Long before government legislation on traditional healers (about to come into play) they have been pro-actively making the connections.

Even though most of our respondents from Masangane view ARVs as a "resurrection factor" of great importance, so much so that they are willing to constrain their health-seeking behaviour according to the appropriate biomedical treatment protocols, there remain some key indications that this produces conflict for them. One of them expresses his frustration this way:

> *The ARVs are right. The only thing that I do not like about them is that you are not supposed/allowed to mix them with other things. You understand that we are black people, we have other beliefs, even the witchcraft. While you are using ARVs there could be other awkward things on your side that you need to deal differently with. [they all laugh] Some things won't be necessarily needing ARVs but other approaches. [laughter continues] That's the snag.*[230]

Most traditional healers and faith healers we interviewed seem to have no problem with people mixing different health systems. At times they even encourage their own patients to mix their treatment with that from other health systems, even in the case of HIV and AIDS. As Dr Mathe puts it:

> *But according to my opinion I think it's to try one method, if it fails…you can try this and see which way, because…according to my knowledge , there are some diseases, illnesses, which Western Doctors cannot cure, even if you can go to the hospital.*[231]

Dr Mbonge has been involved in putting together an organisation that includes herbalists, sangomas, and faith healers, linking them with the Department of Health in order to assist in the fight against HIV and AIDS. He makes the same point in relation to the public health system per se:

> *I just wish for the organisation to proceed in collaborating with the government so that we also may have opportunities of being known when and how we treat people. For us not to be hidden in our treatment of people because some of the diseases, people are dying even in hospitals. And Western doctors having the inability to treat some of them, when we have the ability to treat them using the traditional way.*[232]

Dr Pinyane, a 'Western' doctor, on the other hand, demonstrates a certain level of tolerance only within strict limits:

> *My personal feeling about the sangomas is, as long as they are doing no harm, I have no animosity towards them. I accept their presence, and I accept that they are a necessary part of the cultural management of the individual. I have great anger when they interfere with my management. I feel, you know, I feel very strongly, that if they propose that their treatment will kill my patients and will take over my role, I will fight that to the end.*[233]

In general, in the context of different traditions in which health systems are rooted, we discern a residual level of animosity. Perhaps the ongoing and eloquent silence or lack of communication between these health systems is a symptom of this animosity. We came across very little evidence of cross-referrals, which might offer one way of moving to a more cooperative framework between different health systems and a better response to an irrevocable plurality of systems and mixing of strategies. At this point, in the areas within which Masangane works, there is a prevailing lack of trust and lack of communication between the different healing systems. These health systems do not really understand one another.

6.6 Masangane's response to plurality

Health providers from traditional and faith realms are divided. There are those who see nothing wrong with mixing and even encourage their clients to use different health apporaches. Others are more rigid, especially in respect of AIDS related illnesses. As we have noted at several points above, however, Masangane and its doctors generally discourage mixing and, indeed, the use of any health systems other than ART.

Dr Nabiso, as we have already noted, is very vocal about this, sure scientifically that ARVs are the only proven and effective treatment for AIDS, and clear about discouraging people from turning to traditional healing. Similarly, both Sukwini and Ntingase, health workers within Masangane, argue that it is difficult to refer or even encourage health seekers to go to traditional healing because it is 'immeasurable', 'not well researched', 'lacks documentary proof about side effects'.[234] Sukwini has strong views on this:

> *Its a bad idea. If you are so stubborn that you want to use your traditional medicine use it, go ahead but do not mix the two…if you want to use your traditional medicine and won't take advice then you will know it is failing then you will stop and use Western medicine but if you use two, how are you going to know which is one is failing.*[235]

Among Masangane clients, faith healing per se does not seem to be a major factor. But religion, or more precisely, one or other *formal expression of religious faith*, is identified by many as one significant asset for their well-being. For example, our survey data indicates that most of the respondents rely heavily on prayer and church support when they are sick, especially in the face of protracted illness such as HIV/AIDS:

> *Maybe it is also because many people run to the church when they are sick. Unfortunately with this disease, it won't go away.*[236]

Leaving aside earlier caveats about the ways in which religion may counteract good treatment practice, this may be regarded as an indicator of the importance of religious faith for resilience. It may also point to the way in which a health system configured along religious lines is a valued element of the strategic mixing of approaches, as we have suggested in earlier chapters.

6.7 Conclusion

The diversity and plurality of health-seeking approaches, or what we here call mixing of health systems, is common among Masangane health seekers. Mixing strategies while on ART is a controversial, even dangerous matter. But it is more often than not the norm in the context in which Masangane works, and it has its own logic.

People mix health systems for various reasons: Desperation, frustration, ease of access, competing claims of effectiveness or lack of trust in public institutions. Most of our respondents say that they do use, or would like to use, multiple health systems, whether concurrently or sequentially. We can also say, with considerable boldness, that:

- ART and other biomedical or 'Western' responses to disease in this context are only part of the picture;
- mixing of health systems is more common than uncommon, perhaps pervasive, and the extent to which mixing is a more rural phenomenon is not known;
- this strategic mixing of health approaches has its own perfectly clear pragmatic logic, in respect of a canny appreciation of the strengths, weaknesses and limits of any one system;

- any particular approach is promoted and evaluated not only individualistically, but also in relation to communal, cultural and social norms and values;
- any one intervention – and ART in particular must be placed within this realisation – must take into account the effects of mixed health systems in the practice of health-seekers;
- mixed practices will not be eradicated, either through experience, a growth in technical or biomedical knowledge among clients, educational processes, preaching or other forms of counter-advocacy, or any form of sanction.

The ambiguities of religion or faith make it difficult for health practitioners, such as the doctors serving Masangane, to integrate religious realities into their practice. Competing or conflicting diagnoses and explanations of illness contribute to this unease, thus reinforcing doctors' tendency to stick with well-known bio-medical interventions and exclude other approaches.

Practitioners of other health approaches e.g. traditional healers and faith healers, like 'Western' doctors, tend to operate in mutual suspicion of each other, and secrecy is not uncommon among those who are outside the dominant bio-medical system. At the same time, tensions between different religiously informed traditions are also present (e.g. African-Western) and we can expect that some health providers take advantage of these tensions as they seek to win clients.

Given the context, there are also incentives to use immune boosters, or to rely on self-help rather than on any formal health approach. This adds to the complexity of health choices and behaviour.

The need to reconcile different approaches to health provision by health practitioners and health authorities is clearly necessary. Though others may have stated this previously, the Masangane research strongly stresses this insight.

Masangane itself might be seen as resting primarily on 'Western' ways of dealing with AIDS and this is certainly true in respect of its treatment practices and protocols. But it also represents something that has become increasingly part of public health thinking, namely the need for a far more holistic response to illness and disease. In the case of Masangane, this includes its comprehensive and integrated range of responses to prevention, care and support beyond its bio-medical activity.

Dr Herman Reuter and Zoliswa Magwentshu

Chapter 7

Conclusions and recommendations

7.1 Introduction, context and aim of report

The concluding chapter serves to bring together the findings of each of the chapters and thus serves as an overview of the findings of the report. The findings are reflected on in the light of the current position of the ART roll out in the country. This allows the drawing out of lessons from Masangane for the role of FBO/Is in the HIV and AIDS crisis and more particularly regarding ART provision.

The study has been undertaken by a team using an emerging theoretical framework that addresses the interface between health and religion. While not detailed, the chapter provides some theoretical reflections on the value of some of the concepts used in the ARHAP framework, based on insights regarding religious health assets and on the way in which the health behaviour of individuals and communities is influenced by their belief systems.

While the preceding chapters in the report have addressed the objectives of the study individually, this chapter allows for cross-chapter reflections based on key themes. These key themes are the role of religion in the health and behaviour of individuals on ART, the insights from the study for the health system, the importance of integrated responses, the potential of replicability and scaling up as well as project sustainability.

Finally, a number of policy issues are identified for future discussion with key role players in the province and nationally. Further research needs are identified, based on the gaps in the study as well as additional areas that the findings suggest.

Meeting of support group

7.2 Limitations of the study

The study was undertaken within a relatively short period of time by an enthusiastic team with some capacity limitations. Without an economist on the team, the findings on the costs and cost effectiveness of the Masangane programme could not be explored. This is taken up below under further research suggestions.

The field site was located a long day's journey from the research team's bases making follow up more difficult. From conception to the final drafting of the report, the Masangane management team was affected by the sickness and eventual death of the Chair, Rev Mgcoyi. Further, the context within which the study was undertaken also changed with the start of ART provision by the State during 2005 at State hospitals or clinics near both major project sites.

It would have been very useful to be able to compare and contrast Masangane with other ARV treatment programmes, especially regarding the role of religion and faith in the ARV treatment programmes of the State, Catholic Church as well as MSF.

Notwithstanding the limitations, the report has highlighted a depth of insight regarding the interface of religion and beliefs with health-related behaviour, which impacts on health outcomes and ultimately the success of ARV treatment.

7.3 Evaluation of content

7.3.1 The Masangane ARV treatment programme – an overview

Masangane has evolved in response to the emerging needs at community level. A series of important partnerships have developed which have facilitated and supported the expanding response to the impact of HIV and AIDS in a rural context. The agency of key individuals has provided links to overseas faith based funding agencies that have supported Masangane's work over a number of years.

Masangane shows evidence of local community connections, partnerships with local private doctors and support from national agencies for treatment guidelines. The particular personal qualities and agency of the treatment manager and co-ordinator, previous chairperson and fundraiser has guided the organisation over time and ensured stability.

Common commitment by the core management team to the delivery of ARVs is underpinned by Christian values, such as respect for the dignity of all, as well as the determination to achieve the maximum return on the limited funds available to the programme. This approach has at times been in conflict with the views of others associated with Masangane.

Masangane serves those in need and not only

Moravians. The socio-demographic profile of the ARV clients shows that the majority are women, half of them being heads of households. As with others in the region, nearly two thirds are unemployed though educated.

In addition to the respondent on ARVs, over half of the households included another person who had been ill for a long time. A third of the households could be described as overcrowded, a problem especially regarding the need for privacy for those with a chronic illness. A fifth of the households the respondents come from are located in more remote settings, making them reliant on collecting water from streams and rivers. This will impact on the ease of providing home based care in this environment.

More than a third of the households had had a death in the household during the past year. The respondents living in these households were more emotionally vulnerable at the time of the survey than others who had not had a death in the household during the previous year.

Faith was reported as playing a major role in the well-being of over two thirds of the respondents and was found to offer a sense of meaning and belonging. The respondents made use of a range of religious practices.

In sum, Masangane serves the needs of the poorest of the poor and its beneficiaries would seem to represent the typical profile of rural people: Unemployed, poor and predominantly women. From the quantitative data, the impact of HIV and AIDS is evident. Deaths and chronic illness in members of the households impact on the well-being of the household. It is likely that many of the women receiving treatment would themselves have cared for household members who are chronically ill or have died. Not surprisingly, depression was found in many women and this was linked to their own self rated health – reported as being fair or poor for nearly three quarters of the women.

It is within this context that the role of faith needs to be understood. Religion was reported as playing a major role in the well-being of over two thirds of the respondents as it offered them hope for the future, helped them to survive as well as giving meaning. Masangane responds to the needs of the community in what it does (providing treatment, care and support) as well as how these services are provided.

7.3.2 Assessment of Masangane as viewed by multiple stakeholders

The various assessments by different stakeholders of Masangane highlight patterns that one might expect in its context (such as tension between activist initiatives and host institutions, competition for resources, skills scarcity). But overall, the picture is clear: Masangane represents a highly successful intervention, sustained now for several years despite all external and internal difficulties, as an effective integrated response to HIV and AIDS.

Moreover, this effectiveness is related to elements of efficiency as well, particularly in terms of access to rural people, speed of response, follow-up and monitoring, and high levels of ARV treatment adherence with a low drop-out rate.

If we add to this the positive benefits that are recorded through Masangane's good use of support groups for people on treatment or seeking treatment, its extensive use of volunteers, treatment assistants and care workers, and its comprehensive response to HIV and AIDS – going beyond treatment to include its earlier programme of orphan care, for example – then it is immediately apparent that an FBO/I such as Masangane is a community asset, and not just a health asset.

Or better put, because of its rooting in the local communities it serves and its multiple means of reaching or including them, some specific to faith-based initiatives, Masangane represents a holistic response to a health crisis. In this it offers a model with significant potential for linking, and thus aligning, the public health system to locally embedded and sensitive agents, including FBO/Is, capable of carrying out tasks relevant to sustainable HIV and AIDS interventions that would otherwise be difficult, if not impossible.

Nevertheless, the research presented in Chapter 3 has also pointed to some limitations in the current Masangane programme. Masangane is meeting the needs of a very poorly served, largely rural population, and was able to make ARVs available well before the national ARV programme began. Masangane is well aware of the extensive demand for ART and other AIDS related services, but it does not have the capacity to meet these needs due to resource and personnel constraints.

Given the overall positive role of the services Masangane provides, the potential role of Masangane-type FBO/Is should be considered to complement the State ARV programme, especially in rural areas.

Further, urgent consideration needs to be given to the financial arrangement needed to provide sustainable ARV treatment to the current and future Masangane beneficiaries.

Currently Masangane is dependent on a few core actors who play key roles in the management of the programme. Management stability, based on a clear organisational framework, roles and responsibilities, is critical for the sustained operation of Masangane. Steps need to be taken to ensure that these are urgently put in place. The relationship with the national Moravian church will also need to be resolved to provide the funders with security regarding their commitment to funding of ARVs and not overall church activities.

The existence and success of Masangane must be attributed in no small way to the social capital in the form of bridging ties used to obtain extensive support and funds accessed through one key player, Rev Renate Cochrane. Further, the international links to funders and national links to agencies such as MSF have provided the resources, support and encouragement to set up the initiative as well as maintain the project.

These ties could be described as helping the communities involved to 'get ahead'. The bonding ties of the support group and the commitment of the volunteers provide evidence of the importance of another aspect of social capital, helping communities to 'get by'.[237] Social Capital could be described as a key component of the existence and success of Masangane.

7.3.3 The impact of the Masangane ARV treatment programme

It is evident then that the impact of Masangane is complex. It is there in tangible structures as much as in their intangible effects in people's lives. It touches various bodies: The physical bodies of its clients, and through that their psycho-spiritual bodies, as well as their social identities. Beyond these the impact is felt in widening circles of the social body – families, villages, schools and churches.

Key to this has been the tangible evidence of the benefit of taking ARVs and the resulting 'resurrection effect', with people becoming 'beautiful again' and being able to work. The wide range of education provided – from treatment literacy to beneficiaries and their supporters through the support groups, to skills development for staff – has contributed to the empowerment of the beneficiaries and the broader community.

Masangane's impact reaches far beyond its direct clients and has changed many lives in the communities where it is functioning. Through the ART programme, social, family and community relations are being restored. There is evidence of this knowledge impacting on the broader community through institutions such as schools and churches; and of Masangane impacting very positively on stigma in the community. Through its awareness and education programmes, and through encouraging affected family members to come to the support groups and be informed and educated about HIV and AIDS, acceptance and re-acceptance of those living with HIV is achieved.

Furthermore, the renewed hope of the beneficiaries through regaining their health has contributed to their self acceptance and many have become positive role models for others. Support groups offer a sense of belonging, fellowship and dignity that is crucial to the health and well-being of beneficiaries. This has often led to a commitment to serve others and is one reason for the well established volunteer support for Masangane.

7.3.4 The 'value added' of Masangane as a FBO/I offering ART

In probing what value is added by a specifically *faith based* health intervention such as Masangane's ART programme, some practical advantages become evident.

Setting up a community programme is much easier if this can be done through an existing structure in the target communities. The church is not only present in these often remote areas, but it has its infrastructure to offer, and conducts meetings that can be utilised for promoting the programme.

Further, a FBO/I approaching the community through an established church benefits from the credibility of this institution, and through it, has access to a volunteer base. These tangible assets available to those establishing FBO/Is within a religious denomination offer a definite comparative advantage.

The norms and rules that religious bodies propagate have become the substance of other major initiatives in the field of HIV prevention or control, in particular through the famous ABC model,[238] and more recently (especially as part of the PEPFAR programme) through the emphasis on 'abstinence only' programmes. Though the ABC model has been used in Masangane's educational programmes, Masangane's stress is less on advocacy of the model than on combating stigma (through education and through the effects of its treatment programme), supporting AIDS orphans, and extending the lives of the parents so that their children do not become orphans in the first place.

The norms, rules and regulations they do propagate (which have to do with adherence to ARV treatment protocols primarily) function mainly in support of these activities. For those on ART, the support of some sort of intact family is thus strongly emphasised, as is care for each other, monitoring through a buddy system, openness in confronting HIV positive status, and support from families and friends for those who do acknowledge their status. Virtually all of these norms or values are linked to religious ideas or beliefs in the Christian tradition about compassion, love and hope although they are by no means exclusive to Christian groups.

Apart from one expression of discomfort with Masangane's religious nature, only positive comments were made by respondents regarding the role of the church – and this in itself ought to be probed further. We also have to consider that it may be difficult for those benefiting from a church programme to voice their concern with areas of the programme with which they are uncomfortable.

In other circles there is much concern about the

role of churches regarding ART, especially of churches who undermine ART programmes by their teaching. Thus they may proclaim that "the blood of Jesus is sufficient for healing" and no medical treatment is required for those with AIDS; or go even further in suggesting that entering into an ART programme in itself constitutes an admission of disobedience and lack of faith.

To its credit, Masangane as a programme has been able to maintain a connection to the teaching, values and structures of the religious tradition within which it is embedded while maintaining a scientific approach to the actual treatment it offers. To be able to call on the resources of its religious tradition, and yet remain open to new possibilities in responding to AIDS; to offer a Christian embrace to those with HIV – wherever they come from – and draw them into a well controlled bio-medical treatment programme is no mean feat. And in this context, its faith-based character clearly adds considerable value. While it may be difficult to measure this contribution, it is very obviously an important part of Masangane's success.

7.3.5 Plural health systems and health seeking behaviour

The diversity and plurality of health-seeking approaches, or what we here call mixing of health systems, among Masangane health seekers is common. Mixing strategies while on ART is a controversial, even dangerous matter. But it is more often than not the norm in the context in which Masangane works, and it has its own logic.

People mix health systems for various reasons: Desperation, frustration, ease of access, competing claims of effectiveness, lack of trust in public institutions. Most of our respondents say that they do use, or would like to use, multiple health systems, whether concurrently or sequentially. We can also say, with considerable boldness, that:

- ART and other biomedical or 'Western' responses to disease in this context are only part of the picture;
- mixing of health systems is more common than uncommon, perhaps pervasive, and the extent to which mixing is a more rural phenomenon is not known;
- this strategic mixing of health approaches has its own perfectly clear pragmatic logic in respect of a canny appreciation of the strengths, weaknesses and limits of any one system, keeping in mind that any particular approach is promoted and evaluated not only individualistically, but also in relation to communal, cultural and social norms and values;
- any one intervention – and ART in particular must be placed within this realisation – must take into account the effects of mixed health systems in the practice of health-seekers;
- mixed practices will not be eradicated, either through experience, a growth in technical or biomedical knowledge among clients, educational processes, preaching or other forms of counter-advocacy, or any form of sanction.

The ambiguities of religion or faith make it difficult for health practitioners, such as the doctors serving Masangane, to integrate religious realities into their practice. Competing or conflicting diagnoses and explanations of illness contribute to this unease, thus reinforcing doctors' tendency to stick with well-known bio-medical interventions and exclude other approaches.

Practitioners of other health approaches e.g. traditional healers and faith healers, like 'Western' doctors, tend to operate in mutual suspicion of each other, and secrecy is not uncommon among those who are outside the dominant bio-medical system. At the same time, tensions between different religiously informed traditions are also present (e.g. African-Western) and we can expect that some health providers take advantage of these tensions as they seek to win clients.

Given the context, there are also incentives to use immune boosters, or to rely on self-help rather than on any formal health approach. This adds to the complexity of health choices and behaviour.

The need to reconcile different approaches to health provision by health practitioners and health authorities is clearly necessary. Though others may have stated this previously, the Masangane research strongly stresses this insight.

Masangane itself might be seen as resting primarily on 'Western' ways of dealing with AIDS and this is certainly true in respect of its treatment practices and protocols. But it also represents something that has become increasingly part of public health thinking, namely the need for a far more holistic response to illness and disease. In the case of Masangane, this includes its comprehensive and integrated range of responses to prevention, care and support beyond its bio-medical activity.

7.4 Synthesis and reflection: The interface of religion and health

7.4.1 Generalisability of findings regarding Masangane

Based on the data collected in this study and our analysis of it, certain elements of ARHAP's theoretical and conceptual framework have been enhanced. Here we summarise points around three of them: Tangible and intangible religious health assets, conceptualising the body, and the interface between religion and health.

Chapter Four, on the impact of Masangane as a treatment programme, is structured around a set

of *tangible and intangible religious health assets*. The data strengthens the claim we have made that tangible assets, usually more visible to health systems and policy makers, are only half the picture, and that intangible assets do indeed have an impact and contribution to health systems and well-being that is nonetheless crucial.

Support groups, for example, offer their members a sense of belonging, fellowship and dignity that is crucial to their health and well-being. Norms and values of a faith tradition, another example, play a significant role in shaping health-seeking behaviour and hence, the reception of health intervention strategies from others such as public health agencies and government.

Regarding *the body*, a concept that appears relatively straightforward from a biomedical point of view, we have suggested in various ways that health-seekers in an African context more often than not work with and live out of a conception of the body that is not limited to the physical individual entity. Indeed, decisions about health are made with a complex sense of the body in mind, including a view that relates (an important word in this context) the individual person and her or his physical body to the family, the community, the ancestors and the earth itself in important respects.

We may therefore speak of health and health interventions being addressed to an internal, an external, and a social body, as well as the body that makes up the *polis* (the life of a people together).

The crucial element that emerges is that these are in principle and often in practice not separable kinds of bodies when it comes to understanding health. This has a direct impact, then, on how people seek health, how they respond to interventions by others, and what they will regard as "more healthy".

It may be, then, that in a specific situation their individual body takes second place to what they perceive as the health of the family or community.

Throughout this study, we have dealt with the i*nterface between religion and health*, noting that our field work, and that of others in ARHAP, makes clear that the two concepts are not easily separated in an African context. Indeed, they have been strongly separated in 'Western' science only under the influence of a radical Cartesianism that is being eroded internally by developments in particle physics, cosmology, microbiology and ecological sciences, for example.

In the context of Masangane the language of religion pervades many aspects of the practice of health care and ART in particular, as is evident in phrases such as "resurrection effect", "hope", "prayer", "Moravian devotional book", or "Jesus's example of caring for the marginalised".

This is particularly the case when it comes to explanatory frameworks for illness and the means of achieving health, with very little evidence that people in the context within which Masangane works will (ever?) accept mono-causal views on illness or how to deal with it.

Relational and spiritual realities in this respect are no less significant for diagnosis and treatment than biomedical ones, and it seems that it would be a grave mistake to plan health systems and policies on the assumption that realities other than the biomedical cannot be addressed, or can only be addressed within particular specialisations (e.g. psychiatry).

What is clear from our study is that the interface between religion and health needs to be comprehended as a complex whole, and that this needs to be embodied in policies and practices that generate an alignment of best practices between health systems and religious bodies, initiatives or institutions.

This is both a strategic and a development imperative for the public health system, if health interventions are to be accepted and sustainably and deeply embedded in local communities.

Similarly, it is imperative that religious leaders and bodies sharpen their own understanding of the interface between religion and health as a complex whole. One outcome of this may be that they train their personnel as professionally as possible in order to maximise their contribution to health in society.

7.4.2 Understanding Masangane as a religious health asset

The diagrams and discussion that follow expand on these last points by reference to our analysis of the Masangane case.

The study aimed to explore the role of Masangane – a religious health asset – as a possible model for a replicable response to HIV and AIDS. In conceptualising the added value of ARVs being provided by a FBO/I it is necessary to unpack the roles of the various actors. Traditionally health and religion have been seen as separate or tangential. Referring to Figure 5 on the right, it is clear that in the case of Masangane, a FBO/I providing health services, the interface is far from tangential.

Some of these services are provided by a number of role players in the private sector on a contractual basis. Among these are the doctors and laboratories providing what, in the ARHAP framework, would be classified as 'tangible' assets.

At the other extreme are the range of support services traditionally provided by faith communities to those who are ill, such as prayer, care and support. These services could be largely classified as being 'intangible' although they might be accompanied by certain tangible transfers such as food or transport.

Masangane bridges these two worlds, providing a continuum of care that includes both tangible and intangible assets, thus integrating the particular

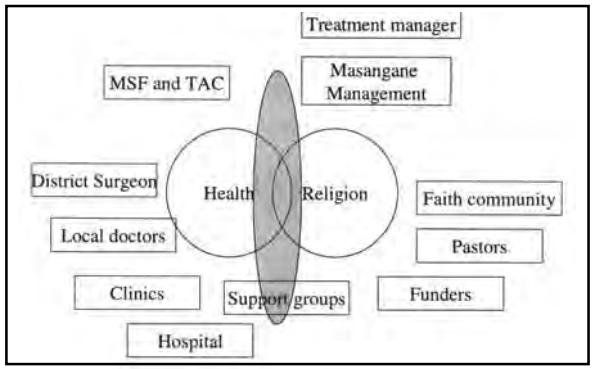


Figure 5: Key role players in Masangane treatment

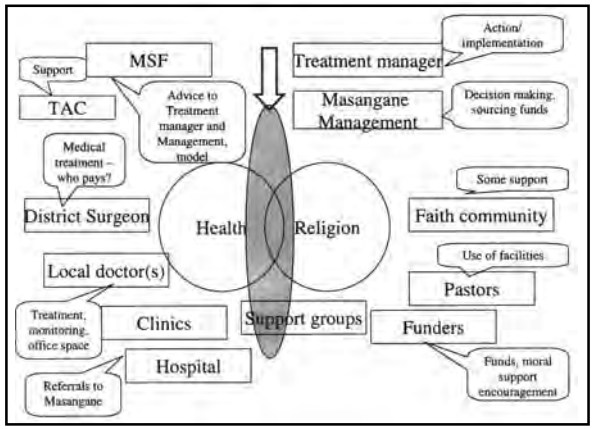


Figure 6: Tangible assets of Masangane

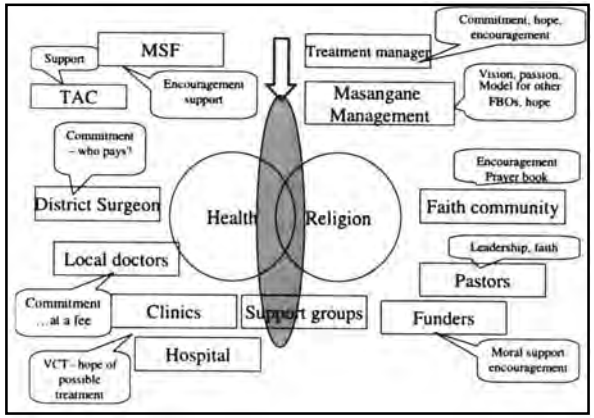


Figure 7: Intangible assets of Masangane

strengths of the allopathic health system with those of the faith community and thereby contributing to a much more comprehensive response to health and illness.

The integrated nature of the Masangane treatment programme appears to be highly valued by those on treatment. This includes at least the following:

- The dignity with which people are treated – not being shoved from pillar to post
- The role of Masangane in helping to address stigma in churches so that they can be re-accepted into their communities
- Leadership in Masangane by someone who is on ARVs
- Access to treatment, offering hope
- The treatment (taking of pills) being ritualised and thereby integrated into belief systems
- The support groups offering encouragement, a sense of belonging and self acceptance
- The opportunity to be able to give (through volunteering) and not only receive
- Masangane going the extra mile over difficult territory to reach into the homes of their clients with care and support
- The continuum of care – for instance knowing that if they die, their children will be cared for through the Masangane orphan programme

Using the ARHAP framework, what appears to be highly valued is the integration of the drugs to address the physical condition of the body, with the person's belief system and social context, referred to as the spiritual and social body.

From a 'Western' medicine perspective, what is valued could be described as the integration of the physical healing (control of the virus with ARVs) with the psycho-social aspects of the individual as well as reintegration and re-acceptance into the community.

The integration of care across the continuum by Masangane may well be what beneficiaries have been subconsciously referring to when describing the Masangane drugs as different, or expressing in their reluctance to be transferred to public institutions for their ARVs.

This takes us to the potential role of FBO/Is in health care especially in a context of HIV and AIDS as well as what insights can be drawn from this evaluation for the roll out of ARVs in South Africa.

7.5 Generic evaluation

7.5.1 Role of FBO/Is in ART: "Stepping Stones", "Continuum of Care" and "Trust"

FBO/Is have been identified by the state (Operational Plan 2003) to play a role in prevention, care and support. From Masangane's experience it would appear that FBO/Is have a further role in partnering the state in helping in the provision of treatment, and especially treatment literacy. Given the Eastern Cape Government's desire to double the number of people on ART by the end of 2006, it would seem crucial to engage productively with FBO/Is in the province.

Here the most important dimension is enrolling people appropriately into ART, when they need it and as soon as they need it. We would describe this as seeing suitably oriented and motivated FBO/Is as *"Stepping Stones"* into ART, providing treatment literacy, starting clients on ART while offering the necessary support, and monitoring adherence during the initial months of treatment.

In addition, FBO/Is such as Masangane provide a critical *"continuum of care"* that utilises the strengths of commitment and endurance, typical for faith traditions, to respond at different levels of human need (physical, psychological, emotional, relational and spiritual).

Trust and credibility, as emerges clearly from the Masangane study, are important commodities of FBO/Is in many contexts, especially in deprived and marginalised sectors of society. Just as this trust and credibility can be used for unhelpful or unhealthy outcomes (the usual prejudice vis-à-vis FBO/Is), it is vital to see the reverse side of the coin. It also acts as a foundation for addressing stigma by overcoming it through reference to the faith tradition itself (e.g. the reference to Jesus's acceptance of lepers is often heard) or by virtue of the community authority and trust that many religious leaders have (e.g. Rev Mgcoyi's clear positive impact in building Masangane in the first place, in large part because of his status both as a chief, teacher and a reverend).

7.5.2 Health systems

This study has shown that Masangane as a FBO has been able to deliver ARVs to a group of over 75 people successfully. The markers of the success are the high rate of adherence, low fall out rate, positive spirit in the individuals as well as the preference of the participants to remain with Masangane rather than be transferred to the state health ARV programme. Masangane has been serving two rural communities that at the time of establishment had no other options as far as access to ARVs via the state was concerned. At this stage, many of the ARV clients come from rural areas and are helped in covering the costs of transport to the weekly support groups. Given the high rate of poverty in the Eastern Cape in general, and the rural areas in particular, this initiative is in some small way addressing inequity issues.

Since the inception of the Masangane ART programme, public health ARV sites have been developed in Matatiele at Taylor Bequest Hospital, as well as at Frontier Hospital in Queenstown. As a result, other ARV opportunities are now available to the clients. Given this situation, it is appropriate to consider the following as a way forward:

- Whether Masangane should continue to provide ARVs with donor (overseas/church) funding?
- Whether Masangane should in some way establish a partnership with state ARV facilities so as to provide support for state programmes and source drugs for participation through the state at existing sites?

Stigma a thing of the past: support group members with Masangane T-shirts

- Whether a very specific and potentially vital role for ARV roll-out in such a partnership is not the introduction of clients into ART, including treatment literacy, accompanied by ongoing support group membership once clients are transferred to the public ART programme (this was referred to as the 'stepping stone' model above)?
- Whether another role, for which FBO/Is may be well positioned, is to develop new programmes in rural local authorities as a precursor to the state roll out to these areas?

7.5.3 Masangane as an integrated rural response to HIV and AIDS

Masangane has been able to develop and expand new services based on the needs of the people they serve. The original project was developed in response to the growing numbers of orphans in the communities served by a Moravian pastor. Funds were sought for this purpose and in time the needs for other services grew, such as home based care, for which purpose Masangane partnered with the community based Noncedo HBC project. Support groups and finally the provision of treatment, monitoring and support further expanded the range of services provided.

This wide range of services extends beyond the response typically provided by church-based groups by including treatment. As a result, people are seen and addressed in their totality, for instance by drawing their family members into the treatment process. Further, the services Masangane provides are popular in part because of the importance given to faith and belief systems, as evidenced in comments from its clients about "taking pills with the Word of God" or their reluctance to accept ARVs from elsewhere on the grounds that Masangane ARVs are special and somehow more effective.

While a state ARV programme would be hard pressed to provide the range of services that Masangane provides, there is an opportunity to consider how a FBO/I could work in partnership with the provision of ARVs by the state to help meet the needs of rural communities including those living on farms who are very poorly served by the infrequent district mobile health service.

It is suggested that a short report be written drawing from the findings of Masangane as an integrated response to HIV and AIDS in a rural context with a view to discussing this with key officials in the national and provincial departments of health.

7.5.4 Potential replicability, scaling up

The Masangane model provides a very exciting opportunity for faith based organisations to be more actively involved in the provision of treatment, care and support. In fact, this model is already being replicated in other communities in South Africa, Malawi and Zimbabwe.

One aspect limiting the potential replication is the lack of clearly documented protocols for the well managed existing treatment, monitoring and support. It is suggested that a process be undertaken to carefully document the protocols in use and in this way to document the whole of Masangane as a 'best practice model'.

Another issue limiting replication of Masangane is the lack of careful documentation showing all the costs of various aspects of the programme. This should also include the costs incurred by the beneficiaries out of pocket, such as transport and child care expenses when attending support groups or accessing treatment.

A key observation from the current assessment of Masangane has been the limited capacity Masangane has for expansion at the two main sites. This is largely as a result of the capacity of the single treatment manager. She was managing 60 clients on ARVs in Matatiele, as well as overseeing the treatment of further 25 clients in Shiloh. In addition she had other management responsibilities, such as overseas travel to visit funders and involvement in workshops across Southern Africa. Clearly she was stretched to her limits.

In terms of the State Operational Plan 2003, State ARV clinics have a ratio of 500 patients to each doctor, supported by 1,75 nurses. Discussion at the Free State ARV conference in 2005 highlighted that different models of treatment required varying numbers of managers.[239] Given this situation, it is suggested that the potential replicability of Masangane be carefully assessed in the light of the possible models of partnership as explored below.

The potential replicability of Masangane also depends on the identification of passionate teams to run other sites modelled on Masangane. It would appear that the faith component of the management team as well as their agency to be able to address problems as they emerge is very important. Providing experienced people to help train and support staff at the new sites would also be of critical importance.

7.5.5 Sustainability

The sustainability of Masangane needs to be assessed using a number of criteria. The operation of the organisation has changed over time from a Faith Based Initiative to what could soon be an independent NGO. Indeed, according to a recent Annual Report, Masangane is now registered as a Non-Profit Organisation, which in principle could allow it to operate independently of the Moravian Church, depending on how specifics of its constitution are adjusted over time.

It would appear that the future of Masangane depends on three key things. First, that ongoing funding is secured; second, that people are appointed who can ensure that it can be managed as a project on its own; and third, that the current relationship and tensions between Masangane and the Moravian Church are resolved in order to secure the confidence of all involved, including the funders of the project, specifically in relation to trust that the funds will be used as designated, in accordance with agreed budget lines.

Masangane has operated with well established national and international links. It is suggested that Masangane and other sites, developed on the basis of the Masangane model, invest in strengthening ties with other local actors such as the local AIDS Councils, other faith communities and obviously the clinics and state ARV sites in the area.

In terms of the treatment programme itself, it is important to note that Masangane was never meant to be a permanent or long-term supplier of ARVs or drugs. It began this work partly to save the lives of mothers and thus prevent increasing numbers of orphans, and partly as an act of advocacy to pressurise government into provision of ART, especially in generally underserved rural areas. The key question to be faced soon by Masangane is which services to continue, and which new services to introduce while phasing out ART.

7.6 Policy recommendations

§ *Public health to take note of importance of faith dimension for quality of care*

The evaluation of Masangane has highlighted that its clients appreciate the way in which their belief system was integrated into the continuum of treatment, care and support.

It is suggested that the public health system consider how some of the experiences and lessons from Masangane could be integrated into their current practice at ART sites.

§ *Potential role of FBO/Is and NGOs in aspects of State ART provision requires greater alignment of responses*

The Masangane study has highlighted the success of a FBO/I in providing treatment literacy, getting people onto ARVs quickly as well as the longer term stabilisation of treatment and adherence.

Given the need for scaling up the roll out by the State and the very time-intensive nature of these activities, a better alignment between religious health assets and public health systems is important, and it is proposed that the possible partner-

ship role of FBO/Is and NGOs in undertaking these tasks should be very seriously considered.

§ *Support the role of churches/ religious communities to work with public health ART programme: Contributing 'value added', location & reach to underserved populations*

Faith based communities have an extensive reach across the country, a very wide membership and facilities that could be used especially in more remote locations.

The role of these FBO/Is in the ART programme should be carefully considered, given the tangible and intangible religious assets that can also contribute to health.

In particular, our research suggests that collaboration with FBO/Is (and NGOs or CBOs that are not faith-based, where this is appropriate) in the first phase of ART – treatment literacy and stabilisation on ART – is a particularly important point of intervention and alignment in order to scale up responses and enhance adherence to treatment protocols.

§ *Public health could, where appropriate, encourage support groups to draw on the faith experience of members*

Masangane has shown that the support group members value the integration of faith dimensions into their activities.

It is also possible that FBO/Is could take a lead in initiating ART support groups for their members and others, so that this aspect is integral.

§ *Deepen understanding of health seeking behaviour: Plurality of health systems and mixing*

The study found that there is a prevalence of people mixing multiple health seeking strategies, simultaneously or consecutively.

Current public health practice needs to urgently develop strategies to help people integrate the mixing in a way which is safe and work towards an overall ART supportive environment by providers of all healing modalities.

§ *Education and training of religious leaders*

Every effort is needed to help churches and other FBO/Is understand the potentially positive roles they can play. Churches should be actively encouraged to participate in this approach. This study has highlighted the eminently worthwhile role that the sensitive use of religious traditions can have in impacting on health outcomes.

The appropriate training of religious leadership, therefore, is likely to be important for the public health system and should be encouraged. Such training has to be framed in terms of the self-understanding of their particupar traditions, and in ways that open up the kinds of responses we see in the case of Masangane.

This should best be undertaken through bodies such as the SA Council of Churches, regional AIDS Councils, the African Network of Religious Leaders Living with AIDS (ANERELA) and other fora where religious leaders can be targeted.

§ *Religious leadership need to discourage stigma, encourage ART take-up & support for those on ART*

The overwhelming evidence from the study shows that religious communities and leaders in particular can play a very important role in addressing stigma, encouraging the take-up of ART and in providing a supportive environment for members on ART. This needs to be an ongoing activity, which requires support from the leadership of religious denominations.

Religious leaders at all levels need actively to develop or strengthen structures and networks that allow for sharing resources and optimizing local responses.

7.7 RECOMMENDATIONS FOR FURTHER RESEARCH

§ *Comparison with other ART services*

Masangane, though small in scale, offers an integrated service that is valued by its clients. We suggest a study that would have as its aim the comparison between Masangane and other ART services, considering the range of services offered, views of clients as well as documenting lessons learned and good practice for replication by other FBO/Is and NGOs working in the same field.

It is suggested that the findings of this Masangane evaluation be assessed in relation to other ART programmes such as the public health ART programme as well as the Catholic Bishops' Conference's ART programme. The comparison could also be extended to comprehensive ART programmes of other NGOs, such as MSF itself or other programmes modelled on the MSF approach.

§ *Cost effectiveness*

In order to assess the feasibility of the replicability of all or aspects of Masangane by other FBO/Is, it is suggested that a cost effectiveness evaluation be undertaken.

§ *Assessment of equity considerations in those in need of ARVs*

There is concern in some circles that the public ART programme may not be reaching the poorest

of the poor. It is not clear to what extent Masangane is reaching clients who may not otherwise be able to access the state ART programme. Benefit Incidence Analysis may be one way in which research could be used to assess the extent to which the current ART programme in the area served by Masangane is actually meeting the needs of the poorest.

§ *Assessing 'value-added' by religion*

This study has highlighted a range of benefits in the ART programme run by Masangane due to the value added by its values and religious ethos and approach. One question that needs to be further explored is how the 'value-added' by religion, where it involves 'intangible benefits', may be better assessed. Two possible directions of study include comparing the benefits of 'intangible religious health assets' with the interventions by similar, secular NGOs, and exploring the use of tools developed in disciplines such as social psychology.

Mother and two children

Endnotes

[1] Marais H (2005) *Buckling: The impact of HIV/AIDS in South Africa.* Centre for the Study of AIDS, University of Pretoria, Pretoria

[2] http://www.unaids.org/ 2006.

[3] Marais (2005) *Buckling*.

[4] http://www.hsrcpress.co.za/index.asp?id=2134 2004.

[5] Lurie M, Williams B, Zuma K et al. (2003) "The impact of migration on HIV-1 transmission in South Africa: A study of migrant and non-migrant men and their partners". *Sexually Transmitted Diseases*. 30(2):149-156, February 2003.

[6] Singh G (2005) *Patterns of migration, settlement and dynamics of HIV/AIDS in South Africa, Forced Migration Studies*. University of Witwatersrand, Commissioned by SA Cities Network, Johannesburg (unpublished), p98.

[7] Goudge J and Govender V (2000) *A review of experience concerning household ability to cope with resource demands of ill health and health care utilisation.* Regional Network for Equity in Health in Southern Africa with Centre for Health Policy, WITS and Health Economics Unity, UCT. Equity Policy Series No.3

[8] Singh (2005) *Patterns of migration*, p39.

[9] Shisana O and Simbayi L (2002) *Nelson Mandela/HSRC Study of HIV/AIDS South African National HIV Prevalence, Behavioural Risks and Mass Media Household Survey*, HSRC, Cape Town; Shisana O et al. (2005) *HSRC Nelson Mandela South African National HIV Prevalence, HIV Incidence, Behaviour and Communication Survey*, HSRC, Pretoria.

[10] Speech by the Minister of Health, World AIDS Day, 1 December 2005. http://www.doh.gov.za/docs/sp/2005/sp1201.html

[11] Speech by the Minister of Health, World AIDS Day, 1 December 2005. http://www.doh.gov.za/docs/sp/2005/sp1201.html

[12] International Treatment Preparedness Coalition (2005) *Missing the target: A report on HIV/AIDS treatment from the frontlines*, 28 November 2005. http://www.journaids.org/treatment.php#teatmentinsatimeline (Sourced 9 March 2006).

[13] World Health Organisation 2006 Universal Access by 2010, www.who.int/hiv/universalaccess2010 (sourced 9 March 2006) This data from the WHO is a general estimate ballpark figure of those who have treatment compared to those in need of it in South Africa.

[14] This was evident in the Free State ARV Conference held in Bloemfontein in March/April 2005. Doherty J, Loveday M, Stewart R, Thomas L (2005) *Conference report: Implementing the Comprehensive Care and Treatment Programme for HIV and AIDS patients in the Free State: Sharing experiences*, Health Systems Trust (HST), Durban.

[15] Harrison D (1997) *Health Systems Trust Update*, HST, Durban.

[16] The population of the Eastern Cape province was 61.2% rural compared to South Africa as a whole, being 42.5% rural. HST (2005) *South African Health Review* (SAHR) 2005. Health Systems Trust (HST), Durban, p267.

[17] HST (2005) *SAHR 2005,* p302.

[18] Actuarial Society of South Africa (ASSA). www.assa.org.za

[19] Shisana and Simbayi (2002) *Nelson Mandela/HSRC Study;* Shisana et al. (2005) *HSRC Nelson Mandela Survey;* Thomas E, Colvin M and Zuccarini C et al. (2004) *HIV Employee Prevalence Study and KAP for Buffalo City Municipality,* Medical Research Council (unpublished).

[20] Shisana et al. (2005) *HSRC Nelson Mandela Survey*.

[21] Eastern Cape Government. "Eastern Cape expands its AIDS treatment plan", Press statement, February 24, 2006.

[22] General Household Survey 2004. StatsSA. http://www.statssa.gov.za/newsletters/KZNNewsletterJuly05.pdf

[23] Schmid B (2002) "The Churches' Response to the HIV/AIDS Pandemic: A Case Study of Christian Agencies in the Cape Town Area", Unpublished dissertation, University of Cape Town.

[24] Contact ARHAP-UCT, Department of Religious Studies, University of Cape Town (arhap@humanities.uct.ac.za); or ARHAP-Emory, Department of Global Health, Rollins School of Public Health, Emory University, Atlanta (djones9@sph.emory.edu).

[25] For this purpose, ARHAP is using a modified GIS tool based on WHO's HealthMapper system, and its own Participatory Inquiry into Religious Health Assets, Networks and Agency (PIRHANA) tool.

[26] This notion of assets and agency rests, inter alia, on the "capabilities approach" of Nobel Prize winning economist, Amartya Sen (1999) *Development as Freedom*. Random House, New York.

[27] De Gruchy S (2003) "Of Agency, Assets and Appreciation: Seeking Some Commonalities between Theology and Development." *Journal of Theology for Southern Africa* 117: 20-39; Kretzmann J and J McKnight (1993) *Building Communities from the inside Out: A Path toward Finding and Mobilizing a Community's Assets*. ACTA Publications, Chicago.

[28] The interview schedule can be accessed at www.ARHAP.uct.ac.za

[29] The questionnaire can be accessed at www.ARHAP.uct.ac.za

[30] Masangane Annual Report, October 2005.

[31] KII – Noziwe – 3:98 (127:127)

[32] KII – Ntingase – 18:38 (115:115)

[33] KII – Hlubi – 9:18 (39:39)

[34] KII – Thembiwe – 8:2 (25:25)

[35] KII – Rev Tait – 2:29 (121:121)

[36] KII – Noziwe – 3:73 (94:94)

[37] KII – Noziwe – 3:72 (94:94)

[38] KII – Noziwe – 3:74 (94:94)

[39] KII – Noziwe – 3:72 (94:94)

[40] KII – Sukwini – 11:33 (89:89)

[41] KII – Noziwe – 3:69 (92:92)

[42] KII – Thembiwe – 8:4 (31:31)

[43] KII – Noziwe – 3:76 (94:94)

[44] KII – Noziwe – 3:13 (30:30)

[45] Interview – Dr Nabiso – 13:9 (19:23)

[46] KII – Hlubi – 9:21 (45:45)

[47] The theme of hope is a prominent one in religious discourses; cf. for example, the extensive and influential work of Jürgen Moltmann in the Christian tradition over the last forty years.

[48] On the importance of "survival" in the first place, before one speaks of "resistance" or "empowerment", see the valuable study on this theme by Beverly Haddad (2000) "African Women's Theologies of Survival: Faith, Feminisms and Development". Unpublished dissertation,

University of Natal, Pietermaritzburg.

[49] The term "clients" is used by Masangane itself, and this report will reflect this usage.

[50] FG – Matatiele June – 16:28 (125:125)

[51] FG – Matatiele June – 16:37 (143:143)

[52] FG – Matatiele June – 16:20 (119:119)

[53] FG – Matatiele June – 16:17 (111:111)

[54] KII – Thembiwe – 8:13 (63:67)

[55] For an example of some work on African tradition and taboos in an AIDS context see Parry S (2002) *Responses of the churches to HIV/AID: Three Southern African Countries*. World Council of Churches, Ecumenical HIV/AIDS Initiative in Africa, Southern Africa Regional Office, Harare & Geneva.

[56] KII – Rev Venter – 1:35 (72:72)

[57] KII – Noziwe – 3:59 (85:85)

[58] Harrison D (1997) *HST Rural Health Update*. HST, Durban

[59] Andrews G and Pillay Y (2005) "Strategic priorities for the health system (2004-2009)" in *South African Health Review*, HST, Durban. p14.

[60] HST (2004) *Ukhahlamba Health District exit report*, DC 14. HST, Durban. p21-23.

[61] KII – Hlubi – 9:58 (129:129)

[62] FG – Shiloh June – 17:5 (32:32)

[63] Interview – Dr Nabiso – 13:2 (7:7)

[64] KII – Noziwe – 3:84 (100:100)

[65] KII – Ntingase – 18:60 (168:168)

[66] KII – Sukwini – 11:98 (282:282)

[67] KII – Rev Doran – 25:7 (17:17); updated Feb 2006.

[68] KII – Ntingase – 18:89 (258:258)

[69] KII – Dr Pinyane – 15:5 (10:10) and 15:22 (37:37)

[70] KII – Noziwe – 3:29 (40:40)

[71] KII – Thembiwe – 8:57 (176:176)

[72] Interview – Mvali & Xola – 28:1 (37:37)

[73] Interview – Dr Nabiso – 13:8 (11:11)

[74] Informal interview

[75] KII – Noziwe – 3:109 (173:173)

[76] KII – Noziwe – 3:16 (32:32), 3:30 (42:42)

[77] KII – Hlubi – 9:55 (126:126). Some volunteers used to get as little as R100/month; others considerably more, depending on their position and duties. This situation has recently been amended.

[78] KII – Ntingase – 18:116 (347:347)

[79] KII – Rev Doran – 25:5 (15:15), updated Feb 25, 2006.

[80] KII – Sukwini – 11:41 (89:89)

[81] KII – Ndawo – 10:61 (20:20)

[82] KII – Rev Venter – 1:54 (126:126)

[83] Interview – Mvali & Xola – 28:3 (259:265)

[84] KII – Ndawo – 10:47 (80:80)

[85] KII – Noziwe – 3:41 (61:61)

[86] KII – Noziwe – 3:43 (67:67)

[87] KII – Rev Tait – 2:40 (177:177)

[88] KII – Dr Suttner – 12:5 (14:14)

[89] KII – Sukwini – 11:49 (141:141)

[90] KII – Sukwini – 11:54 (147:147)

[91] KII – Ms Kobler – 4:11 (28:29)

[92] KII – Ms Crane – 5:6 (21:21)

[93] KII – Noziwe – 3:42 (63:63)

[94] KII – Rev Venter – 1:60 (138:140)

[95] KII – Rev Venter – 1:77 (161:161)

[96] Report & Questions – 26:22 (123:123)

[97] KII – Rev Tait – 2:63 (231:231)

[98] KII – Rev Tait – 2: 48 (193:193)

[99] KII – Rev Tait – 2:60 (223:223)

[100] KII – Rev Venter – 1:99 (144:144)

[101] KII – Rev Venter – 1:34 (68:68)

[102] Report & Questions – 26:31 (133:133)

[103] Informal follow-up interview – Feb 2006

[104] KII – Noziwe – 3:70 (92:92)

[105] Uphoff N (1999) "Understanding Social Capital: Learning from the Analysis and Experience of Participation", in Dasgupta and Seregeldin, *Social Capital: A Multifaceted Perspective*, World Bank, Washington DC, USA

[106] These are roughly equivalent to the clients' physical bodies (the external body, upon which ART works, for example), their psychological well-being (related to the internal body), and their relationships to family and community (the social body) upon which much of their health and its sustainability depends. We also consider "the body politic", the greater social body within which individuals, families and communities act out their existence. See Germond P (2004) "Bophelo: Towards a working definition – finding alternatives to the words 'religion' and 'health'". ARHAP Working Paper. University of the Witwatersrand, Johannesburg.

[107] FG – Matatiele June – 16:47 (167:167)

[108] FG – Shiloh June – 17:34 (129:129)

[109] KII – Sukwini – 11:94 (250:250)

[110] Interview – Noziwe – 27:1 (48:48)

[111] KII – Sukwini – 11:81 (228:228)

[112] KII – Noziwe – 3:113 (36:36)

[113] KII – Noziwe – 3:106 (167:167)

[114] KII – Thembiwe – 8:15 (96:96)

[115] KII – Rev Venter – 1:54 (126:126)

[116] KII – Rev Venter – 3:55 (126:126)

[117] KII – Hlubi – 9:54 (123:123)

[118] KII – Hlubi – 9:51 (123:123)

[119] KII – Thembiwe – 8:21 (184:184)

[120] KII – Rev Venter – 1:48 (116:116)

[121] KII – Rev Tait – 2:61 (227:227)

[122] FG – Matatiele June – 16:16 (107:107)

[123] KII – Sukwini – 11:95 (257:257)

[124] FG – Shiloh June – 17:41 (148:148)

[125] KII – Ndawo – 10:51 (68:68)

[126] KII – Noziwe – 3:108 (171:171)

[127] KII – Noziwe – 3:26 (40:40)

[128] KII – Noziwe – 3:63 (85:85)

[129] KII – Noziwe – 3:61 (85:85)

[130] FG – Matatiele June – 16:59 (214:214)

[131] FG – Shiloh June – 17:30 (109:109)

[132] KII – Noziwe – 3:92 (105:105)

[133] FG – Matatiele June – 16:56 (202:202)

[134] The "self" or "internalised" stigma is a well documented aspect of individual stigmatisation of HIV/AIDS. See for example, Malcolm A et al. (1998) "HIV/-related stigmatization and discrimination: its forms and contexts" *Critical Public Health*. Vol. 8 (4): 347-370.

[135] FG – Shiloh June – 17:40 (146:146)

[136] FG – Matatiele June – 16:21 (119:119)

[137] KII – Sukwini – 11:80 (228:228)

[138] The name Masangane means 'to embrace'.

[139] KII – Ndawo – 10:58 (17:17)

[140] Interview – Noziwe – 27:2 (54:54)

[141] See DIFAEM (2005) *Global assessment of faith-based organisations' access to resources for HIV and AIDS response*. (DIFAEM) German Institute for Medical Mission, Tübingen; Green EC (2003) *Faith-based organizations: Contributions to HIV prevention*. US Agency for International Development and The Synergy Project, TvT Associates, Harvard Center for Population and Development Studies, Washington DC; Parry S (2002) *Responses of the churches to HIV/AIDS: Three Southern African Countries*., World Council of Churches, Ecumenical HIV/AIDS Initiative in Africa, Southern Africa Regional Office, Harare and Geneva; Tiendrebeogo G and Buykx M (2004) *Faith-based organisations and HIV/AIDS prevention and impact mitigation in Africa*. Koninklijk Instituut voor de Tropen, Amsterdam, Netherlands. For a complete review of such literature, see Olivier et al (2006) *ARHAP Literature Review: Working at the Intersection of Religion and Public Health*. ARHAP Working Paper. University of Cape Town, Cape Town.

[142] KII – Ndawo – 10:71 (94:94)

[143] FG – Shilo June – 17:45 (77:77)

[144] KII – Rev Venter – 1:56 (126:130) and 1:52 (122:122)

[145] FG – Shilo June – 17:20 (79:79)

[146] FG – Matat June – 16:56 (200:202); KII – Nisani – 7:63 (123:123)

[147] FG – Shilo June – 17:20 (79:79)

[148] FG – Shilo June – 17:23 (81:81)

[149] KII – Dr Suttner – 12:22-24 (43:45)

[150] KII – Rev Tait – 2:40 (177:177) & 2:41 (177:177); KII – Thembiwe – 8:8 (47:47). Se also Reinikka R and Svensson J (2003) *Working for God? Evaluating service delivery of religious not-for-profit health care providers in Uganda*. World Bank, Washington DC.

[151] KII – Nisani – 7:60 (111:111)

[152] KII – Ndawo – 10:66 (74:74)

[153] This refers to the etymological origins of the term "religion", from the Latin "religare", that which binds or ties people to each other.

[154] FG – Matat June – 16:7 (62:62); KII – Ms Crane – 5:2 (11:11); KII – Ms Kobler – 4:21 (59:60); KII – Sukwini – 11:120 (354:354)

[155] KII – Noziwe – 3:94 (107:109)

[156] FG – Shilo June – 17:25 (85:85)

[157] FG – Matat June – 16:75 (258:258)

[158] FG – Matat June – 16:76 (263:263)

[159] KII – Sukwini – 11:119 (351:351)

[160] KII – Hlubi – 9:70 (167 :167)

[161] KII – Ms Kobler – 4:20 (56:56); KII – Nisani – 7:90 (184 :184)

[162] KII – Nisani – 7:93 (188:188)

[163] KII – Nisani – 7:94 (194:194)

[164] KII – Thembiwe – 8:26 (232:232) and 47 (577:577)

[165] KII – Dr Suttner – 12:11 (21:21)

[166] FG – Matat June – 16:8 (66:66)

[167] We refer here to the widely acknowledged "religiosity" of South Africa (and many other African countries, see Garner RC (2000) "Safe sects? Dynamic religion and AIDS in South Africa". *Journal of Modern African Studies* 38(1): 41-69.) This means that for a majority of Africans, their interpretations of life and health are powerfully religious (see Benn C (2002) "The influence of cultural and religious frameworks on the future course of the HIV/AIDS pandemic". *Journal of Theology for Southern Africa* 113: 3-18).

[168] KII – Hlubi – 9:69 (167:167)

[169] KII – Hlubi – 9:69 (167:167)

[170] FG – Shilo June – 17:22 (81:81); KII – Nisani – 7:92 (188:188)

[171] KII – Hlubi – 9:75 (182:182)

[172] KII – Rev Venter – 1:4 (26:26)

[173] FG – Matat June – 16:69 (68:68)

[174] FG – Matat June – 16:10 (70:70)

[175] FG – Matat June – 16:71 (72:72)

[176] KII – Ndawo – 10:69 (89:89)

[177] KII – Hlubi – 9:56 (129:129)

[178] KII – Sukwini – 11:130 (381:381)

[179] KII – Hlubi – 9:76 (185:185)

[180] KII – Nisani – 7:71 (141:141)

[181] KII – Dr Pinyane – 15:9 (15:15)

[182] FG – Shilo June – 17:50 (175:175)

[183] KII – Sukwini – 11:5 (21:21)

[184] ABC = Abstinence, Be faithful, use Condoms

[185] Lazarus S (2004) "An Exploration of how Native American Worldviews, Including Healing Approaches, can Contribute to and Transform Support Services in Education". University of Western Cape (SA National Research Foundation – Indigenous Knowledge Systems), Cape Town.

[186] KII – Ntingase – 18:78 (221:221)

[187] KII – Hlubi – 9:62 (141:141)

[188] Cant S and Sharma U (1999) *A New Medical Pluralism?*, UCL Press, London.

[189] Field notes – R Ngubo – Observation of Support group, 16 March 2006, Matatiele.

[190] This is not the place to go into the complex cosmological and anthropological structures of African views of health, healing and illness, but we may refer, as one example, to the common African view of the individual person as inherently embedded in the family, community, nation, ancestors and environment, in relation to which any affliction must be understood. Illness, then, has several levels of causal explanation, and all must be dealt with simultaneously once the problem is diagnosed. The biological identity of the individual is an insufficient framework of causality in this context.

[191] FG – Matatiele June – 16:30 (127:127)

[192] FG – Shilo June – 17:13 (47:47)

[193] FG – Shilo June – 17:43 (188:188)

[194] Murove MF (2005) "African bioethics: An explanatory discourse". *Journal for the Study of Religion* 18 (1), p25.

[195] Murove (2005) "African bioethics", p27.

[196] It is worth noting that the proliferation and power of 'superstition', that is, of views of the world or reality that cannot be positively, scientifically established, is considerable in even the most 'developed' Western societies (witness the astonishing range of healing strategies that cancer patients are willing to try out, for example). Mixing, both simple and complex, of health systems or philosophies is common and the same issues arise there as in Africa, albeit in different idiomatic or

cultural frameworks.

[197] FG – Shiloh June – 17:1 (9:13)

[198] FG – Matatiele June – 16 :2 (18:20)

[199] KII – Dr Suttner – 12:10 (21:21)

[200] FG – Matatiele June – 16:52 (183:183) and 16:53 (191:191)

[201] FG – Matatiele June – 16:54 (193:193)

[202] KII – Sukwini – 11:110 (329:329)

[203] KII – Noziwe – 6:6 (28:28)

[204] KII – Noziwe – 6:7 (30:30)

[205] KII – Dr Pinyane – 15:12 (22:22)

[206] See Germond P and Cochrane JR (n.d.) "Health-worlds: Conceptualizing Society and the Human Being in the Interface between Religion and Health", Unpublished paper. A "healthworld", their concept, incorporates peoples' conceptions of health, their health seeking behaviour, and the conditions of health that affect them. These conditions are shaped by health policies of governments, the variety of health practices within a given region, the interaction between health and religious practices, and the social and environmental determinants of health. The ontological philosophical foundation of any particular healthworld, it is suggested, lies in the goal of comprehensive health and well-being.

[207] KII – Nisani – 7:24 (38:38); see also KII – Nisani – 7:77 (150:150)

[208] Survey Questionnaire 14.

[209] KII – Dr Pinyane – 15:17 (31:31); 15:15 (29:30)

[210] KII – Sukwini – 11:106 (317:317)

[211] KII – Ntingase – 18:81 (229:229)

[212] KII – Sukwini – 11:117 (345:345)

[213] Scott JC (1991) *Domination and the arts of resistance: Hidden transcripts*. Yale University Press, New Haven.

[214] KII – Dr Nabiso – 13:21 (58:59)

[215] KII – Dr Nabiso – 13:23 (61:61)

[216] KII – Dr Suttner – 12:20 (36:36)

[217] KII – Dr Nabiso – 13:28 (67:67)

[218] KII – Dr Vela – 21:1 (23:23)

[219] KII – Dr Mathe – 19:6 (123:123)

[220] KII – Sukwini – 11:115 (339:339)

[221] KII – Nisani – 7:75 (150:150)

[222] KII – Nisani – 7:79 (152:152); 7:81 (158:158)

[223] KII – Noziwe – 6:3 (27:27)

[224] KII – Sukwini – 11:105 (317:317)

[225] KII – Ntingase – 18:85 (245:245)

[226] KII – Dr Nabiso – 13:22 (59:59)

[227] KII – Noziwe – 6:5 (28:28)

[228] KII – Dr Pinyane – 15:17 (31:31); 15:15 (29:30)

[229] Field notes, B Schmid, March 2005.

[230] FG – Matatiele June – 16:48 (141:141)

[231] KII – Dr Mathe – 19:5 (119:119)

[232] KII – Dr Mbonge 20:8 (71:71)

[233] KII – Dr Pinyane – 15:12 (23 :23)

[234] KII – Sukwini – 11:125 (367:367)

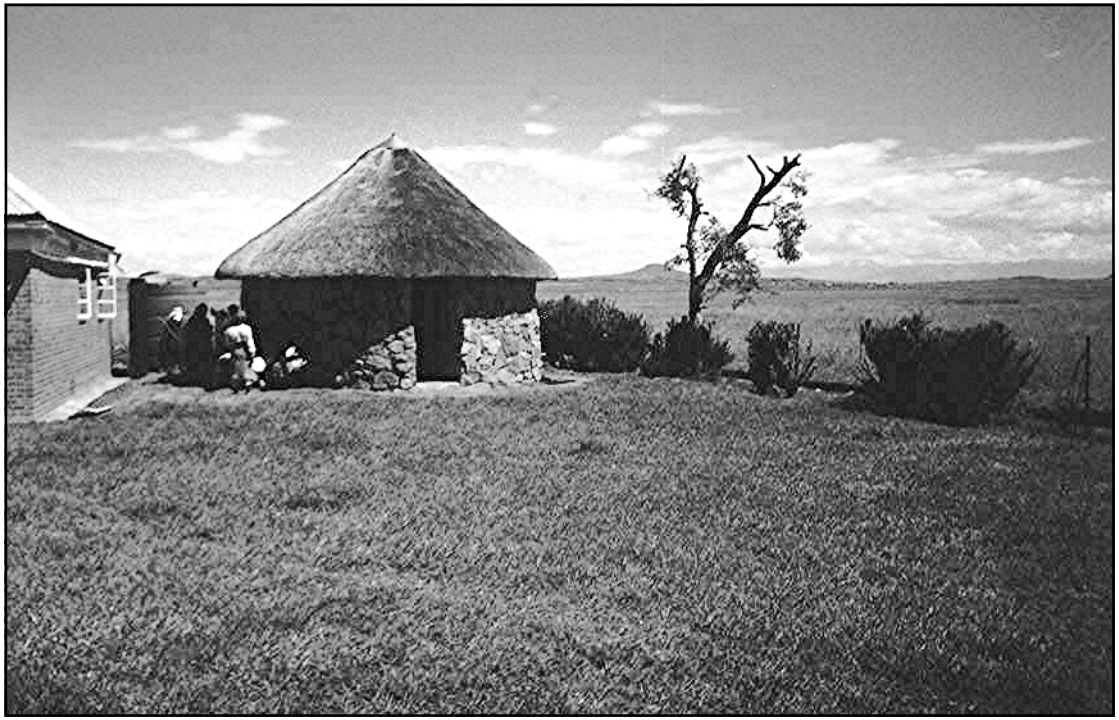
[235] KII – Sukwini – 11:112 (332 :332)

[236] FG – Matatiele June – 16:61 (222 :222)

[237] Uphoff N (1999) "Understanding Social Capital: Learning from the Analysis and Experience of Participation", in Dasgupta and Seregeldin, *Social Capital: A Multifaceted Perspective*, World Bank, Washington DC, USA.

[238] ABC = Abstinence, Be faithful, use Condoms

[239] Doherty, J, Loveday, M. Stewart R, Thomas L (2005) *Conference Report: Implementing the Comprehensive Care and Treatment Programme for HIV and AIDS patients in the Free State: Sharing Experiences*, Health Systems Trust, Durban.



Appendix A

The Limits and Promise of Qualitative Research in the Masangane Case Study

James R Cochrane

[A personal perspective]

Qualitative research considerations

Claims for qualitative research can be treated positively or negatively: Overrated if they are not carefully delimited; or discarded if they are not seen as having scientific validity.

What follows, therefore, is a brief commentary on the claims we can make about the results of our qualitative research in the Masangane case study in relation to giving a reasonable assurance of their (scientific) validity. This is important if practitioners and policy makers are to feel that we have provided something substantial to work with in the results we have produced and the recommendations that flow from them.

Our own biases

At the outset, following Murphy and Dingwall, I note that for qualitative researchers, as for quantitative researchers, it is "both impossible and, indeed, largely undesirable … to approach the empirical work *tabula rasa*."(1) Whatever one's method, qualitative or quantitative, "observations are necessarily impregnated with prior assumptions and references" and "informed by previous empirical studies carried out in some other settings." As with all researchers, therefore, we have drawn for our analysis and judgements on resources that are part of own personal and academic autobiographies and our reading of relevant literature.

Moreover, our presence in the research process, whether in the form of asking questions to fill in questionnaires, in interviews, in focus groups, or through participant observation, has inevitably affected the data we have collected.

We have sought to be sensitive to this, but whether using indigenous discourses and linguistic constructs, or recording responses in full (digitally) and then translating and transcribing them, or simply spending time among those whom we studied, we cannot assume that the transcripts that result capture all of the truth or the nuances of the interaction that occurred in the process.

Taking James Scott's way of putting the point (2), there will be discourses that are hidden from us, spoken offstage so to speak and hence not public, or coded in ways that we cannot decode fully and hence disguised as something else. This is inherent in the research process.

Realist rather than relativist

It is also worth noting Murphy and Dingwall's "subtle realist" view on qualitative research, which means that one accepts that the world exists independently of us as observers, and constrains the observations that can be made, even if it is true that any observation is irreducibly an interpretation of the world.

While we cannot make claims of certainty about what we have learned, therefore, we can warrant claims on the basis of the rigour of our work and the adequacy of our evidence and argument.

An inductive-deductive spiral

In this regard, it is the case that we have used a combination of inductive and deductive approaches, as is normal in scientific work, to analyse our data. This means that we approached our research with an open mind about what we would find in the field, but also with certain theories to guide our analysis of what we found as well as the formulation of the questions we posed. This is in accordance with mature versions of "grounded theory" (3).

A comparative case study

Here, however, the Masangane case study faces one significant limitation that should, if possible, be addressed in a second round of field work. We did not have the means to do a comparative study of another FBO/I, or an NGO that is not faith-based, doing similar or related work. There is no doubt that such comparative studies would help to determine whether our claims in relation to the "value-added" that a faith-based initiative brings are fully justifiable.

Lifeworld context rather than behavioural explanation

Further, our results do not *explain* people's behaviour as such. We cannot claim that we have fully captured the understandings and meanings that make people behave in one way or another. On the other hand, our results do offer some identification of the "stock of knowledge, formulations, rhetorical strategies" (1) that shape the way in which Masangane works, with implications for policy. Similarly, this identification reaches to health-seekers as well, also offering clear pointers to issues that will be important for policy and any intervention in delivering health care.

If these are the limits I would place upon our claims, what then are the benefits of qualitative research as we have used it in studying Masangane? Again following Murphy and Dingwall, I note at least three such benefits.

First, qualitative methods are useful in *richly describing* practices and the organizational contexts within which they occur. Our report conveys this clearly.

Second, rich description, by virtue of the insights it offers about health-seeking behaviour, organizational dynamics and worldview frameworks, *helps those who have to make decisions* about policy and interventions in any attempt at changing things for the benefit of clients or the organization.

Third, more than that, it is important to *acknowledge, respect, and address the functionality of these practices* (in our case, those of Masangane and its clients) in their context. If this is not done, we should expect that inappropriate or ineffective interventions might be carried out by policy makers and other decision makers outside the immediate community and its context, possibly evoking hostility, engendering a lack of co-operation, or even provoking active resistance to an intervention.

In effect, qualitative research therefore enables us to pay attention, in ways *that quantitative research cannot adequately do*, to the organizational and relational context that – potentially and often actually – has a significant impact on the outcome of any intervention. Our chapter on mixed health-seeking strategies in the context of Masangane makes this point clearly.

Combining different methods

Qualitative research is flexible and oriented to discovery in its open-endedness and inductive aspects. This allows it profitably to be combined with quantitative research.

We have done this in linking the 'client survey' to our key informant data where possible. Often called "triangulation", I note Murphy and Dingwall's distinction between two versions of this combination of different methods and their skepticism about one of them.

The first uses multiple methods primarily to overcome the partiality of data drawn from one method alone, thus increasing the comprehensiveness of the study. This, in my view, is what we have done in the Masangane case study.

The second version assumes that the use of multiple data sources confirms or establishes the validity of findings from one method through the use of another. Murphy and Dingwall are more critical of this claim, and it should perhaps not be stated too strongly. Why?

Concordance between the different kinds of data, where it is evident, does strengthen our confidence in the generalizability of our research findings. But different insights or results from different kinds of data might be just that, and not evidence that the information is either invalid or really contradictory. Differences may emerge for multiple other reasons.

So one has to be particularly cautious about "triangulation" that uses qualitative methods to validate quantitative results, or vice versa. One could fall prey to many weaknesses that Murphy and Dingwall describe, including that: different kinds of data might share the same systematic distortions or errors of randomness; different methods might not produce equivalent data; and, arbitrarily treating one method as superior to another cannot be used to explain different results from different kinds of data.

Given these limitations, any claims that the one of our methods necessarily validates the other must be made very cautiously.

More importantly, however – and this is a vital point – our use of multiple methods can be said with confidence to be particularly important in providing a *comprehensive* analysis of Masangane. The value of using multiple methods of data collection and analysis can be seen in the emergent *rich layering of reality*.

The need for a longitudinal study

Another value of the description provided by qualitative research lies in its ability to highlight significant but otherwise obscure dimensions of a phenomenon. In this regard, qualitative research is good at getting at process, in this case of Masangane, elaborating something of its dynamic nature.

Here the Masangane case study is incomplete at one important point – that of duration or a longitudinal perspective. Our results reflect the status and development of Masangane over a relatively short period of time.

Things change quickly in the field of HIV and AIDS, and organizations themselves change as the challenges do, or because particular people who are important are either new or no longer there. It would add a great deal to our understanding of the kind of phenomenon Masangane represents to be able to carry out a longitudinal study, a follow up that would repeat some of the work but also reshape it on the basis of knowledge already gained. This should help fill in what Murphy and Dingwall call "the gaps between an intervention and its outcome" (1).

Accountability to those researched and its relationship to the research process

From the outset we intended to share our findings with all those research subjects we could arrange

to meet prior to completion of this report, in order to present to them a draft version. This is an important ethical obligation of accountability to Masangane.

This we have done in a report back to members of Masangane who could be there, and to others who were invited by Masangane as guests. Sometimes qualitative research may treat such further interaction as part of the research itself, specifically, as a way of validating (or otherwise) the findings of the researchers.

This is a notion that is criticized by Murphy and Dingwall as potentially naïve about the purpose of the research, about the role of differing interpretations in it, and about the possibility of getting any interpretations subsequently that are not affected by the context of the report back itself in ways that, post facto, alter what was learned in the first place. This is because a report back meeting creates a new relational context, one that includes new dynamics for varying reasons on the part of participants.

So, for example, it is likely at our report back meeting to Masangane that changed circumstances generated new relational and operational dynamics within Masangane itself that we, at most, would only have intuited.

Similarly, the mere fact that a research team was presenting a final (draft) report, and not in the first place beginning with open-ended questions, alters the nature of what one gets back.

Another possible limitation is that new people were at the meeting who had not been present in any of the research, which complicates any judgements one might make about what is said and why.

Furthermore, at the hermenutic level, that is, in terms of a theory of interpretation, a qualification would have to be made about views expressed in public that are designed to address that particular public rather than the research questions per se. In this case, for example, church leaders who were present are likely to elicit certains kinds of discourse and not others, perhaps contrary to what had been said in private interviews.

At best then, I would suspect, it might be that feedback from such an occasion can help us see where we have missed things, hear interpretations we may not have heard before, and suggest new research questions that might be followed up that are valued by the subjects themselves. And that is of value.

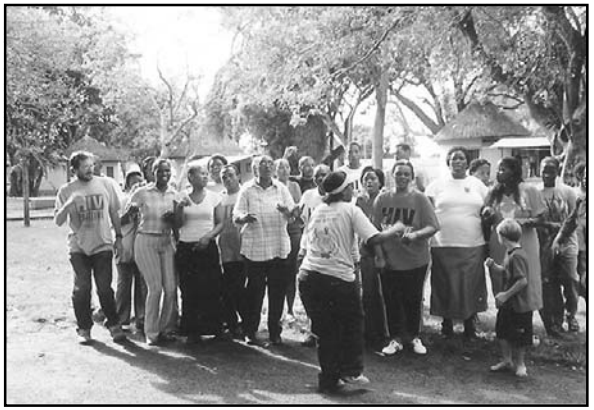
The relevance of our study

Notwithstanding the necessary qualifications that one might make, and while taking them into account, there are good and strong grounds for using qualitative research, and for trusting the kinds of information that it provides enough to be able to shape decisions and policy around it. Its relevance in the case of the Masangane study is twofold.

First, it has allowed us to uncover and explain, on the basis of solid evidence, original insights and knowledge about faith-based organization such as Masangane in relation to public health interventions and systems. We believe that this report offers some significant results in this respect, that it adds to our current state of knowledge, and that this is of importance to public health policy.

Second,it has relevance to the generalizability of our research findings. The fact that we have focused intensely on one programme means that we can say little about other programmes. Yet the benefits of such an intensive study on a carefully chosen case go well beyond the individual case. The use of qualitative research as a key component of this study has been central to achieving this aim.

1. Murphy E, Dingwall R. Qualitative methods and health policy research. New York: Aldine de Gruyter, 2003.
2. Scott JC. Domination and the arts of resistance: hidden transcripts. New Haven: Yale University Press, 1991.
3. Strauss A, Corbin J. Basics of qualitative research: grounded theory products and techniques. Newbury Park, CA: Sage, 1990.



Masangane members and supporters

Appendix B

List of Names of Primary Documents (Interviewees)

According to stakeholder groups:

Church leaders:

P 1: KII – Rev Venter
P 2: KII – Rev Tait

Masangane management:

P 7: KII – Nisani
P 9: KII – Hlubi
P10: KII – Ndawo
P25: KII – Rev Doran
P26: Report & Questions – Church-project relationship

Staff and volunteers:

P 3: KII – Noziwe
P 8: KII – Thembiwe
P11: KII – Sukwini
P18: KII – Ntingase
P27: Interview – Noziwe

Clients:

P 8: KII – Thembiwe
P11: KII – Sukwini
P16: FG – Matat June
P17: FG – Shiloh June
P28: Interview – Mvali & Xola

Funders:

P 4: KII – Ms Kobler
P 5: KII – Ms Crane

Doctors:

P12: KII – Dr Suttner
P13: Interview – Dr Nabiso
P14: KII – Dr Nabiso
P15: KII – Dr Pinyane
P22: Interview – Nurse

Traditional healers:

P19: Interview – Dr Mathe
P20: Interview – Dr Mbonge
P21: Interview – Dr Vela

In numerical order:

P 1: KII – Rev Venter
P 2: KII – Rev Tait
P 3: KII – Noziwe
P 4: KII – Ms Kobler
P 5: KII – Ms Crane
P 7: KII – Nisani
P 8: KII – Thembiwe
P 9: KII – Hlubi
P10: KII – Ndawo
P11: KII – Sukwini
P12: KII – Dr Suttner
P13: Interview – Dr Nabiso
P14: KII – Dr Nabiso
P15: KII – Dr Pinyane
P16: FG – Matat June
P17: FG – Shiloh June
P18: KII – Ntingase
P19: Interview – Dr Mathe
P20: Interview – Dr Mbonge
P21: Interview – Dr Vela
P22: Interview – Nurse
P25: KII – Rev Doran
P26: Report & Questions – Church-project relationship
P27: Interview – Noziwe
P28: Interview – Mvali & Xola

- KII = Key informant interview, people with direct knowledge of Masangane and its work
- FG = Focus group, conducted with groups of Masangane clients
- Interview = follow-up interviews with key informants or interviews with others who have relevant insights

"Let us Embrace": The Role & Significance of an Integrated Faith-Based Initiative for HIV and AIDS

Liz Thomas
Barbara Schmid
Malibongwe Gwele
Rosemond Ngubo
James R Cochrane

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In particular, we thank Renate Cochrane, Zoliswa Magwentshu, Nomhle Xulubana, the late Rev Fikile Mgcoyi, other staff, management committee members, clients and volunteers for their participation in assisting with this research. We thank, too, the doctors who spoke to us. And we thank Kgetheng Dlamini and Mary Bennet for additional technical and field work support at a critical point in the research process as well as April Butchart for entering quantitative data. Also in the field with us at one point was Beate Jakob of DIFÄM (Deutsches Institut für ärtzliche Mission) in Germany, one of the agencies providing financial support to Masangane's treatment programme.

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The authors of this research report are alone responsible for its writing, its judgements and its conclusions; no-one else should be held responsible for its errors.

University of CAPE TOWN

African Religious Health Assets Programme

Dept. of Religious Studies
University of Cape Town
Private Bag
7701 Rondebosch
South Africa
Email: arhap@humanities.uct.ac.za
Phone: +27 -21 650 3457/8

Interfaith Health Program
Rollins School of Public Health
Emory University
1256 Briarcliff Road, Bldg A, Suite 107
Atlanta, GA 30306, USA
Email: djones9@sph.emory.edu
Phone: +1 -404 727 5246

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